

The Failure of Gender Dysphoria Treatment in Oxfordshire

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Introduction

We have prepared this report in order to express our concerns regarding Oxfordshire PCT's provision of funding for the core surgical procedures involved in the treatment of gender dysphoria. We mean to demonstrate that the PCT's current policy and practice are unenlightened, irrational, unethical and essentially unlawful. We understand that the relevant policy is due to be reviewed in March, and urge the PCT to use that opportunity to address the issues highlighted here.

We begin with an acknowledgement that budgetary constraints necessitate the use of priority-setting for the promotion of a fair and equitable distribution of funds. We accept that, with many conflicting demands on the funds available for healthcare in this county, the Treatment Request Panel is under great pressure to serve the community effectively.

With this noted, our concerns are as follows:

- Oxfordshire PCT's policy statement (18b) highlights a basic misunderstanding of gender dysphoria and its appropriate treatment;
- Inadequate assessment has been made of the available evidence for the risk to health associated with the condition, and of the effectiveness of established treatments;
- These factors have led to treatment being prioritised inappropriately;
- The criteria under which treatment may be offered ('exceptional circumstances') have been defined irrationally, leading to an effective blanket ban;
- The policy for the treatment of gender dysphoria is out of line with treatment policies for other conditions, amounting to discrimination;
- Oxfordshire's policy lags behind the treatment policies of other South Central PCTs.

Definitions and Basic Principles

It is our opinion that a funding body cannot expect to be capable of making valid judgements regarding the prioritisation of a particular condition without a clear understanding of the nature of the condition itself. Over the years, gender dysphoria and atypical gender development have received frequent misinterpretations from non-specialist clinicians; this is, in part, owing to the diversity of terminology that is used.

Unfortunately, the terminology listed in Oxfordshire PCT's Policy Statement 18b is inconsistent with what has been adopted as standard by national and international specialist bodies. Furthermore, such inconsistency betrays fundamental misconceptions that are likely to have had ramifications extending to the provision of treatment for this condition.

In the very first line of Policy Statement 18b¹, we read:

“Gender Dysphoria is a psychological state whereby a person demonstrates dissatisfaction with their biological sex, and requests sex reassignment.”

This assertion, implying as it does that all gender dysphoric individuals request sex reassignment, is incorrect. It is true that many *transsexual* individuals will request sex reassignment. However, transsexual people represent only a fraction of those individuals suffering from gender dysphoria.

In the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR²), gender dysphoria is described as *“The experience of... dissonance between the sex experience, and the personal sense of being male or female”*. This type of discomfort, when experienced strongly and persistently, may be symptomatic of Atypical Gender Development, or, to give it its clinical label, Gender Identity Disorder (GID). The DSM-IV-TR defines GID as a *“strong and persistent cross-gender identification and a persistent discomfort with the sex and a sense of the inappropriateness of the gender role”*.

The International Classification of Diseases–10 (ICD-10) identifies transsexualism as one of several diagnoses within the category of GID³. Transsexualism is defined as *“the desire to live and be accepted as a member of the opposite sex, usually accompanied by the wish to make his or her body as congruent as possible with the preferred sex through surgery and hormone treatment.”*

¹ Thames Valley Priorities Committees: Oxfordshire PCT (2006) *Policy Statement 18b: Gender Dysphoria*, Ref TV63

² American Psychiatric Association (2000), *DSM IV TR*

³ World Health Organization (1993), *International Classification of Diseases 10 (ICD)*, [F64.0]

The above is summarised in *Atypical Gender Development – A Review*⁴, a paper whose purpose was to summarise all knowledge currently available regarding such conditions:

“Atypical gender development is given the clinical label, Gender Identity Disorder (GID), in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR, American Psychiatric Association, 2000). This is a rare condition in which individuals experience their ‘gender identity’ (the psychological experience of oneself as male or female) as being incongruent with their phenotype (the external sex characteristics of the body). The personal experience of this discomfort is termed gender dysphoria. In its profound and persistent form, it is known as transsexualism.”

In its internationally recognised Standards of Care⁵, the World Professional Association for Transgender Health (WPATH) considers the severity of gender dysphoria according to a series of clinical thresholds:

“A clinical threshold is passed when concerns, uncertainties, and questions about gender identity persist during a person’s development, become so intense as to seem the most important aspect of a person’s life, or prevent the establishment of a relatively unconflicted gender identity.” Gender identity is referred to as a person’s struggles that *“reflect various degrees of personal dissatisfaction with sexual identity, sex and gender demarcating body characteristics, gender roles, gender identity, and the perceptions of others. ... When dissatisfied individuals meet specified criteria in one of two official nomenclatures – the International Classification of Diseases-10 (ICD-10) or the Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition (DSM-IV) – they are formally designated as suffering from a gender identity disorder (GID). Some persons with GID exceed another threshold – they persistently possess a wish for surgical transformation of their bodies.”*

WPATH also emphasises the following:

“When the gender identity disorders first came to professional attention, clinical perspectives were largely focused on how to identify candidates for sex reassignment surgery. As the field matured, professionals recognised that some persons with bona fide gender identity disorders neither desired nor were candidates for sex reassignment surgery.”

While there are still no good practice guidelines for the UK, the WPATH guidelines continue to be used to dictate common policy. However, draft guidelines⁶, produced by the Royal College of Psychiatrists, have the following to say:

⁴ GIRES et al. (2006) *Atypical Gender Development - A Review*, International Journal of Transgenderism, 9(1) 29-44

⁵ The Harry Benjamin International Gender Dysphoria Association (2001) *Standards of Care for Gender Identity Disorders*, Sixth Version

⁶ Wylie et al (2006) *Good Practice Guidelines for the Assessment and Treatment of Gender Dysphoria*; RCPsych Intercollegiate SoC Committee, Draft Document v8.3b

“Treatment should be patient-centred and should recognise the individual’s preferences, needs, and circumstances. Treatment should not be prescriptive but should allow choices for individuals with regard to their treatment which are clinically safe. It is imperative that those experiencing this condition are accorded a substantial role in determining the kind of treatments that are appropriate for them, the pace at which treatment should progress and the duration and sequencing and where practicable providers of its individual elements.”

Oxfordshire PCT’s Policy Statement 18b, however, seems only to acknowledge the validity of a single care pathway:

“Management can be lengthy and expensive and comprises assessment, psychotherapy, real life experience, hormonal therapy and surgery.”⁷

The post-diagnostic elements of this pathway echo the established sequence of ‘triadic therapy’ (hormones, real-life experience, and surgery). The WPATH standards of care make extensive reference to this approach; however, there is again an emphasis on allowing flexibility in individual patient treatment plans:

“the diagnosis of GID 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 need or want all three elements of triadic therapy.”⁸

Accepted practice, therefore, relies on recognition of the diversity of manifestations of gender dysphoria, and does not identify any single prescriptive path to treatment. Instead, the most appropriate course of treatment is assessed on an individual basis at Gender Identity Clinics (GICs) such as the one at Charing Cross Hospital.

In conclusion, we believe that Oxfordshire PCT’s conflation of different categories of atypical gender development under the broad heading of ‘gender dysphoria’, and its apparent failure to recognise a diversity of possible treatment pathways, limits the practical value of the policy decisions that follow under Policy Statement 18b.

⁷ Thames Valley Priorities Committees: Oxfordshire PCT (2006) *Policy Statement 18b: Gender Dysphoria*, Ref TV63

⁸ The Harry Benjamin International Gender Dysphoria Association (2001) *Standards of Care for Gender Identity Disorders*, Sixth Version

Risks associated with Untreated Gender Dysphoria

Transsexualism is now understood to be innate and somatic⁹ rather than a lifestyle choice; similarly, it is debatable whether transsexualism and other manifestations of atypical gender development should be classified as psychiatric disorders. However, the extreme Gender Dysphoria experienced by transsexual individuals may be considered a serious psychiatric condition that causes debilitating psychological distress, with alarmingly high associated rates of suicidality and self-mutilation among those refused surgery. Thus, untreated sufferers commonly represent a significant burden on psychiatric and social services. This view is expressed by the Parliamentary Forum on Transsexualism¹⁰:

“Deprived of appropriate treatment, trans people are likely to function less well and to suffer ongoing health problems resulting in a greater strain on the National Health Service.”

And by the American Medical Association¹¹:

“GID, if left untreated, can result in clinically significant psychological distress, dysfunction, debilitating depression and, for some people without access to appropriate medical care and treatment, suicidality and death... Delaying treatment for GID can cause and/or aggravate additional serious and expensive health problems, such as stress-related physical illnesses, depression, and substance abuse problems, which further endanger patients’ health and strain the health care system.”

The personal accounts of transsexual people and their clinicians further demonstrate that surgical considerations often represent, quite literally, a matter of life and death¹².

A recent research project commissioned by the British Government’s Equalities Review¹³ included the largest survey ever conducted into suicidal tendencies among trans¹⁴ people. Of over 800 respondents, a high rate of attempted suicide was reported. *“Almost 14% of adult trans people have attempted to commit suicide more than twice, and 34.4%, over 1 in 3, reported having attempted suicide at least once as an adult.”* Alarmingly high as these figures are, they may in fact be underestimates, owing to the

⁹ GIRES et al. (2006) *Atypical Gender Development - A Review*, International Journal of Transgenderism, 9(1) 29-44

¹⁰ Parliamentary Forum on Transsexualism (2005); *Guidelines For Health Organisations Commissioning Treatment Services for Individuals Experiencing Gender Dysphoria And Transsexualism*; London, Parliamentary Forum on Transsexualism

¹¹ American Medical Association House of Delegates Resolution 122 (2008)

¹² Kotula, D. (2002) *In The Phallus Palace*, W.E Parker (consulting editor) Alyson Publications, Los Angeles

¹³ Whittle, Turner, and Al-Alami (2007) *Engendered penalties: transgender and transsexual people’s experiences of inequality and discrimination*; available online at www.pfc.org.uk/file/EngenderedPenalties.pdf

¹⁴ It may be noted that ‘trans’ is used here as a collective term for a variety of different gender variant identities; it may be considered a sociological expression of what clinicians describes as ‘atypical gender development’.

tendency of people not to disclose past suicide attempts; in addition, this survey only sampled the living, so instances of successful suicide were not included.

It was suggested that it would be difficult to conceive of any other demographic group of whom over a third would attempt suicide at least once in adulthood, especially as other evidence suggested that *“this is, on the whole, an otherwise well functioning group who have achieved very good educational level, and who are not suffering from a severe clinically diagnosed depressive illness.”* The survey asserts that the high instance of suicidality does not therefore stem from inherent psychiatric instability, but from the weighty burden of gender dysphoria and discrimination suffered by trans people: *“Practitioners, at every level of medicine, ignore the trans person’s abilities to cope with ongoing crises that would destroy other people, their educational standing and the nature of the actual illness they are presenting with.”*

The Gender Identity Research and Education Society (GIRES) emphasises the role of medical practitioners in reducing the risk of suicide among trans people, through appropriate medical treatment¹⁵:

“It is also understood that suicidality is relatively common in trans people. Many report that they were at their most vulnerable around the time that they finally sought treatment because they realised that they could not continue as they were... So those making decisions about funding and providing treatment need to take account of the impact on mental health if treatment is denied or unreasonably delayed.”

Extra considerations are presented in the Department of Health’s recent guidance on the care of gender variant people¹⁶, which identifies surgery as being *“not only a desirable, but an urgent and constant preoccupation – even an obsession”* for some patients. *“Delays in the ‘system’, whether clinical or financial, cause a great deal of stress”*, while *“The inability to access timely treatment may also be a cause of suicidal feelings.”* As well as suicide, a number of other risks is identified:

“Stress leads a number of trans people to self-harm and even to attempt suicide.... These feelings may occur at any time, but they are often associated with the realisation that it is impossible to continue life in the pre-transition role. For some, the choice is stark: either the gender issue is addressed, or there is no future... Through frustration or anxiety, or both, some trans people self-harm by cutting their arms and legs and, occasionally, their offending sex characteristics, such as breasts (trans men) or the penis and scrotum (trans women). Alcohol and other substance misuse may also be a factor, especially where there is family breakdown and social isolation.”

¹⁵ GIRES et al. (2009) *A guide to trans users rights*; document published by GIRES and funded by the Department of Health

¹⁶ GIRES et al. (2008) *Guidance for GPs, other clinicians and health professionals on the care of gender variant people*; document issued by the Department of Health

The document goes on to reference a recent examination of the high incidence of trans people in the sex industry¹⁷; data from this article are used to highlight another area of concern:

“Delay in accessing treatment may also drive some trans people into sex work in order to pay for private services. They may be living very risky lives both in terms of sexually transmitted diseases and potential violence. Worldwide, the number of transgender people who are HIV positive is high. Figures for the UK are not known, but they might be anticipated to be lower since treatment for gender variance is available on the NHS.”

Collectively, these factors may render Oxfordshire PCT’s recent restrictions on the provision of treatment for gender dysphoria rather less financially viable in the long-term than a more accommodating funding policy would have been. As the Priorities Forum heard during a meeting in 2006:

“The cost of not treating patients could potentially be high, if costs of dealing with complications following private treatment are taken into account.” ... “[Dr Chris Bass] noted that this is a group of patients which can use a lot of NHS resources in terms of psychiatric care and crisis team services.”¹⁸

In conclusion, severe gender dysphoria can incur both a high risk for sufferers and a significant drain on the funds allocated for healthcare. Press for Change, a leading political lobbying and educational organisation within the UK, which readily describes severe untreated Gender Dysphoria as a fatal disorder¹⁹, emphasises that *“Gender reassignment surgery is a one-off expense, enormously cheaper than the alternative... The alternative for transsexual people who are not treated is likely to be that (if they do not kill themselves) they become a lifelong burden on the psychiatric and/or social services, unable to lead a normal life, unable to work (and pay taxes) or to make a contribution to society.”*

¹⁷ Clemenz-Nolle, Marx, Guzman and Katz (2001); HIV prevalence, risk behaviours, health care use, and mental status of transgender persons: implications for public health intervention; American Journal of Public Health 91 (6): 915-921

¹⁸ Stirzaker et al (2006) Oxfordshire Priorities Forum – Minutes of Meeting 27/09/06

¹⁹ Press for Change (1998) *Health and Social Care*; available online at www.pfc.org.uk

The Efficacy of Surgical Techniques

In spite of the risks and potential costs associated with untreated Gender Dysphoria, Oxfordshire PCT imposes stifling limitations on the funds available for surgical treatment, using the contention that the efficacy of such techniques is unproven:

*“GRS core surgical procedures are a Low Priority treatment due to the limited evidence of clinical effectiveness and are not routinely funded.”*²⁰

This policy has been adopted despite an apparent understanding that there is *“an anomaly in funding patients only to a certain stage of their transition”*²¹. Indeed, it is widely acknowledged that treatment for this condition must be holistic to be effective; that gender dysphoria is *“appropriately treated by hormone therapy accompanied by surgery, where required by the service user, rather than by psychotherapeutic interventions alone.”*²². Above all, it should be stressed that there has not been a single recorded instance in which a transsexual person has become adjusted to the gender they were assigned at birth as a result of psychotherapy²³. Professionals in the field of gender dysphoria understand and accept that:

*“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.”*²⁴

The importance of the holistic approach is further expressed in the draft standards of care prepared by the Royal College of Psychiatrists²⁵:

“Gender treatment should be established on a multi-disciplinary basis and may include input from psychology, psychiatry, psychotherapy, nursing, speech and language therapy, endocrinology, dermatology, surgery, social work and other related professions.”

The conviction is later expressed that care pathways that, where necessary, include surgery are regarded as effective:

“Treatment involving a combination of hormone administration and usually some combination of gender confirming surgical procedures, following

²⁰ Thames Valley Priorities Committees: Oxfordshire PCT (2006) *Policy Statement 18b: Gender Dysphoria*, Ref TV63

²¹ Stirzaker et al (2006) Oxfordshire Priorities Forum – Minutes of Meeting 27/09/06

²² Parliamentary Forum on Transsexualism (2005); *Guidelines For Health Organisations Commissioning Treatment Services for Individuals Experiencing Gender Dysphoria And Transsexualism*; London, Parliamentary Forum on Transsexualism

²³ Meyer et al (2001) *The standards of care for gender identity disorders, sixth version*; Journal of Psychology and Human Sexuality, 13: 1-30

²⁴ Green (1999); Report cited in *Bellinger v Bellinger*, Court of Appeal, Judgement, July 17th 2001, TLR 22-11-2000

²⁵ Wylie et al (2006) *Good Practice Guidelines for the Assessment and Treatment of Gender Dysphoria*; RCPsych Intercollegiate SoC Committee, Draft Document v8.3b

psychiatric/psychological assessment and accompanied by psychological support, is deemed to lead to excellent outcomes.”

The WPATH standards of care²⁶ have much the same to say:

“Sex Reassignment is Effective and Medically Indicated in Severe GID. In persons diagnosed with transsexualism or profound GID, sex reassignment surgery, along with hormone therapy and real-life experience, is a treatment that has proven to be effective. Such a therapeutic regimen, when prescribed or recommended by qualified practitioners, is medically indicated and medically necessary. Sex reassignment is not “experimental”, “investigative”, “elective”, “cosmetic”, or optional in any meaningful sense. It constitutes very effective and appropriate treatment for transsexualism or profound GID.”

Indeed, WPATH has recently issued a separate document clarifying its professional consensus on the matter:

“The current Board of Directors of the WPATH herewith expresses its conviction that sex reassignment, properly indicated and performed as provided by the Standards of Care, has proven to be beneficial and effective in the treatment of individuals with transsexualism, gender identity disorder, and/or gender dysphoria. Sex reassignment plays an undisputed role in contributing toward favourable outcomes, and comprises Real Life Experience, legal name and sex change on identity documents, as well as medically necessary hormone treatment, counselling, psychotherapy, and other medical procedures... Medically necessary sex reassignment procedures also include complete hysterectomy, bilateral mastectomy, chest reconstruction or augmentation as appropriate to each patient (including breast prostheses if necessary), genital reconstruction (by various techniques which must be appropriate to each patient, including, for example, skin flap hair removal, penile and testicular prostheses, as necessary), facial hair removal, and certain facial plastic reconstruction as appropriate to the patient... These medical procedures and treatment protocols are not experimental: decades of both clinical experience and medical research show they are essential to achieving well-being for the transsexual patient.”²⁷

It should therefore be noted that, in many cases of severe gender dysphoria, treatment plans must include provision for surgical procedures if successful outcomes are to be obtained. This has lately been acknowledged by the American Medical Association:

“An established body of medical research demonstrates the effectiveness and medical necessity of mental health care, hormone therapy and sex reassignment surgery as forms of therapeutic treatment for many people diagnosed with GID... Health experts in GID, including WPATH, have

²⁶ The Harry Benjamin International Gender Dysphoria Association (2001) *Standards of Care for Gender Identity Disorders*, Sixth Version

²⁷ Whittle et al; *WPATH Clarification on Medical Necessity of Treatment, Sex Reassignment, and Insurance Coverage in the USA* (2008); Issued by the World Professional Association for Transgender Health, Inc. and available online at www.wpath.org

*rejected the myth that such treatments are “cosmetic” or “experimental” and have recognised that these treatments can provide safe and effective treatment for a serious health condition.”*²⁸

The same position is expressed in a recent review of the current medical understanding of atypical gender development:

*“The hormonal, surgical and psychological procedures of transition reduce the dissonance between the psychological identification as male or female, on the one hand, and the phenotype and associated gender role on the other. Such treatments are regarded as highly successful.”*²⁹

These assertions may appear bold in the light of the lack of large-scale research into medical care for severe gender dysphoria. As clinical incidences of this condition are so rare, and its manifestations so diverse, the only standardised research that has historically been possible is on a relatively small scale. However, *“not all that counts can be counted, and not all that can be counted counts”* – particularly in experimental psychology. For many working in the field of gender dysphoria, the conspicuously favourable outcomes observed for individual patients selected for surgery (over 60 years of established practice) have provided compelling evidence for the efficacy of such procedures. As observed at an Oxfordshire Priorities Forum meeting³⁰, *“Charing Cross is a very large clinic with a long-standing reputation in the field; in twenty years of practice, they have only had three patients who reverted to their original gender”*.

Having noted the relevance of a consideration of the outcomes of individual cases, we wish to state our conviction that there is in fact a consistent trend in the formal studies available for review, demonstrating that treatment regimes that include surgery will result in a particularly high percentage of favourable outcomes for patients suffering from extreme gender dysphoria.

A comprehensive review of post-surgical follow-up studies on transsexuals, spanning a period of thirty years, concluded, *“In over 80 qualitatively different case studies and reviews from 12 countries, it has been demonstrated during the last 30 years that the treatment that includes the whole process of gender reassignment is effective.”*³¹

Later studies have provided further evidence in support of this conclusion. Rates of regret are consistently low: one study³² calculated a regret rate of 3.8%, and found that regrets were commonly associated with poor surgical

²⁸ American Medical Association House of Delegates Resolution 122 (2008)

²⁹ GIRES et al. (2006) *Atypical Gender Development - A Review*, International Journal of Transgenderism, 9(1) 29-44

³⁰ Stirzaker et al (2006) *Oxfordshire Priorities Forum – Minutes of Meeting 27/09/06*

³¹ Pfäfflin and Junge (1998); *Sex Reassignment. Thirty Years of International Follow-up Studies After Sex Reassignment Surgery: A Comprehensive Review, 1961-1991*; English Ed. by Jacobson and Meier

³² Landén (1999); *Transsexualism, Epidemiology, Phenomenology, Etiology, Regret after Surgery, (3.8%, n=233), and Public Attitudes*; PhD thesis, Institute of Clinical Neuroscience, Göteborg University, Sweden

results rather than with any desire to de-transition. Another study³³ found that 98% of patients expressed no regrets post-operatively. In addition, 91.6% were satisfied with their overall appearance; the other 8.4% were neutral. In a group that had previously suffered from extreme gender dysphoria, it might be considered quite remarkable that, following surgery, not one patient's physical appearance had given cause for personal dissatisfaction.

Similar results were obtained in a study³⁴ that observed a satisfaction rate of over 90%: "*Male-to-female surgery can achieve excellent cosmetic and functional results... None of the present patients claimed to regret their decision to undergo gender-transforming surgery.*" Here again, as in other studies³⁵, any dissatisfaction was generally associated with poor surgical results, many of which could easily be corrected through secondary surgery. Furthermore, as the quality of surgical procedures improves, it can be expected that rates of dissatisfaction should decrease over time – certainly, the most recently published study³⁶ showed an especially high rate of satisfaction at 98%.

Other studies have found that careful identification of suitable patients on the basis of stringent selection criteria (such as those recommended in the WPATH standards of care) is associated with improved outcomes³⁷; under such regimes, one relatively early study³⁸, which assessed success on the basis of patient satisfaction and psychological functioning, found success rates of 97% and 87% in female-to-male and male-to-female individuals respectively.

With such consistent indications for a high success rate associated with surgery for gender dysphoric people, it is unsurprising that every major professional organisation concerned with the treatment of gender dysphoria has urged that funds be made available for surgical procedures. It is emphasised that "*these treatments are cost effective rather than cost prohibitive*"³⁹, and that funding for surgery should be seen as an investment, saving public money in the longer term. Certainly, the cost of treating this condition represents a tiny fraction of Oxfordshire PCT's overall budget.

³³ Smith, Van Goozen, Kuiper and Cohen-Kettenis (2005); *Sex Reassignment: outcomes and predictors of treatment for adolescent and adult transsexuals*; Psychological Medicine, 35, 89-99

³⁴ Krege et al (2001); *Male-to-female transsexualism: a technique, results and long-term follow-up in 66 patients*; Journal of Urology International, 88, 396-402

³⁵ Lawrence (2003); *Factors Associated with Satisfaction or Regret Following Male to Female Sex Reassignment Surgery*; Archives of Sexual Behavior, 32, 299-315

³⁶ Schonfield (2008); *Audit, Information and Analysis Unit: audit of patient satisfaction with transgender services*

³⁷ Eldh (1997); *Long-term Follow Up After Sex Reassignment Surgery*; Scandinavian Journal of Plastic Reconstruction Surgery, 31, 39-45

³⁸ Green and Fleming (1990); *Transsexual Surgery Follow-up: Status in the 1990s*; Annual Review of Sex Research 1, 163-174

³⁹ Whittle et al; *WPATH Clarification on Medical Necessity of Treatment, Sex Reassignment, and Insurance Coverage in the USA* (2008); Issued by the World Professional Association for Transgender Health, Inc. and available online at www.wpath.org

In 2008, the American Medical Association resolved to “support public and private health insurance coverage for treatment of gender identity disorder”; and to “oppose categorical exclusions of coverage for treatment of gender identity disorder when prescribed by a physician.”⁴⁰ Such enlightened policy acknowledges that “Professionals who provide services to patients with gender conditions understand the necessity of SRS, and concur that it is reconstructive, and as such should be reimbursed, as would any other medically necessary treatment.”⁴¹ It also comes in the wake of a recent statement from WPATH:

“The WPATH Board of Directors urges health insurance carriers and healthcare providers in the United States to eliminate transgender or transsex exclusions and to provide coverage for transgender patients and the medically prescribed sex reassignment services necessary for their treatment and well-being, and to ensure that their ongoing healthcare (both routine and specialised) is readily accessible.”⁴²

In the UK, the published view of the Parliamentary Forum on Transsexualism is that “In cases of adult gender dysphoria/transsexualism health commissioners are responsible for funding... specific gender confirmation surgery when appropriate.”⁴³ It goes on to recommend the following:

“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.”

While such directives are not binding on PCTs, it must be appreciated that the Parliamentary Forum included the foremost specialists in the field of gender dysphoria, and that its recommendations have therefore emerged from a weighty collective body of professional experience:

“The Forum comprises the UK’s leading experts on transsexualism, in both the legal and medical fields, a number of MPs. 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. The Forum also includes Professor Kevan Wylie, Chair of the committee set up by the Royal College of Psychiatrists in collaboration

⁴⁰ American Medical Association House of Delegates Resolution 122 (2008)

⁴¹ Monstrey, De Cuypere and Ettner (2007); *Surgery: General Principles*. In Ettner et al (eds) *Principles of Transgender Medicine and Surgery*. New York: Haworth Press (2007), p.94

⁴² Whittle et al; *WPATH Clarification on Medical Necessity of Treatment, Sex Reassignment, and Insurance Coverage in the USA* (2008); Issued by the World Professional Association for Transgender Health, Inc. and available online at www.wpath.org

⁴³ Parliamentary Forum on Transsexualism (2005); *Guidelines For Health Organisations Commissioning Treatment Services for Individuals Experiencing Gender Dysphoria And Transsexualism*; London, Parliamentary Forum on Transsexualism

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.”

If Oxfordshire PCT chooses to dismiss the available evidence for the efficacy of surgery, together with the recommendations stated in the internationally recognised standards of care, the collected views of a number of professional bodies, and the expertise of specialist practitioners at Charing Cross GID and elsewhere, that is its prerogative. However, it must be aware that its autonomy does not remove its responsibility to allocate available funds effectively and equitably. As explained in the good practice guidelines drafted by the Royal College of Psychiatrists⁴⁴:

“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.”

The possibility of encountering such litigation should be regarded as an extremely serious consideration. In the case that first established the legal parameters in cases of medical funding for gender dysphoric patients requiring surgery⁴⁵, judgement was passed in favour of the three transgender claimants, setting a precedent that has informed every subsequent legal dispute of this nature. In delivering his judgement, Lord Justice Auld concluded:

“there is a strong and respectable body of medical opinion that considers gender reassignment procedures to be effective in suitable and properly selected cases... it is unreal to submit that body of opinion to research trials of the type envisaged in the health authority’s paper. I emphasise that the mere fact that a body of medical opinion supports the procedure does not put the health authority under any legal obligation to provide the procedure... However, where such a body of opinion exists it is in my view not open to a rational health authority simply to determine that a procedure has no proven clinical benefit while giving no indication of why it considers that that is so... I am therefore driven to the conclusion that the health authority has not demonstrated that degree of rational consideration that can reasonably be expected of it before it decides in effect to give no funding at all to a procedure supported by respectable clinicians and psychiatrists, which is said to be necessary in certain cases to relieve extreme mental distress.”

This case was also highly significant in demonstrating difficulties with the concept of 'exceptional circumstances' for gender dysphoria, as explored in our next section.

⁴⁴ Wylie et al (2006) *Good Practice Guidelines for the Assessment and Treatment of Gender Dysphoria*; RCPsych Intercollegiate SoC Committee, Draft Document v8.3b

⁴⁵ Appeals Court judgement of *North-West Lancashire Health Authority v A, D and G* (QBC 1999/0226/4; 0228/4; 0230/4)

The Case for Exceptionality

Oxfordshire PCT does not explicitly acknowledge gender dysphoria's status as an illness, instead merely describing it as a *“psychological state”*⁴⁶, but the listings of this condition in the ICD-10⁴⁷ and the DSM-IV-TR⁴⁸ clarify the medical consensus on the matter, as we have seen. Those suffering from gender dysphoria are therefore entitled to care for this condition under the NHS, and PCTs are legally obliged to make appropriate treatment available⁴⁹; the courts have recognised genital reassignment surgery as a valid and appropriate treatment⁵⁰. Nonetheless, as the Parliamentary Forum on Transsexualism observed, *“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.”*⁵¹

For any treatment that is regarded as ‘low priority’ and therefore rarely commissioned, it is necessary for PCTs to identify clinical conditions under which funding may be provided, to ensure equitable provision of services. Oxfordshire PCT has chosen to specify that this treatment will be funded in ‘exceptional circumstances’; however, interpreting provisions of this nature may be problematic in the case of gender dysphoria, as the Priorities Forum is aware:

*“David Roche stated that it is legal to have a policy which says that treatment of gender dysphoria is a low priority provided you acknowledge that there can be cases with overwhelming clinical need. DR acknowledged that this is a difficult area and [Dr Ljuba Stirzaker] stated that the Herceptin situation showed the problems with ‘envisaging’ exceptional circumstances and demonstrating that one patient would benefit more than another.”*⁵²

The issues associated with such a policy may be illustrated through reference to the Appeals Court judgement in the case of *North-West Lancashire Health Authority v A, D and G*⁵³, which established that it is unlawful for any health authority to impose anything resembling a blanket ban on genital reassignment surgery through prioritisation policies. There are demonstrable similarities between current practice in Oxfordshire and the policy then espoused by North-West Lancashire Health Authority, which had resolved

⁴⁶ Thames Valley Priorities Committees: Oxfordshire PCT (2006) *Policy Statement 18b: Gender Dysphoria*, Ref TV63

⁴⁷ World Health Organization (1993), *International Classification of Diseases 10 (ICD)*, [F64.0]

⁴⁸ American Psychiatric Association (2000), *DSM IV TR*

⁴⁹ Parliamentary Forum on Transsexualism (2005); *Guidelines For Health Organisations Commissioning Treatment Services for Individuals Experiencing Gender Dysphoria And Transsexualism*; London, Parliamentary Forum on Transsexualism

⁵⁰ Appeals Court judgement of *North-West Lancashire Health Authority v A, D and G* (QBC 1999/0226/4; 0228/4; 0230/4)

⁵¹ Parliamentary Forum on Transsexualism (2005); *Guidelines For Health Organisations Commissioning Treatment Services for Individuals Experiencing Gender Dysphoria And Transsexualism*; London, Parliamentary Forum on Transsexualism

⁵² Stirzaker et al (2006) *Oxfordshire Priorities Forum – Minutes of Meeting 27/09/06*

⁵³ Appeals Court judgement of *North-West Lancashire Health Authority v A, D and G* (QBC 1999/0226/4; 0228/4; 0230/4)

only to fund treatment in ‘exceptional circumstances’, for which an ‘overwhelming clinical need’ could be identified. In the courts, it was suggested that these conditions may not easily be applicable to the case of gender dysphoria, and the Health Authority’s practical application of policy was deemed to be unsuitable.

Indeed, in his Appeals Court judgement, Lord Justice Auld described the health authority’s policy and practice as indicative of a *“failure properly to evaluate such a condition as an illness suitable and appropriate for treatment”*. As he observed, the exceptional circumstances for which surgical intervention would be approved effectively required patients to be suffering not only from gender dysphoria, but also from other attendant psychiatric problems:

*“The Authority’s relegation of what was notionally regarded as an illness to something less, in respect of which an applicant for treatment had to demonstrate an overriding clinical need for treatment, confronted each respondent with a very high and uncertain threshold... The 1995 Policy gave no indication of what might amount to an overriding clinical need or other exceptional circumstances; nor did the 1998 Policy, save in paragraph 5.1 in which it emphasised the likely rarity and unpredictability of such circumstances, and instanced as a possibility when “the problem”... was the cause of serious mental illness. Expert assessment that a patient needs the treatment would not do; demonstration of the existence of some other illness was a necessary condition for consideration for treatment.”*⁵⁴

Lord Justice Auld considered that the Health Authority *“does not in truth treat transsexualism as an illness, but as an attitude or state of mind which does not warrant medical treatment”*. We have seen that Oxfordshire PCT regards gender dysphoria as *“a psychological state whereby a person demonstrates dissatisfaction with their biological sex, and requests sex reassignment”*⁵⁵. As this policy statement acknowledges no stronger description of the psychiatric effects of gender dysphoria than *“dissatisfaction”*, it is scarcely surprising that a diagnosis of gender dysphoria is not itself regarded as sufficient for surgery to be offered. As funding will only be approved *“where there is evidence of significant health status impairment (e.g. inability to perform activities of daily living)”*⁵⁶, it would appear that Oxfordshire PCT too requires patients to be suffering from another attendant illness before surgery will be offered.

It is difficult to imagine how gender dysphoria might precipitate *“significant health status impairment”* in any other than a psychiatric sense, so we can assume that Oxfordshire PCT will only offer surgery to patients who have reached a state of depression or psychiatric instability so acute that they are unable to *“perform activities of daily living”*. This is, I would suggest, a self-fulfilling prophecy: as we have seen, a catastrophic deterioration in mental

⁵⁴ Appeals Court judgement of *North-West Lancashire Health Authority v A, D and G* (QBC 1999/0226/4; 0228/4; 0230/4)

⁵⁵ Thames Valley Priorities Committees: Oxfordshire PCT (2006) *Policy Statement 18b: Gender Dysphoria*, Ref TV63

⁵⁶ Thames Valley Priorities Committees: Oxfordshire PCT (2006) *Policy Statement 18b: Gender Dysphoria*, Ref TV63

health is a predictable consequence of the inability to access necessary treatment for this condition⁵⁷. However, to make this condition a *prerequisite* for surgery is not just irresponsible, but decidedly unethical.

As observed by Mr Blake, a barrister appearing on behalf of the Applicant at the High Court in our reference case:

*“To require the condition to go untreated until it had caused an additional severe illness disregarded the duty on Health Authorities to prevent illnesses and constituted inhuman or degrading treatment.”*⁵⁸

Such policy also places transsexual people in the archetypal *Catch-22* situation, in that patients must demonstrate a good degree of mental stability before they can be referred for surgery. This paradox was noted by Lord Justice Hidden in his High Court judgement⁵⁹:

“There is the additional complication that if, as the evidence suggests to be likely, they develop a further and additional serious psychiatric pathology other than being transsexual, they may then constitute an exception to this policy but, in that event, they will be precluded medically from pursuing the gender re-assignment surgery because of the existence of the requirements for a stable personality in order to undergo the operation and transformation.”

Indeed, the WPATH Standards of Care name as one of their Readiness Criteria for surgery:

*“Demonstrable progress in dealing with work, family, and interpersonal issues resulting in a significantly better state of mental health (this implies satisfactory control of problems such as sociopathy, substance abuse, psychosis, suicidality, for instance).”*⁶⁰

Accordingly, prior to referring transsexual people for surgery, the GIC at Charing Cross require them to have consistently presented in a manner congruent with their personal gender identity for two years, while working and socializing in a healthy and functional manner. This would seem incompatible with an “inability to perform activities of daily living”.

As affirmed by Mr Blake, the barrister in our reference case:

“the suggestion by the respondents that psychotic depression or suicidal state might be a good reason for authorising the treatment was itself based on an error in understanding the medical evidence. A patient could only be suitable for surgical treatment if he had a stable mind and had come to a clear and ordered decision and, thus, psychotic depression was a counter-indication of successful surgery. The requirement that the patient be suffering another

⁵⁷ GIRES et al. (2008) *Guidance for GPs, other clinicians and health professionals on the care of gender variant people*; document issued by the Department of Health

⁵⁸ *R v North West Lancashire Health Authority ex parte A, D & G* (1998)

⁵⁹ *R v North West Lancashire Health Authority ex parte A, D & G* (1998)

⁶⁰ The Harry Benjamin International Gender Dysphoria Association (2001) *Standards of Care for Gender Identity Disorders*, Sixth Version

illness in addition to the illness of GID demonstrated that the ban on GID treatment was in fact blanket and admitted of no exception... To require patients to suffer from another disease before treating them was absurd. To require them to suffer pathological psychiatric disorder as a result of non-treatment before treating them was absurd and ineffective since effectively it would preclude a transsexual from surgery.”⁶¹

In addition, it is demonstrably unethical for a health authority to exploit the psychiatric stress attendant to gender dysphoria as a means of imposing an effective blanket ban on appropriate treatment.

If psychiatric health status impairment can be ruled out as a legitimate example of exceptional circumstances under which surgery can be offered, we are left with no clear idea as to what sort of conditions would qualify. In *Guidance for considering "exceptionality" in individual cases*⁶², a general policy statement issued by Oxfordshire PCT, the observation is made that:

“Due to the individual circumstances of each patient, it is not possible to identify ‘exceptional’ clinical circumstances in advance.”

While such a flexible approach is entirely prudent, health authorities are nonetheless required to demonstrate that there exists at least a reasonable potential for exceptional circumstances to be identified for this condition, in order to confirm that the policy does not amount to a blanket ban⁶³. In the case cited above, Lord Justice Auld commented that:

“Dr. Sudell’s observation... that it was “difficult to imagine what an exceptional clinical need for” gender reassignment might be, is understandable.”⁶⁴

Unfortunately, the PCT’s policy statements provide no clear guidance on what might qualify as a legitimate ‘exceptional’ case of Gender Dysphoria, for which surgery might be funded. However, Policy Statement 80b does list some examples of general considerations that cannot be used to inform the case for exceptional circumstances:

“Meeting the accepted indications for a treatment does not, in itself, provide a basis for an exception... The fact that a patient is likely to respond to the requested treatment does not, in itself, provide a basis for an exception.”⁶⁵

For purposes of comparison with our reference case, the estimation of Lord Justice Buxton was that North-West Lancashire Health Authority's policy statement *“contents itself with saying that clinical advice that a patient is suitable for surgery will not be regarded as providing an overriding clinical*

⁶¹ *R v North West Lancashire Health Authority ex parte A, D & G* (1998)

⁶² South Central Priorities Committees: Oxfordshire PCT (2008) *Policy Statement 80b: Guidance for considering "exceptionality" in individual cases*, Ref TV78

⁶³ Press for Change (1998) *Health and Social Care*; available online at www.pfc.org.uk

⁶⁴ Appeals Court judgement of *North-West Lancashire Health Authority v A, D and G* (QBC 1999/0226/4; 0228/4; 0230/4)

⁶⁵ South Central Priorities Committees: Oxfordshire PCT (2008) *Policy Statement 80b: Guidance for considering "exceptionality" in individual cases*, Ref TV78

need or exceptional circumstances justifying intervention: which in its context was tantamount to saying that the service will not be provided at all.”

We believe that meaningful criteria for ‘exceptional circumstances’ do exist for this condition, but that Oxfordshire PCT has habitually disregarded such criteria. We have seen that transsexual people represent only a fraction of people treated for gender dysphoria, and not all transsexuals will necessarily demonstrate a clinical need for surgery; the infrequent surgical referrals are for a minority of patients who are considered ‘exceptional’ within the experience of specialist practitioners at Gender Identity Clinics such as the one at Charing Cross Hospital. We strongly believe that the insight and expertise of these specialists should be allowed appropriate weight in informing individual funding decisions; instead, the Priorities Forum (with its own limited comprehension of the condition) has displayed a consistent propensity to dismiss the clinical recommendations of authorities in the field of gender dysphoria, and without being able to offer any properly considered explanation for why.

While, in *individual* cases, the reasoning behind the Priorities Forum’s decisions remains relatively obscure, the *categorical* rationale for the PCT’s prioritisation of genital reassignment surgery has already been identified: “GRS core surgical procedures are a Low Priority treatment due to the limited evidence of clinical effectiveness”⁶⁶. This echoes North-West Lancashire Health Authority’s past reservations regarding the evidence for the efficacy of surgery as a treatment for gender dysphoria. Mr Blake, a barrister appearing on behalf of the Applicant at the High Court, maintained that:

*“the purported proviso for “overriding clinical need” was in practice meaningless since the respondents failed to recognise that gender reassignment is the only effective treatment for diagnosed transsexuals who had passed the “real life” test and were otherwise suitable for surgery. If the clinical assessment of demonstrable need was incapable of overriding the policy, then nothing could override it.”*⁶⁷

In his Appeals Court judgement, Lord Justice Auld acknowledged this as an issue:

“if a Regional Health Authority devises a policy not to provide treatment save in cases of overriding clinical need, it makes a nonsense of the policy if, as a matter of its medical judgment, there is no effective treatment for it for which there could be an overriding clinical need.... If the Authority considers the cause of such a condition to be untreatable by hormonal treatment and surgery, it is hard to see how it could regard the condition itself as an overriding need for such treatment.”

It would appear that Oxfordshire PCT has fallen into the same trap. It is logically inconsistent to list genital reassignment surgery as a low priority

⁶⁶ Thames Valley Priorities Committees: Oxfordshire PCT (2006) *Policy Statement 18b: Gender Dysphoria*, Ref TV63

⁶⁷ *R v North West Lancashire Health Authority ex parte A, D & G* (1998)

treatment owing to “*limited evidence of clinical effectiveness*”, but to define the exceptional circumstances under which it will be offered as “*evidence of significant health status impairment (e.g. inability to perform activities of daily living)*”. These considerations inhabit disparate logical categories, one appertaining to the treatment, the other to the condition.

In order to illustrate this point, we submit two enthymemes, each of which is consistent according to its own premises:

The treatment is not always effective: funding will be provided in cases where the treatment can be predicted to be effective.

And:

The condition does not always affect a person’s health: funding will be provided in cases where a person’s health is affected.

Each of these logical forms displays internal consistency. However, it is not possible to construct a valid logical argument by mixing and matching their component terms, as Oxfordshire PCT has done:

The treatment is not always effective: funding will be provided in cases where a person’s health is affected.

We identify this inconsistency as yet another reason for the essential irrationality of Oxfordshire PCT’s current policy.

In his Appeals Court judgement in the case of *North-West Lancashire Health Authority v A, D and G*, the conclusion reached by Lord Justice Auld was that:

*“the ostensible provision that [the health authority] makes for exceptions in individual cases and its manner of considering them amount effectively to the operation of a ‘blanket policy’ against funding treatment for the condition”*⁶⁸

We conclude this section by reaffirming our belief that the same is true of the policy and practice adopted by Oxfordshire PCT.

⁶⁸ Appeals Court judgement of *North-West Lancashire Health Authority v A, D and G* (QBC 1999/0226/4; 0228/4; 0230/4)

Policy in Context

Having already considered the medical categorization of conditions that come under the heading of atypical gender development, we wish briefly to draw attention to the status of transgender people as a societal group. The trans population is scarcely abundant⁶⁹, and is widely dispersed geographically and sociographically; nonetheless, the experiences and concerns common to transgender people act as incentives for individuals to come together and, increasingly, to network.

Historically, this group has occupied an uneasy position on the LGBT spectrum – although sexuality and gender identity are separate issues, transgender individuals commonly encounter prejudice also shared by homosexual and bisexual people. In addition, the process of self-discovery and acceptance ('coming out' after being 'closeted', for example) is often similar for individuals of these groups – indeed, many transgender people find an exploration of their sexuality a helpful step on the path towards coming to terms with their gender identity.

Transgender people frequently find themselves the victims of bigotry and irrational discrimination⁷⁰; those who are perceived as transgressing gender boundaries are prone to be treated with suspicion, ridicule and hatred by those around them. Accompanying the widespread ignorance of the status of transsexualism as an innate condition rather than a lifestyle choice, there exists a pervasive disregard for the emotional torment experienced by those who are denied medical treatment or social acceptance in their personally identified gender. Popular misunderstanding of trans identities is fuelled by unfavourable and stereotyped media depictions of transgender people⁷¹, and by sensationalist reporting from unscrupulous and exploitative journalists⁷².

The Equalities and Human Rights Commission recognises the right of UK citizens to be protected from unlawful discrimination on the grounds of gender identity⁷³. Furthermore, a recent paper prepared by GIRES and many of the UK's leading authorities on atypical gender development stated that:

*"it is imperative to emphasise that attention to the needs of trans people should be extended on the basis of human rights, justice and equality. Medical and scientific findings are often amended and clarified, but the right of individuals to appropriate care and respect remains."*⁷⁴

⁶⁹ The Harry Benjamin International Gender Dysphoria Association (2001) *Standards of Care for Gender Identity Disorders*, Sixth Version

⁷⁰ Whittle, Turner, and Al-Alami (2007) *Engendered penalties: transgender and transsexual people's experiences of inequality and discrimination*; available online at www.pfc.org.uk/file/EngenderedPenalties.pdf

⁷¹ Serano (2007) *Whipping Girl: A Transsexual Woman on Sexism and the Scapegoating of Femininity*; Seal Press

⁷² Bindel (2007) *My trans mission*; article in The Guardian, available online at <http://www.guardian.co.uk/commentisfree/2007/aug/01/mytransmission>

⁷³ Equality and Human Rights Commission (2008) *Equality and Discrimination*, available online at www.equalityhumanrights.com

⁷⁴ GIRES et al. (2006). Atypical Gender Development - A Review, *International Journal of Transgenderism*, 9(1) 29-44

The substance of these remarks is echoed in the NHS Plan (2000), which emphasises the importance of non-discriminatory practices in its Principle 3:

*“The National Health Service of the 21st Century must be responsive to the needs of different groups and individuals within society”*⁷⁵

Nonetheless, a recent research project prepared as part of the UK Equalities Review was severely critical of the treatment of trans people by the NHS:

*“The NHS is a service, and like other service providers has used the excuse of the lack of protection against discrimination in goods, services, facilities and housing to provide an atrociously bad level of provision for trans people.”*⁷⁶

We would suggest that there exists a requirement for a formal investigation into the possibility that the failings of Oxfordshire PCT's policy 18b stem in part from institutionalised discrimination against transgender people. It should be noted that such discrimination might not necessarily be the result of direct transphobia or cissexism on the part of those involved in drawing up and implementing policy. As we have observed, the PCT is under great pressure to deliver the most effective care possible within a limited budget, but its prioritisation is carried out under the watchful eye of a medically untutored public; the Priorities Forum may therefore find itself susceptible to the weight of popular biases in its attempt to justify funding decisions to the local community.

While we appreciate the importance of public involvement and accountability, we emphasise that the widespread ignorance and prejudice that surround popular perceptions of transsexualism should not have any place in the formulation of policy. A responsible PCT will refuse to allow itself to be swayed by common prejudice; however, the infrequency of transsexualism within the general population, coupled with society's general disinterest in the promotion of transgender rights, may serve to lower the perceived threat of sanctions for discriminatory treatment, making gender dysphoria an easy target for funding cutbacks.

We do not believe that it is possible to reach any firm conclusions regarding this matter on the basis of the information available to us; an internal investigation by the PCT's own regulatory body could potentially present a stronger indication of whether the Priorities Forum might have deviated from its own Ethical Framework in the formulation of policy. At this stage, we will merely note apparent inconsistencies in the PCT's prioritisation of funds, through comparison with the provision made for certain other treatments.

Like gender dysphoria, cancer receives a huge amount of media attention;

⁷⁵ Department of Health (2000) *The NHS Plan: a plan for investment, a plan for reform*; Command Paper Cm 4818-I

⁷⁶ Whittle, S, Turner, L, Al-Alami, M (2007); *Engendered penalties: transgender and transsexual people's experiences of inequality and discrimination* (www.pfc.org.uk/file/EngenderedPenalties.pdf)

however, there is considerably more public support for NHS provision of cancer treatments than for that of genital reassignment surgery. This may go some way towards explaining why such treatments are often funded even when studies suggest that they may be of limited efficacy. The treatment of breast cancer using trastuzumab (Herceptin) is a case in point. Although hailed as a wonder drug, the evidence for its effectiveness is not compelling, with some trials showing little improvement in the data for patient survival⁷⁷. Large-scale analysis suggests that 18 patients must be treated to save the life of a single patient such that “*For every 100 suitable patients prescribed Herceptin, 94 will have been exposed to the side-effects without any benefit, at a cost of £400,000 per recurrence prevented*”⁷⁸. Of the side-effects mentioned, cardiac dysfunction gives the greatest cause for concern; this may be developed by as many as 1 in 25 patients⁷⁹, and can be expected to make a significant contribution to the all-cause mortality of those treated. In spite of these considerations, Oxfordshire PCT’s policy statement for trastuzumab use states that “*funds will be normally available to accommodate the costs should clinicians decide that it is appropriate.*”⁸⁰

With rather more compelling evidence for the efficacy of genital reassignment surgery in carefully selected cases, it is surprising that Oxfordshire PCT does not show a similar degree of respect for the professional opinion of specialist clinicians working in the field of gender dysphoria, particularly considering the relative cost-effectiveness of the treatment in question.

Instead, GRS is given the same prioritisation as aesthetic surgery⁸¹, despite the clear message from WPATH and other professional authorities that genital reassignment is not cosmetic⁸². Such organizations recognise GRS as being reconstructive; it therefore appears rather inconsistent of Oxfordshire PCT to deny genital surgery to transsexuals except in ‘exceptional circumstances’, while equivalent surgery is offered to intersex individuals with ambiguous genitalia as a matter of course. Indeed, transsexualism is increasingly being regarded as a true intersex condition; this was acknowledged by the Court of Appeal in Madrid⁸³, which found that genital reassignment surgery should be offered on an equal basis with corrective surgery for other intersex conditions.

⁷⁷ Thynne (2006) *Is Herceptin a wonder drug?* BBC Panorama, internet link at <http://news.bbc.co.uk/1/hi/programmes/panorama/4678430.stm>

⁷⁸ Littlejohns (2006) *Trastuzumab for early breast cancer: evolution or revolution?*; *Lancet Oncology* 7: 22–3

⁷⁹ Albanell, Codony, Rovira, Mellado, and Gascon (2003) *Mechanism of action of anti-HER2 monoclonal antibodies: scientific update on trastuzumab and 2C4*; *Advances in Experimental Medicine and Biology* 532: 253 – 268

⁸⁰ Thames Valley Priorities Committees: Oxfordshire PCTs (2006) *Policy Statement 79b: The use of trastuzumab (Herceptin) for early breast cancer*
Ref TV71

⁸¹ Thames Valley Priorities Committees: *Oxfordshire PCTs (2008) Policy Statement 6d: Aesthetic surgery procedures* Ref TV11

⁸² The Harry Benjamin International Gender Dysphoria Association (2001) *Standards of Care for Gender Identity Disorders*, Sixth Version

⁸³ *Katia v Madrid Institute of Health (IMSALUD)* (2004) Social Sciences Division 30, Madrid

We believe that a significant change in Oxfordshire PCT's attitudes towards transsexualism, and an amendment of its understanding of atypical gender development to reflect the current medical viewpoint, will be necessary to inform a more progressive, enlightened policy for the treatment of such conditions. As to whether the PCT's current stance indicates any form of irrational discrimination against transgender people as a group, we leave our conclusions unmade, to be inferred both from the evidence presented here and from future comparative examination of its prioritisation strategies.

Policy in Practice, and the Position of Oxfordshire within NHS South Central

The practical impact of Oxfordshire's current policy statement (18b) has been elucidated for us by psychiatric consultants both at Charing Cross GIC and at the John Radcliffe Hospital in Oxford. Since the implementation of this policy, it would appear that there have been no instances in which genital reassignment surgery has been granted to a trans woman, although there have been several cases for which funding has been denied.

In addition, however, a single funding application for genital reassignment surgery for a trans man *has* been granted, an intriguing observation in consideration of the fact that genital reassignment is several times more expensive for trans men than for trans women, and has both a far higher associated risk of complications and a significantly lower expected improvement in quality of life⁸⁴. While we fully accept the legitimacy of granting NHS funding for surgery for a trans man, it seems incongruous that no trans woman has received funding for an operation that is both more cost effective and statistically more likely to be beneficial.

Further research indicates that this single case of funding was only approved under duress; it is a cause for concern that we have been unable to identify any single factor other than the patient's successful legal action against the PCT that might have informed perspectives on his case for exceptional circumstances. We believe that, if there were indeed no significant clinical factors that differentiated that patient's circumstances from those of other patients, the Priorities Forum ought to have subsequently adjusted its interpretation of policy in the light of the court's decision, if only to satisfy the equitability requirements specified as part of its Ethical Framework.

In order to substantiate the received facts regarding Oxfordshire PCT's practical approach to funding genital reassignment surgery, we made an enquiry of the PCT under the Freedom of Information Act (2000), to establish exact figures for funding approvals and funding denials for genital reassignment surgery since December 2006, when Policy Statement 18b was adopted.

We had been informed that the other PCTs within the same Strategic Health Authority have maintained a policy of funding surgery where necessary and appropriate. In order to gain further perspective on the situation at a regional level, we expanded our enquiries to cover all PCTs within the NHS South Central Strategic Health Authority. We requested equivalent information to that which had been received from Oxfordshire PCT, to ensure fair comparison with the data already obtained. We required that the figures should be derived from the same time bracket.

We had hoped to be able to use the statistics we received to substantiate the consistency between policy and practice within each PCT, and to highlight the disparity between current practice in Oxfordshire and that elsewhere.

⁸⁴ Stirzaker et al (2006) *Oxfordshire Priorities Forum – Minutes of Meeting 27/09/06*

However, while the results of our Freedom of Information requests have already been compiled in full, we are still awaiting permission to disclose this information. The full version of this report, including our consideration of the figures for funding across the South Central PCTs, will be made available as soon as permission to disclose has been granted from the each of the PCTs in question. For now, we will draw comparisons between the PCTs merely through examination of their policy statements.

The Central South Coast policy⁸⁵ (shared by the Isle of Wight, Hampshire, Southampton, and Portsmouth PCTs) is rather different to that of Oxfordshire. As well as demonstrating a more sophisticated grasp of the correct medical classifications involved, this policy shows much greater clarity in specifying eligibility criteria for surgery relating to gender reassignment:

“Eligibility for gender reassignment surgery:

Referral for GRS should be initiated only by the specialist GID service. Authorisation should be sought from the Specialist Services Commissioning team before patients are referred for surgery.

The patient eligibility criteria for surgery are adapted from the Harry Benjamin criteria. The criteria are identical for both biological males and females seeking genital surgery:

- *Competent to consent to receive treatment consistent with safe clinical practice (usually aged 18 years or above);*
- *Usually 12 months of continuous hormone therapy (for those without a medical contraindication);*
- *A minimum of 24 months of continuous full-time real-life experience;*
- *Regular participation in psychotherapy during real-life experience;*
- *Demonstrable knowledge of the length of hospitalisation, possible complications and post-surgical requirements of the various surgical procedures.*

In addition, patients must demonstrate progress in consolidating gender identity role, and in dealing with work, family and interpersonal issues.”

This policy does not require ‘exceptional circumstances’ to be satisfied for genital reassignment surgery to be funded. Instead, it is merely necessary for patients to have satisfied the eligibility criteria and to be referred by specialist practitioners at a Gender Identity Clinic:

“Referral for GRS should be initiated only by the specialist GID service. Approval should be sought from the Specialist Services Commissioning team before patients are accepted for surgery. The Specialist Services team will require confirmation that the eligibility criteria are met, before approving the referral.”

An exceptionality clause is, however, applied for other surgeries, listed as non-core:

⁸⁵ Central South Coast Specialist Services Confederation (2006) *Commissioning Policy for Gender Identity Disorder Services*

“Non-core GRS, including breast augmentation and other cosmetic surgical procedures will not normally be funded. Individual requests for such procedures will be considered only on an exceptional basis.”

In summary, the Central South Coast PCTs determine whether to fund core genital reassignment surgery on the basis of sensible and relevant criteria identified by leading authorities in the field of gender dysphoria treatment. Non-core procedures may be funded under exceptional circumstances. In Oxfordshire, by contrast, core surgical procedures have essentially been allocated an equivalent status to non-core treatments, while specialist professional guidance is essentially ignored for all practical purposes.

In structure at least, the policies of the Berkshire⁸⁶ and Buckinghamshire⁸⁷ PCTs are comparatively similar to the one prepared by Oxfordshire PCT. This reflects the composition of SHAs prior to the 2006 merger.

There do, however, seem to be several differences in opinion, divided cleanly between Berkshire and Buckinghamshire on the one hand, and Oxfordshire on the other. Some of these differences may have little impact in practice; we have identified three that we believe may be significant. The Berkshire and Buckinghamshire statements agree that:

“There is a clear consensus that equitable access to services for initial diagnostic assessment, hormone therapy and surgery is essential for those patients fulfilling the Harry Benjamin International Gender Dysphoria Association criteria.”

We have underlined the elements missing from the equivalent clause in the Oxfordshire statement. The differences would seem to be reflective of Oxfordshire PCT's lack of conviction in the evidence for the efficacy of treatment for gender dysphoria. Certainly, the assertions of Berkshire and Buckinghamshire PCTs more closely resemble WPATH's assurances that *“These reconstructive procedures are not optional in any meaningful sense, but are understood to be medically necessary for the treatment of the diagnosed condition”,* and *“decades of both clinical experience and medical research show they are essential to achieving well-being for the transsexual patient”*⁸⁸.

The priorities recommendations also differ slightly between counties. For Berkshire and Buckinghamshire, recommendation (4) reads as follows (as before, the underlining is ours):

“GRS is a Low Priority treatment due to the limited evidence of clinical effectiveness and is not routinely funded. Funding will be approved for core

⁸⁶ Thames Valley Priorities Committees: Berkshire PCTs (2006) *Policy Statement 4a: Gender Dysphoria*; Ref TV63

⁸⁷ Thames Valley Priorities Committees: Buckinghamshire/Milton Keynes (2006) *Policy Statement 23: Gender Dysphoria*; Ref TV63

⁸⁸ Whittle et al; *WPATH Clarification on Medical Necessity of Treatment, Sex Reassignment, and Insurance Coverage in the USA* (2008); Issued by the World Professional Association for Transgender Health, Inc. and available online at www.wpath.org

Gender Reassignment Surgery if the patient fulfils the current International Harry Benjamin Criteria and has been recommended as suitable for surgery by a specialist NHS Gender Identity Clinic.

In the policy statement for Oxfordshire, only the first sentence is included; the qualifying sentence that follows in the case of Buckinghamshire and Berkshire is missing altogether in the Oxfordshire statement. In practice, this qualifying sentence can be expected to have a similar impact to the full eligibility criteria listed in the Central South Coast policy, as the latter criteria were themselves adapted from the Harry Benjamin Criteria.

There is also a slight difference to be noted in the consideration of exceptional circumstances, listed in the *Notes*. Berkshire and Buckinghamshire state that:

“Exceptional circumstances may be considered where there is evidence of significant health impairment and there is also evidence of the intervention improving health status.”

As we have already seen, Oxfordshire’s version of the above reads as follows:

“Potentially exceptional circumstances may be considered by the patient’s PCT where there is evidence of significant health status impairment (e.g. inability to perform activities of daily living.)”

We have argued that Oxfordshire PCT’s criteria for exceptional circumstances do not follow logically from its reasoning behind the allocation of Low Priority status to genital reassignment surgery. The exceptional circumstances criteria of Berkshire and Buckinghamshire do not share this fallacy: as the specific criteria for funding genital reassignment surgery have already been elucidated in recommendation (4) of each statement, it is clear that these exceptional circumstances clauses only apply to non-core procedures. The policy statements identify such procedures as effectively cosmetic; therefore, any failure to provide them would not normally be expected to result in *“significant health impairment”*, and offering them as treatment would normally not be expected to improve a patient’s health status. The exceptional circumstances listed share a logical congruence with these premises.

We conclude this section by expressing our considered opinion that Oxfordshire PCT’s funding policy for genital reassignment surgery represents an anomaly among the collected policies of PCTs within NHS South Central. We trust that the increased role of the SHA in determining local priorities, and in particular, the impact of the recently established Special Commissioning Group (SCG) for this region, will result in amendments to Oxfordshire PCT’s policy, to place this county in line with the rest of the region. Besides eliminating the inequalities inherent in the present ‘postcode lottery’, such intervention might be expected to result in a more enlightened and rational policy for Oxfordshire.

Our Conclusions – a Review

In summary, we believe that Oxfordshire PCT's current policy for the funding of treatment for gender dysphoria is in urgent need of review, together with its established practice in this area. We do not feel that the PCT has given proper consideration to the available evidence-based research and specialist advice it has been presented with; these deficiencies have resulted in inappropriate prioritisation of treatment. The PCT's estimation of 'exceptional circumstances' lacks internal rationality, rendering its policy meaningless in practice, such that an effective blanket ban has been imposed on appropriate and necessary surgical procedures. Such policy is inconsistent with that adopted by all other PCTs in the region.

We consider these lapses to be negligent and unethical, and potentially symptomatic of institutionalised discrimination against transgender people. We advise those responsible for local priority-setting to make the necessary amendments to Policy Statement 18b as a matter of urgency.