

# **A review of access to NHS gender reassignment services (England only)**

## **Introduction**

The Equality and Human Rights Commission (the Commission) has prepared this review in response to concerns expressed by trans advocacy groups and individuals that they experience particular difficulties accessing NHS gender reassignment services. The NHS is subject to the public sector equality duty and to the Human Rights Act and both of those have implications for how the NHS delivers gender reassignment services.

Although the Health and Social Care Bill 2011 is still under parliamentary scrutiny, preparation for the restructuring of the NHS is underway, including changes to the way in which NHS services are commissioned. This report is intended to feed into current thinking and decisions on how gender reassignment services can be provided in the new NHS structure.

The review draws on available qualitative research, views from trans individuals, trans advocacy groups and clinicians, as well as a desk analysis by the Commission of publicly available Primary Care Trust and Specialist Commissioning Group policies on the commissioning of gender reassignment services. It builds on the 'Trans Research Review' conducted for the Commission in 2009 and which highlighted the inequalities and discrimination trans people face in the UK. It will be of interest to medical, health policy and legal professionals and members of the trans community.

The Commission recognises that there are significant and increasing financial constraints in the health sector that will have to be taken into account when decisions are made on funding gender reassignment services, as with any service. The evidence in this report suggests, however, that there are various practical steps that can be taken to improve the consistency of access to services and consistency of decision-making, the knowledge and confidence of GPs, the quality of available information, the scrutiny of services and the experience of service users.

Recommendations in this review are for the new NHS Commissioning Board, General Medical Council and other professional bodies which represent GPs, such as the Royal College of GPs and the British Medical Association, the Department of Health in England, local authorities, the Care Quality Commission and Monitor.

# Gender reassignment

## Definitions

The term "gender dysphoria" is commonly used as a "diagnosis" by medical professionals to describe the discomfort that arises when the experience of oneself as a man or as a woman is incongruent with the sex characteristics of the body and with the associated gender role. In transsexual people, the discomfort is extreme and they have to deal with it by transitioning, usually with medical assistance, to a gender role inconsistent with the sex assigned to them at birth. Transsexualism is not a lifestyle choice. A person has to be experiencing "gender dysphoria" in order to obtain gender reassignment treatment in the NHS.

For the purposes of clarity, the term gender reassignment is used throughout this document to refer to the process of change from one gender to another (otherwise known as "transition"). For further information on definitions, refer to Annex A.

## Measuring service need

There are no reliable figures available on the size of the trans population in the UK or in England. Nor is there any central data on how many people request or receive gender reassignment services in England. Whether and how to obtain an accurate measure of the size of the trans population is a highly controversial topic, given the sensitivity of the issues and is not addressed in this report. The lack of data on service need or current usage does, however, raise substantial practical problems in ensuring that health services are targeted to needs. It means that commissioners cannot:

- estimate national demand for gender reassignment services;
- assess the extent of any inequalities and levels of discrimination that the trans population face relative to the wider population when accessing healthcare, and;
- monitor progress in increasing equality and reducing discrimination with regards to variation in access to gender reassignment services.

While data availability is limited, PCTs and Specialist Commissioning Groups do collect data on the number of commissioning decisions made in relation to gender reassignment treatment. However, this data is not publicly available and also does not include the number of people in the

trans population who are refused treatment or who may require treatment but are not able to access it. Whilst only available on request, it is possible to measure caseload levels in gender identity clinics across England. However, while these numbers are helpful in looking at trends over time especially for future planning of funding allocation by Primary Care Trusts, the numbers only record those that have successfully dealt with the various hurdles in place when trying to access a clinic's service. Nevertheless, the caseload numbers are significant in some areas. For example, Charing Cross Gender Identity Clinic recorded 1876 'unique caseloads' in 2010/11<sup>1</sup>.

In order to try and mitigate the difficulties in measuring the number of people trying to access gender identity services in Scotland, a Gender Reassignment Working Group has been established. Initial scoping and mapping work of the four gender identity clinics/services in Scotland allows service providers to establish current use:

- Sandyford – 390 patients (between 2009-11)
- NHS Lothian – 145 patients (between February 2010-Feb 11)
- NHS Highland – 21 patients (between 2010-11)
- NHS Grampian – not known at this time

It should be noted however, that the numbers noted here only count those that have successfully navigated the process and do not necessarily represent current levels of need. This issue is even more pertinent when one considers that there is also no reliable data on the number of people who travel abroad in order to undergo gender reassignment because it is cheaper and faster than the NHS route, although anecdotal evidence suggests this may be a common route for those who can afford it.

### **Key findings:**

- Robust data on the national demand for, and usage of, gender reassignment services is unavailable. This creates problems for commissioners in understanding possible demands for the service and monitoring need.

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<sup>1</sup> It should be noted that these numbers will include an element of double counting as they include people who are: accessing gender reassignment care for the first time, returning from a voluntary break in the process and, those who have completed the process, but have been referred to the clinic for a general medical complication.

- PCTs and Specialist Commissioning Groups do collect data on the number of commissioning decisions made in relation to gender reassignment treatment. However, this data is not publicly available and also does not include the number of people in the trans population who are refused treatment or who may require treatment but are not able to access it.

## **Why is gender reassignment an equality and human rights issue?**

The provision of gender reassignment services is relevant to a number of legal obligations that apply to public authorities under the Equality Act 2010 and the Human Rights Act 1998, and to the principles set out in the NHS Constitution.

### **The Equality Act 2010**

The Equality Act came into force on 1 October 2010 and extends the previous legal protection for transsexual people who have the protected characteristic of gender identity. Unlike previous equality law, the Act does not require a person to be under medical supervision to be protected from discrimination, but does require the person to be "proposing to undergo, is undergoing or has undergone a process (or part of a process) for the purpose of reassigning the person's sex, by changing physiological or other attributes of sex"<sup>2</sup>.

As part of the Equality Act, a new public sector equality duty came into force on 6 April 2011 which harmonises the equality duties for race, gender and disability and extends them to cover eight equality strands: age, disability, gender, gender identity, pregnancy and maternity, race, religion or belief and sexual orientation<sup>3</sup>. The purpose of the general equality duty is to integrate consideration of equality and good relations into the day-to-day business of public authorities and for organisations to consider how they could positively contribute to the advancement of equality and good relations. It requires equality considerations to be reflected into the design of policies and the delivery of services, including internal policies, and for these issues to be kept under review. The general equality duty applies to all public bodies listed in section 19 of the Equality Act 2010, for example, the Department of Health, NHS foundation trusts, the Care Quality Commission and Monitor, and will

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<sup>2</sup> <http://www.legislation.gov.uk/ukpga/2010/15/section/7>

<sup>3</sup> It also covers marriage and civil partnership, but only in relation to the elimination of discrimination.

include GP commissioning consortia and the NHS Commissioning Board. It applies to the public functions of the General Medical Council. The general equality duty also applies to other organisations such as private bodies or voluntary organisations which are carrying out public functions as defined by the Human Rights Act.

The duty will therefore require NHS bodies, inspectorates and the Department of Health itself to consider how their policies and practices can be designed to promote equality for trans people, as for other equality groups defined by the Equality Act 2010.

This is not restricted to gender reassignment services only, as there are also issues and concerns related to the provision and quality of general medical services for trans people. For example, there are issues around gender specific treatments such as mammograms and cervical smears because post-operative females are not identifiable as such, even on cursory gynaecologic examination (Ettner, 2007)<sup>4</sup>. Another example concerns the medical risks associated with hormone use and smoking, which require attention because patients who smoke and take estrogens face a significantly higher risk of thromboembolic complications than those who do not. The risk of polycythemia (a blood condition), and polycythemic stroke is also increased by androgen supplementation with concurrent smoking (Darby & Anawalt, 2005)<sup>5</sup>. Gender reassignment services are, however, the priority health issue identified by most trans advocacy groups and the focus of this report.

### **The Human Rights Act 1998**

The Human Rights Act (HRA) 1998 is also relevant to the provision of gender reassignment services. The Act requires public bodies carrying out public functions to take account of the human rights dimensions of services for which they are responsible. Article 8 of the Convention, the right to a private and family life, is particularly applicable to NHS gender reassignment services. The concept of the right to a private and family life covers the importance of personal dignity and autonomy and the interaction a person has with others, both in private or in public. Respect for one's private life includes respect for individual sexuality, the right to personal autonomy and physical and psychological integrity. Providers of NHS gender reassignment services should therefore be taking

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<sup>4</sup> Ettner, R. (2007) Principles of transgender medicine and surgery, Routledge Taylor & Francis Group.

<sup>5</sup> Darby, E. & Anawalt, B.D. (2005) Male hypogonadism: an update on diagnosis and treatment. *Treat Endocrinol.* 2005;4(5)1-18

account of the human rights dimensions of those services. The barriers which trans people have described in accessing these services with dignity, may raise human rights issues and cause distress to them at a vulnerable and sensitive point in their lives.

### **The NHS Constitution**

Trans people also have rights under the NHS Constitution, which describes the objectives of the NHS, the rights and responsibilities of the various parties involved in healthcare (patients, staff, trust boards) and the guiding principles which govern the service. These rights cover access, quality of care and environment, access to treatments, medicines and screening programmes, respect, consent and confidentiality, informed choice, patient involvement in healthcare and public involvement in the NHS, and complaints and redress. NHS bodies, primary care services, and independent and third sector organisations providing NHS care in England are required by the Health Act 2009 to have regard to the NHS Constitution. In practice, this means that NHS services should be provided in a non-discriminatory way and there should be no absolute absence or refusal of service.

### **Access to NHS gender reassignment services**

The route to gender reassignment starts with the individual GP, then requires support from PCTs to fund treatment, then requires patients to meet the varying criteria of the specialist gender identity clinics. Service users and trans advocacy groups report a range of barriers at each stage. Burns (2006)<sup>6</sup> describes gender reassignment care pathways as a complex system of barriers which trans people have to navigate. She cites as examples, the lack of choice about which provider to go to, and long waiting lists for treatments. Combs (2010)<sup>7</sup> indicates that trans people are not always aware of what gender reassignment services are available through the NHS and, as a result, often assume that in order to obtain these services, they have to go private.

### **The role of GPs**

Trans people state that GPs play an important first line role for them in the process of seeking gender reassignment treatment. Whittle et al (2007)<sup>8</sup> state, "it is crucial to have the support of one's GP when

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<sup>6</sup> Burns, C. (2006) Not so much a Care Path...More a Steeplechase, Press for Change

<sup>7</sup> Combs, R.M (2010) Where gender and medicine meet: Transition experiences and the NHS

<sup>8</sup> Whittle, S., Turner, L. & Al-Alami, M. (2007) Engendered Penalties: Transgender and Transsexual People's Experiences of Inequality and Discrimination, London: The Equalities Review

undergoing gender reassignment - not only is the first step a referral from one's GP to see a consultant psychiatrist, but they are involved in writing referral letters and monitoring general health at all stages".

Yet according to the respondents to Whittle et al's (2007) study, 21 per cent of GPs either did not want to help, or in 6 per cent of cases, refused to help. Another study by Whittle et al (2008)<sup>9</sup> suggested that 30 per cent of respondents in Europe experienced what the study defined as "the minimum acceptable level of assistance" - a practitioner wanting to help, but lacking information about health care. Respondents to this study reported that they were refused treatment because a medical practitioner did not approve of gender reassignment. Combs (2010) also describes lack of knowledge about gender reassignment by GPs and that the standard of practitioner knowledge about gender reassignment (and other trans healthcare related needs such as cervical screening) is not uniform across the NHS<sup>10</sup>. Whilst the Department of Health has produced guidance for GPs on the care of gender variant people,<sup>11</sup> the Gender Identity and Research Society believes that there is a lack of awareness about this guidance amongst GPs.

### **Funding from PCTs and Specialist Commissioning Groups**

UK case law<sup>12</sup> has clarified that it is unlawful for PCTs to impose anything that amounts to a blanket ban on funding for gender reassignment, even for a limited period, because gender dysphoria is a medical condition and, as such, it should be treated on the NHS. Whilst a commissioning or funding group is still permitted to accord any treatment "low priority", it is unlawful to use this as a "blanket policy" whereby transsexualism becomes effectively barred from treatment. However, research and referrals to the EHRC suggest that there are still problems experienced by trans people attempting to access treatment and there is debate about the extent to which these problems are linked to wider funding issues impacting on a range of NHS services, or to the low priority attributed to gender reassignment services in particular, compared with other areas of healthcare (Combs, 2010).

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<sup>9</sup> Whittle, S., Turner, L., Combes, R. & Rhodes, S. (2008) Transgender Eurostudy: legal survey and focus on the transgender experience of health care

<sup>10</sup> Combs, R.M (2010) Where gender and medicine meet: Transition experiences and the NHS

<sup>11</sup> NHS, Guidance for GPs, other clinicians and health professionals on the care of gender variant people, 2008

<sup>12</sup> 1999 Court of Appeal ruling (A.D & G v Lancashire Health Authority)

The Commission's analysis of NHS PCT and Specialist Commissioning Group (SCG) policies on gender reassignment services (between October 2010 - February 2011) has revealed considerable variation.

Of the PCTs, policies were publicly available online for only a small number (25 out of 151). More up-to-date policies may now exist for some PCTs, so the following conclusions are based on those few policies that were publicly available online up to February 2011. Comparison of the policies viewed was made more difficult by inconsistent terminology, varying focus of criteria for eligibility, level of detail and variations in the date when they were produced. Some policies included eligibility criteria and a summary of the decision making process; however they did not provide any understanding of the interpretation of the eligibility criteria nor the realities of the decision-making process. Nor did they reveal how decisions are made and the justification for these decisions. There was much inconsistency across PCTs, even from a small number of policies analysed, which indicates geographically unequal access to gender reassignment services.

There was also considerable variation in the tone of policies which, whilst these do not tell us whether or not gender reassignment is any more available in one PCT than another, do indicate quite different approaches to the provision of this type of health service. In some cases, there is negativity of tone that could dissuade a trans person from trying to access services. For example, Herefordshire PCT's Low Priority Treatment Policy states that "gender reassignment will not be funded, except in exceptional circumstances and following individual case consideration by the Named Patient Panel prior to patient beginning gender reassignment programme". In contrast, Heywood, Middleton and Rochdale PCT's Effective Commissioning Policy states "once a patient has been accepted onto a gender reassignment care pathway, any appropriate treatment on the pathway will be provided. It would be inappropriate to place a 'hold' on treatment for non-clinical reasons, as to do so would cause enormous stress and be very damaging to the patient".

Of the SCGs, eight out of ten policies were obtained, with most being freely available online and some obtained from the SCG after a request by email. No policy was acquired for South East SCG despite two requests for a copy and West Midlands SCG does not have responsibility for commissioning gender reassignment services.

Initial analysis of these policies focused on which treatments were considered to be "core" and "non-core" treatments for gender reassignment. There was consensus on the genital surgeries that were considered to be "core". Some variability exists amongst SCGs regarding "non-core" treatments (for example those considered to be cosmetic such as breast augmentation, hair removal, rhinoplasty and voice modification), with some SCGs funding these treatments subject to particular criteria being met. For example, East Midlands SCG states that breast augmentation may be funded if a penectomy and orchidectomy has been carried out. There were also differences in policies relating to funding for reversal of gender reassignment procedures, with some policies stating that these will not be funded at all, whilst other policies either did not specifically address this or stated that it would be provided subject to meeting specific criteria. Some good practice was, however, also identified. For example, Yorkshire & Humber SCG has extended the policy on gender reassignment services to now encourage monitoring of outcomes.

Whilst there was a large degree of consensus amongst SCG policies regarding genital surgery, an opposite story emerged amongst PCT policies which displayed considerable variation, particularly regarding breast augmentation and mastectomy (despite mastectomy being listed as a "core" procedure in all SCG policies). Some PCTs listed these treatments as "core" whilst others considered them to be "cosmetic" and so classified them as "non-core" therefore removing funding possibilities.

Evidence also suggests that SCG commissioners are restricted in their ability to track patients' progress (and likely demand) in the system because of management of NHS numbers by the NHS Care Records Service. In response to the Gender Recognition Act 2004, which provided transsexual people with legal recognition of their acquired gender, the NHS Care Records Service has supplied patients with a new NHS number and identity, providing that they have, or have had, 'gender dysphoria', lived in the acquired gender throughout the preceding two years and intend to continue to live in the acquired gender until death. As well as causing difficulties for SCG commissioners, this approach to management of NHS numbers is also problematic for patients themselves, particularly those moving between clinics, from private to NHS services or simply taking time out of the pathway because clinics may lose their records or not have a complete history of their gender reassignment care. This often means that patients have to repeat themselves every time they see someone new – even within a clinic.

## **From policy to practice**

Evidence from legal challenges suggests that requests for "non-core" and "cosmetic" gender reassignment procedures are less supported than "core" gender reassignment surgery. In the recent *AC v Berkshire West PCT* [2010] EWHC (Admin) case, the argument for Primary Care Trust funding of £2,300 for breast surgery to complete the transition from male to female was rejected on the grounds of clinical and cost effectiveness. Lawyers for the Primary Care Trust said that surgery was not an essential part of gender reassignment treatment and that there was no good evidence that it would be cost-effective or clinically effective in the case of AC. Anecdotal evidence has also indicated that requests for surgery are further affected by the use of exceptional case reviews to consider such requests and that these reviews are problematic because they do not define what "exceptions" are.

## **Commissioning restrictions**

Recent examples suggest that financial pressures leading to rationing of services will increase the restrictions on access to NHS gender reassignment services over the next few years. For example, at the end of 2010, West Kent PCT postponed all referrals for gender reassignment until the new financial year due to financial pressures.

There is also evidence about the restriction of access to these services because of concerns about the efficacy of gender reassignment treatments. A report by Outen (2009)<sup>13</sup> on gender reassignment treatment in Oxfordshire describes "stifling limitations on the funds available for surgical treatment by Oxfordshire PCT using the contention that the efficacy of such techniques is unproven".

These concerns have, however, been challenged for not considering evidence on the long-term success of gender reassignment treatments. Outen (2009) describes that, for many clinicians working in the field of gender reassignment, the favourable outcomes observed for patients selected for surgery (over 60 years of established practice) have provided evidence for the efficacy of such procedures. As observed at an Oxfordshire Priorities Forum meeting, which represents clinical and commissioning staff and makes recommendations about which drugs and treatments should be low or high priority, "Charing Cross is a very

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<sup>13</sup> Outen, S. in association with Payne, R. , Busutti, S-C., & Whiteman, A. (2009) The failure of gender reassignment treatment in Oxfordshire

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"<sup>14</sup>. A review of post-surgical follow-up studies on transsexual people, spanning a period of thirty years concluded that "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"<sup>15</sup>. A prospective study by Smith et al (2005) found that no patient was actually dissatisfied, 91.6 per cent were satisfied with their overall appearance and the remaining 8.4 per cent were neutral<sup>16</sup>. A survey in the UK also reported a high level of satisfaction of 98 per cent following genital surgery (Schonfield, 2008)<sup>17</sup>. A further study on outcomes in trans women shows that they function well on a physical, emotional, psychological and social level (Weyers et al, 2009)<sup>18</sup>.

### **Issues with clinical treatment**

NHS gender reassignment services in England are mainly provided at six NHS gender identity clinics. These are:

- West London Mental Health NHS Trust Gender Identity Clinic (sometimes known as the Charing Cross Gender Identity Clinic);
- Nottinghamshire Healthcare NHS Trust Gender Identity Clinic;
- Sheffield Health and Social Care NHS Foundation Trust Gender Identity Clinic;
- Leeds Partnerships NHS Foundation Trust Gender Identity Service;
- The Devon Partnership Trust Gender Identity Clinic (also known as The Laurels); and,
- University Hospitals of Leicester NHS Trust Gender Identity Service.

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<sup>14</sup> Shirzaker et al. (2006) Oxfordshire Priorities Forum - Minutes of Meeting 27/09/06

<sup>15</sup> Pfafflin & Junge. (1998) Sex Reassignment. Thirty Years of International Follow-up Studies After Sex Reassignment Surgery: A Comprehensive Review, 1961-1991; English Ed. by Jacobson & Meier

<sup>16</sup> Smith, YLS. Van Goozen, SHM. Kuiper, AJ & Cohen-Kettenis, PT. (2005) Sex reassignment: outcomes and predictors of treatment for adolescent and adult transsexuals, *Psychological Medicine* 35:88-99.

<sup>17</sup> Schonfield, S. (2008) Audit, Information and Analysis Unit: audit of patient satisfaction with transgender services.

<sup>18</sup> Weyers, S. Elaut, E. De Sutter, P. Gerris, J. T'Sjoen, G. Heylens, G. De Cuypere, G. & Verstraelen, H. (2009) Long-term assessment of the physical, mental and sexual health among transsexual women, *Journal of Sexual Medicine* 6:752-760.

NHS gender identity clinics set their own criteria on access to treatment. Whilst the Commission recognises and supports the need for flexibility in treatment of each trans person, the variable criteria for treatment amongst gender identity clinics does, however, affect what each trans person may be offered depending on which clinic they are referred to. For example, all patients who want to have genital reconstruction surgery have to undergo a Real Life Experience (RLE) process living in the preferred gender identity. However, there is no consistent approach taken by NHS gender identity clinics in respect of the length of time patients are required to undergo RLE. The West London Mental Health Trust gender identity clinic requires patients to undergo RLE for two years whereas the Leeds Partnerships NHS Foundation Trust gender identity service requires patients to undergo RLE over a period of three to six months and, in special circumstances, this can be shortened to a period of one to two months. In general, once a trans person is established with a gender identity clinic, contact with another gender identity clinic is not accepted. This is a particular issue which affects younger trans people who have moved away from home to attend university because they have limited funds to pay for their travel back home for appointments with the gender identity clinic they are registered with<sup>19</sup>.

### **Conforming to stereotypes**

It is the view of advocacy groups that gender identity clinics are slow to see patients and apply a "one size fits all approach to treatment" which puts pressure on trans people to conform to stereotypes in order to access treatment. The suggestion that gender reassignment treatment follows a "one size fits all" approach has also been made by Hines (2006)<sup>20</sup>. She argues that only those who articulate the current medical understanding of gender reassignment are granted gender reassignment, whilst those whose gender identities are more complex or ambiguous are denied treatment. Elsewhere Hines (2007a)<sup>21</sup> suggests that trans people will conform to the medical discourse on transsexualism in order to ensure they receive treatment. This discourse centres on the sense of "being in the wrong body". Patients may articulate this in interactions with psychiatrists, glossing over or denying

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<sup>19</sup> Combs, R.M (2010) Where gender and medicine meet: Transition experiences and the NHS

<sup>20</sup> Hines, S. (2006) 'What's the Difference? Bringing Particularity to Queer Studies of Transgender', *Journal of Gender Studies*, 15(1), pp.49-57

<sup>21</sup> Hines, S. (2007a) 'Transgendering Care: Practices of Care within Transgender Communities' *Critical Social Policy*, 27, pp.462-486

experiences which do not conform to it. One of Hines' (2007a) respondents reported that she gave the doctors the answers that she knew were required to continue treatment.

According to Cromwell (1999, cited in Hines, 2007a), this type of response has led to the replication of a simplistic view of transsexualism which fails to capture the diversity of trans experience. It also encourages an inflexible approach to treatment of gender reassignment which is problematic because not all elements of gender reassignment treatment are necessary or desirable in every case, nor will the sequence confirm rigidly to a standard pattern<sup>22</sup>. These issues also highlight the important role of clinicians in the individual care pathway of each trans person. According to Hines (2006, cited in Hines, 2007b<sup>23</sup>), clinicians "work as regulators within a system that largely continues to pathologise the transgender experience".

### **Clinical views**

Clinicians, however, disagree with some of the messages portrayed by research about the barriers faced by trans people.

Anecdotal views from clinicians express concern about GPs who broadly tend to act as a blockage to enabling access to gender identity clinics either because of lack of knowledge and understanding about trans issues and/or because of low prioritisation of this area of healthcare. Clinicians describe the reluctance of GPs to refer trans people to gender identity clinics so that by the time trans people do reach clinics, they are dissatisfied and this affects their experience of the service.

Clinicians also expressed concern to us about a lack of consistency in funding policies across the PCTs which leads to an added administrative burden at clinics, especially when dealing with referrals from a PCT where there is no service level agreement in place.

Clinicians challenge the view that trans people have to invent life histories in order to qualify for treatment. According to Barrett (2007),<sup>24</sup> patients who present "only what they feel to be important do themselves a disservice because limiting the information they give in this way will limit the ability of the interviewer to make a properly informed decision".

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<sup>22</sup> Parliamentary Forum on Gender Identity (2009) Guidelines for health organisations commissioning treatment services for trans people

<sup>23</sup> Hines, S. (2007b) TransForming gender: Social change and transgender citizenship, Sociological Research Online, Vol 12, Issue 1

<sup>24</sup> Ibid

Barrett (2009)<sup>25</sup> also describes that it is in the interests of clinicians to have a true account of a trans patient's life history because inappropriate treatment produces "drastic, irreversible effects and can be viewed as disastrous". It has also been the subject of negligence litigation and General Medical Council censure<sup>26</sup>.

Reports of unsatisfactory services are also criticised by clinicians for being "anecdotal", lacking robust data and reflecting an ideological view that there is no role for psychiatry in gender reassignment. Whilst outcome measures continue to be developed in relation to gender reassignment services, patient satisfaction surveys used by clinicians to evaluate service user experience have been used to challenge reported evidence about barriers experienced by trans people. For example, adaptation of the US Porterbrook Service user satisfaction questionnaire<sup>27</sup> into a UK clinical service was successful in identifying service user satisfaction with two specialist clinical services for sexual, relationship and gender-related problem areas<sup>28</sup>. 78 per cent of gender clinic service users and 84 per cent of relationship and sexual clinic service users expressed being satisfied or very satisfied with the service. Although breakdown of these results suggested that for those receiving medication from the service, satisfaction was greater in the relationship and sexual service user group than in the gender service. However, satisfaction with clinician factors scored highly, with the exception of flexibility and promptness of appointments in the gender service. According to the survey, "the vast majority of patients from both services would recommend our service to friends or family".

### **Key findings:**

- Research suggests that a range of barriers are experienced by trans people accessing NHS gender reassignment services from referral by GPs to funding by PCTs, to treatment by clinicians.
- The Commission's analysis of PCT and SCG policies on gender reassignment services suggests that access to services is highly

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<sup>25</sup> Barrett, J. (2009) The clinical risks associated with the diagnosis and management of disorders of gender identity, The Royal Society of Medicine Press Limited, 15: 131-134

<sup>26</sup> General Medical Council. Case Reference 2006/0451

<sup>27</sup> Bockting, W., Robinson, B., Benner, A., & Scheltema, K. (2004) Patient Satisfaction with transgender health services, Journal of Sexual and Marital Therapy, 30, 277-294.

<sup>28</sup> Wyle, K., Fitter, J. & Bragg, A. (2009) The experience of service users with regard to satisfaction with clinical services

dependent on where you live and subject to variable criteria for eligibility and type of treatment.

- Some trans advocacy groups describe pressure to conform to medical criteria to access treatments in gender identity clinics. Clinicians disagree and refer to the need for high thresholds for treatment, to avoid clinical negligence. They also cite patient satisfaction surveys used by clinics that show a broadly positive experience.
- Clinicians express concern about GPs preventing access to gender identity clinics because of lack of knowledge and understanding about trans issues and/or low prioritisation of this area of healthcare. Clinicians also express concern about inconsistent funding policies across PCTs.
- Recent examples suggest that financial pressures continue to be used as a reason for restricting access to gender reassignment services. Given limited public funds, this is likely to be a continuing issue. Restricted access to these services has also been justified by concerns about the efficacy of gender reassignment treatments. This has been challenged by clinicians.

## **NHS reforms: an opportunity to address problems?**

Reforms in the NHS offer a timely opportunity for the difficulties and inconsistencies described in accessing NHS gender reassignment services to be addressed.

### **Proposed NHS commissioning arrangements**

Under the proposed NHS commissioning arrangements, the NHS Commissioning Board will be established to manage general practice contracts, set the practice-level budgets for the new Clinical Commissioning groups, monitor and hold Clinical Commissioning Groups to account for their commissioning and directly commission certain services defined as "specialised"; this includes gender reassignment services<sup>29</sup>.

According to the original timetable for NHS reform:

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<sup>29</sup> See Parliamentary Question Number 13488, 09.09.2010, tabled by Caroline Lucas MP, answered by Paul Burstow, Minister of State for Care Services.

- PCTs will be abolished from April 2013<sup>30</sup>.
- An NHS Outcomes Framework will set expectations for performance.
- Local HealthWatch will replace Local Involvement Networks (LINKs).
- Local HealthWatch will be commissioned by the Local Authority, and will provide feedback to them and to HealthWatch England on the delivery of local services.
- All local authorities will have a Health and Wellbeing Board (or similar) which will reflect the greater role of Local Authorities in joint commissioning needs assessments and integrated commissioning with the NHS.
- Local authorities will take on some public health responsibilities. Public Health England will have a national role and some public health functions will be commissioned from NHS organisations.
- Healthcare providers will be subject to a dual monitoring and licensing system through Monitor and the Care Quality Commission (CQC).
- The role of Monitor will change from dealing only with Foundation Trusts to that of economic regulator of all providers in the NHS.
- The CQC will be responsible for ensuring health services meet essential standards and receive feedback via HealthWatch England.

## **Possible ways forward**

### **NHS Commissioning Board**

Oversight of gender reassignment services as a specialised service by the NHS Commissioning Board would be welcomed by the Commission as this may help to ensure consistency via establishing a clear funding policy for all requests for gender reassignment treatments. This policy might help to avoid wide variation in interpretation by GPs and is likely to apply to all trans people who request a referral to NHS gender reassignment services.

By having oversight of NHS gender reassignment services at a national level including funding of these, the NHS Commissioning Board should be well-placed to ensure accountability of GPs on requests for referrals for gender reassignment treatment and to identify constraints within local

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<sup>30</sup> Ibid

gender reassignment services (and services related to these, for example, mental health). There are various methods for assisting the board to achieve this accountability. For example, the board will have powers to step in and provide continuity of primary care services, if failure is apparent<sup>31</sup>.

The Gender Identity Research and Education Society recommends that this opportunity for change adopts the approach set out in the Audit, Information and Analysis Unit survey of patient satisfaction with transgender services (2008)<sup>32</sup> which suggested in the guidance for GPs, that patient choice should include not only the existing gender identity clinics, but other more varied combinations of treatments and clinicians (local, national, private and NHS) where provision is of comparable quality and competitive cost. According to some clinicians, as and when private suppliers are used, it should be a requirement that any private gender identity clinic or practitioner adhere to the forthcoming UK intercollegiate standards of care and quality management system that exists in the NHS. For example, via the essential standards by which all health bodies are assessed by the Care Quality Commission (CQC) and terms of authorisation which are used by Monitor to regulate NHS foundation trusts.

### **The General Medical Council**

The General Medical Council (GMC) has an important role to play as the regulator for GPs in the UK via its legal powers under the Medical Act 1983 which include fostering good medical practice and dealing firmly and fairly with doctors whose fitness to practice is in doubt.

The GMC should consider the extent to which the tools it uses to regulate the standards of GPs provide adequate assurance of effective equality and human rights practice. This will aid the GMC's compliance with the public sector equality duty, in respect of GMC activities which amount to functions of a public nature<sup>33</sup>. It will also aid the GMC's

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<sup>31</sup> <http://www.guardian.co.uk/healthcare-network/2011/mar/10/nhs-commissioning-board-will-cost-400-million>

<sup>32</sup> Schonfield, S. (2008) Audit, Information and Analysis Unit: Survey of Patient Satisfaction with Transgender Services, [http://www.marmotreview.org/AssetLibrary/resources/external reports/NHS - survey of patient satisfaction](http://www.marmotreview.org/AssetLibrary/resources/external%20reports/NHS%20survey%20of%20patient%20satisfaction)

<sup>33</sup> There are two ways in which a person or body can be subject to the duty. It can either be listed in Schedule 19 to the Act, or it can be subject to the duty because it is exercising "a public function" (defined in section 150(5) of the Act as "a function that is a function of a public nature for the purposes of the Human Rights Act 1998

compliance with s6 HRA 1998 to comply with the European Convention on Human Rights, together with positive obligations under Convention law to promote and protect human rights. For example, to practice medicine in the UK all GPs are required by law to be both registered and hold a licence to practice. Licensing will require periodic renewal by revalidation. Revalidation is the process by which licensed GPs will, in future, regularly demonstrate to the GMC that they are up to date and fit to practice. This is expected to begin in late 2012. The EHRC is keen to assist the GMC in this process by clarifying the requirements of equality and human rights law.

The GMC, and other professional bodies which represent GPs, such as the Royal College of General Practitioners and British Medical Association, are also well-placed to review the extent to which medical training of future GPs and ongoing professional training of qualified GPs covers trans healthcare issues as part of wider equality and human rights awareness and understanding, and to promote DoH or NHS guidance for GPs on gender reassignment.

### The Department of Health

The Department of Health (DoH), as the sponsor department responsible for public health in England, has a pivotal role during transition to the new commissioning arrangements to ensure that the NHS Commissioning Board addresses the challenge of ensuring that trans people can access appropriate gender reassignment services wherever they live.

The DoH needs to consider, as part of compliance with the public sector equality duty (PSED), how it can positively contribute to the advancement of equality and good relations in respect of gender identity, and reflect equality considerations into the functions of the NHS Commissioning Board (for example, the Board's oversight of NHS gender reassignment services). The DoH will need to consider how these issues are dealt within the transition arrangements to the new NHS structure, for example, via the sub-regional clusters set up to take over the functions of Primary Care Trusts and handle commissioning offers. Post-transition, it will be important for the DoH to keep these

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(c. 42)). See Explanatory Memorandum to the Equality Act 2010 (Public Authorities and Consequently and Supplementary Amendments) Order 2011 - <http://www.legislation.gov.uk/si/2011/1060/contents/made>

issues under review and the accountability of the NHS Commissioning Board to the DoH will be helpful to ensuring that this happens.

The DoH may wish to consider creating an NHS portal which gives clear information about what gender reassignment services are available in the NHS and work with NHS Choices/NHS Direct to implement this in the new structure. The portal would provide clarity to trans people and GPs about the standard process of referral from a GP, through to treatment at an NHS gender identity clinic.

The DoH may also wish to consider reviewing their current guidance to GPs on gender reassignment and publicising the new guidance.

In responding to these recommendations, the Commission recommends that the DoH draws on the recent experience of NHS Scotland. In response to concerns raised about inconsistent access to, and experiences of, NHS gender reassignment services, the Scottish government has delegated responsibility to NHS Health Scotland to draft a national protocol about access to these services. A working group has been set up, including representatives from the transsexual community in Scotland, which reports on progress to the Commission's Scottish legal team at set points in the process. They have also conducted detailed focus groups with transsexual people across Scotland. The Scottish government has committed to carrying out an equality analysis on the new protocol and incorporating changes to take findings into account.

### **Local authorities**

The Commission recommends that local authorities use the Joint Strategic Needs Assessment (JSNA) as a key tool to assist with mapping local need and provision across the local authority area. JSNA is the method by which local authorities describe the future health, care and well-being needs of local population and the strategic direction of service delivery to meet those needs using data and information on inequalities in local areas. As co-ordinators for public involvement working with local HealthWatch and Health and Wellbeing Boards, local authorities may need to work with local trans people and groups which represent trans people, where these may exist, to help ensure that their perspectives are included in the scrutiny of gender reassignment (and other health) services. Early notification of any consultation is recommended to avoid consultation fatigue because of the voluntary status of trans groups and thus their limited capacity to respond.

## **Monitor and the Care Quality Commission**

The dual licensing role of Monitor and the CQC suggests there is a need to include collective consideration by both bodies about how human rights and equality for trans people can be factored into their judgement of the performance of health services. This may help compliance with the public sector equality duty, under which both bodies will have obligations. For example, Monitor should review the extent to which the Compliance Framework it uses to regulate NHS foundation trusts, refers to the obligations these trusts have under the Human Rights Act 1998 and the Equality Act 2010, including the new public sector equality duty. The CQC needs to ensure that accountability arrangements of HealthWatch England include an explicit requirement for feedback to the CQC on issues related to inadequate commissioning decisions at local levels.

The Commission has a Memorandum of Understanding with the CQC which can be used to identify what additional actions need to be taken to ensure that the new dual licensing function demonstrates compliance with equality and human rights law. We have offered to clarify the requirements of equality and human rights law and to help ensure integration of equality and human rights dimensions of health and care into Monitor's regulatory framework as it responds to a changing NHS.

### **Key findings and recommendations:**

- Oversight of NHS gender reassignment services as a specialised service by the national NHS Commissioning Board is welcome. This should help to ensure consistency by establishing a clear policy for requests for gender reassignment treatments and accountability of GPs.
- The General Medical Council (GMC) has an important role as the regulator for GPs and should consider the extent to which the tools it uses to regulate the standards of GPs provide adequate assurance of effective equality and human rights practice.
- The GMC and other professional bodies which represent GPs may wish to review the extent to which medical training of future GPs and ongoing training of qualified GPs covers trans healthcare issues. They could also promote Department of Health or NHS guidance for GPs on gender reassignment.
- The Department of Health (DoH) has a pivotal role during transition and post-transition, to ensure that the NHS

Commissioning Board addresses the challenge of ensuring that trans people can access appropriate gender reassignment services wherever they live. It can do this via reflecting equality considerations into the functions of the NHS Commissioning Board. The DoH will need to consider how these issues are dealt with the transition arrangements to the new NHS structure and post-transition, the DoH will need to keep these issues under review.

- The DoH may wish to consider creating an NHS portal on NHS gender reassignment services and work with NHS Choices/NHS Direct to implement this in the new structure. The DoH may also wish to consider reviewing their current guidance to GPs on gender reassignment.
- The Commission recommends that the DoH draws on the experience of NHS Scotland who, in response to concern about NHS gender reassignment services in Scotland, asked NHS Health Scotland to draft a national protocol.
- The Commission suggests that the DoH highlights issues relating to NHS numbers for trans people to be picked up in the new NHS information management system.
- The Commission recommends that local authorities use Joint Strategic Needs Assessment to map local need and provision and work with local trans people to include their perspectives in the scrutiny of gender reassignment (and other health) services.
- The dual licensing role of Monitor and the Care Quality Commission can be used to include consideration about how human rights and equality for trans people can be factored into their judgement of the performance of health services.

## **Conclusion**

This review has considered evidence which describes the weaknesses in the current design and delivery of gender reassignment services and lends support to the issues raised by trans advocacy groups and individual complaints to the Commission about difficulties in accessing these services. Given the major changes to the NHS commissioning system, this is a timely opportunity for many organisations engaged in this process to ensure that NHS gender reassignment services offer consistent treatment to all trans people, irrespective of where they live in England. Revisions to NHS gender reassignment services will aid public

authorities in their response to the duty to promote equality under the public sector equality duty. These revisions need to be considered as part of the drive for improving health services for everyone. The Commission, as the body with a statutory remit to promote and monitor human rights; and to protect, enforce and promote equality across the protected grounds which include gender identity, has set out some recommended approaches in this review to aid the key bodies involved in the commissioning and monitoring of gender reassignment services and will be monitoring how these bodies respond to these recommendations over the next year.

## **Annex A - Terminology**

### **Trans and transgender**

The terms 'trans people' and 'transgender people' are both often used as umbrella terms for people whose gender identity and/or gender expression differs from their birth sex, including transsexual people (those who intend to undergo and are undergoing or have undergone a process to live permanently in their acquired gender). Other self-descriptions include androgyne, polygender, pangender or gender queer. Gender variant is also a widely used term to cover any gender expression that is not typical and it is particularly used about young people who may not ultimately undertake gender reassignment.

Whittle *et al* (2007) note that 'trans' is an inclusive term 'adopted in the late 1990s by the UK Government, now commonly used by members of the UK cross-dressing and transsexual community to refer to themselves' (p. 85). The term 'transgender' is also widely used to describe this population. Whittle *et al* (2007) state that 'transgender' is: 'a very broad term to include all sorts of trans people. It includes cross dressers, people who wear a mix of clothing, people with a dual or no gender identity, and transsexual people. It is also used to define a political and social community which is inclusive of transsexual people, transgender people, cross-dressers (transvestites), and other groups of 'gender-variant' people' (p. 85). Non-gendered people may prefer not to be considered under the trans umbrella. The trans community is also subject to common myths and confusion around sexual orientation and gender identity; that trans people are mostly lesbian, gay or bisexual which is not the case. As with the general population, there is a variety of sexual orientation across the heterosexuality, lesbian, gay and bisexual spectrum.

### **Transsexual**

The term transsexual is used to describe people who seek gender reassignment treatment, which may include gender constructive surgery. Transsexual people generally identify with the opposite sex from a young age (Fish, 2007b). Most people who have transitioned permanently, regard themselves, and wish to be regarded by others, as men and women (Burns, 2008). Such people may consider themselves for all intents and purposes members of that gender and not a transsexual person, a fact recognised by the Gender Recognition Act

2004. Where reference to a past gender role is unavoidable, the term man or woman of transsexual history, is sometimes used.

### **Gender dysphoria**

Gender dysphoria is the term which is often used to describe the extreme discomfort that arises when the 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. Whittle *et al* (2007, p. 86) state that this is the "term used by psychiatrists and psychologists to describe the condition transsexual people have – that is not feeling well or happy with their gender as assigned at birth, in terms of both their social role and their body". A "diagnosis" of gender dysphoria is required before gender reassignment treatment.

### **Transvestite or cross-dresser**

These terms refer to people who wear, for short periods of time, the clothes associated with people of the opposite sex. Some may do this because they identify with the opposite sex and therefore may decide to transition full-time at some point. Others may cross-dress for a variety of reasons but wish to remain within their natal sex.

### **Male-to-Female (MtF) and Female-to-Male (FtM)**

Alternative terms for MtF and FtM are (which are not always considered polite) are 'trans woman' and 'trans man' respectively. These are used to describe the direction of the person's 'transition', which marks the stage when trans individuals start to live in the gender role that accords with their innate gender identity. There is disagreement over whom these terms include. Whittle *et al* (2007) and Aston and Laird (2003) apply them to all trans people, but Fish (2007b) appears to apply them more specifically to transsexual people.

### **Intersex conditions**

There are a number of intersex conditions (recently renamed Disorders of Sex Development) some of which lead to physical genital anomalies. Those born with them may experience inconsistency between their gender identity and the gender role assigned at birth. The developmental anomalies that fall under the intersex umbrella may be associated with atypical sex chromosomes such as Klinefelter syndrome (XXY) or Jacob's syndrome (XYY), or mosaicism (a mix of chromosome configurations) or other genetic anomalies, such as Androgen

Insensitivity Syndrome or Congenital Adrenal Hyperplasia in which unusual hormone levels are present in the fetus<sup>34</sup>.

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<sup>34</sup> Gender Identity Research and Education Society (2011)