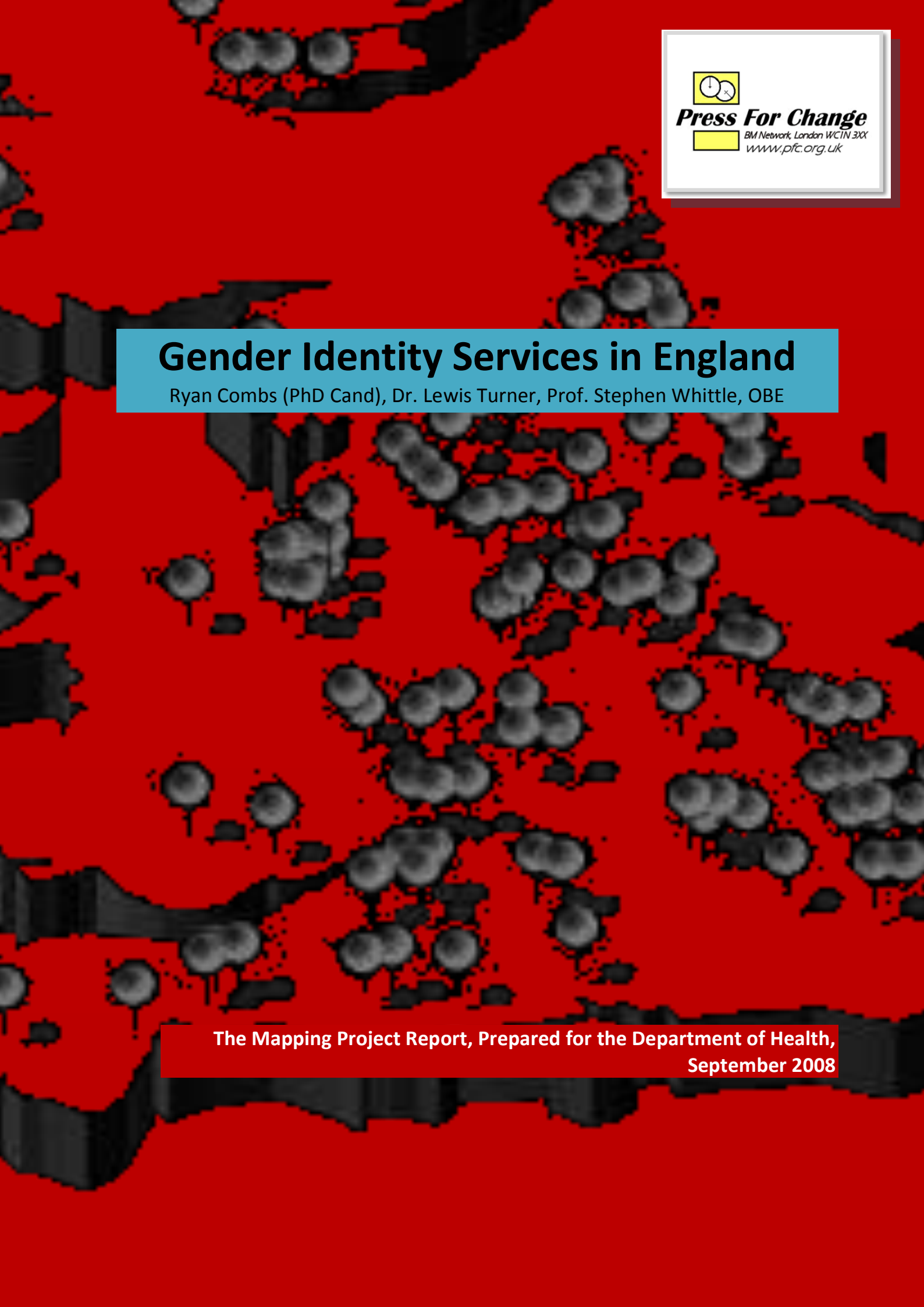


Gender Identity Services in England

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The Mapping Project Report, Prepared for the Department of Health, September 2008

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Prepared for the Department of Health,

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Foreword

This study was undertaken throughout late 2007 and during 2008. It was not easy research to undertake partly due to the politics around gender reassignment treatment. As this study will show, clinicians providing gender reassignment services are embattled on many fronts and many are wary of researchers intruding on their clinical work. The service provision for gender reassignment – or rather the lack of it, can position providers and service users in a difficult relationship at times. Many trans people have been waiting years for an initial assessment and by the time they do come to a clinic, are very frustrated with the process.[1] Additionally there is the controversy around such treatment, with the service rarely being out of the public eye. Indeed the service has an 'image problem' even within the health service, which puts pressure upon those working in the field and commissioning services.

In the UK, service provision for Gender Reassignment started in the 1940s, with several maverick practitioners seeing patients within their private clinics. The first recorded UK surgery was the provision of a bilateral mastectomy and phalloplasty (to create a penis) for the transsexual man Michael Dillon.[2] This was followed by the highly publicised story of Roberta Cowell, though there were probably others out of the public eye.[3] In 1963 a male to female (mtf) trans woman Georgina Turtle estimated that there were "between 3,000 and 15,000 transexualists (sic) in Britain"; an incidence rate of between 1:16,000 and 1:3,000.[4] Turtle acknowledged that there was no factual basis for these figures other than her own personal knowledge and the evidence she had collected.[5]

In the 1970s there were gender reassignment clinics based in very few places. They were often led by some of the great names in the history of psychiatry and endocrinology, who either saw the transsexual person as a 'fascinating' case, or as was the case in a very small number of clinics, a 'certain empathetic' view was taken.[6] There were larger clinics in Newcastle upon Tyne under psychiatrist Professor (later Sir) Martin Roth and endocrinologist and intersex expert Professor Charles N. (Natty) Armstrong, and in London at the Hammersmith (Charing Cross) Hospital under psychiatrist Dr. John

I. Tingle (2006)

II. Hodgkinson, L. (1989)

III. Cowell.R (1954)

IV. It is clear that Turtle is including part time cross dressers and those people who fully transition from one gender role to another, as well as those who undergo medical and surgical gender reassignment.

V. Turtle,G (1963): 48.

VI. Casenotes from interviews with former junior doctors

Randell where, by 1980, he had seen 2438 (1768 male and 670 female) trans patients.

There were several other clinical services, providing a few hours of clinical time in London; at Queen Charlotte's hospital under Professor of Obstetrics and Gynaecology, C J Dewhurst, and at the York Clinic, Guys Hospital under Dr. John M. Annear and at the Royal Bethlem and Maudsley Hospital under psychiatrist Professor Isaac Marks. Finally there was some clinical time provided in Manchester at Withington Hospital (now part of the South Manchester Trust) under the psychiatrist, Professor David Goldberg, and psychologist Jack Kenna of the Gaskell House Unit of the Manchester Royal Infirmary (now Central Manchester Trust). All of these clinics dealt in small numbers, with the clinic of John Randell at the Hammersmith hospital (which became know as the Charing Cross Gender Identity Clinic, and is now the Claybrook Centre) being the largest, though even then in the 1970s figures of patients per year were less than 200.[7] Now there are up to 2500 patients being treated at any one time.[8]

At the time of Turtle's assertion her figures would have been met with incredulity by members of the medical world, but in the early part of the 21st Century it is clear that those numbers are the tip of a much larger iceberg. It is clear that since 1996, following some specific key events such as television screenings of trans people's stories, the numbers of people seeking medical and surgical gender reassignment have risen considerably and now appear to be growing exponentially (see chap 3, para 3.2).

The status of such treatment has always been problematic**.** In the 1950s it was either regarded as a form of madness, or it was regarded as a form of intersex condition by the more enlightened clinicians. For example, the clinicians at Guys hospital and the Maudsley developed surgical techniques for gender reassignment surgery from their hormonal and surgical services for people with an intersex condition. The surgery to form a neo-vagina had been originally developed for CAIS women.[9] However with the appearance of John Randell as a successful expert witness in the Court of Appeal case of Corbet v Corbett it was increasingly seen as a condition requiring psychiatric intervention. [10] Finally, this was verified by the publication of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (third edition, revised) (1980), (DSM IIIR), ensuring that from now on treatment would be based upon a psychiatric model of cross-gender behaviour. Now, in most clinical settings the psychiatrist acts as a 'gatekeeper' to other services such as surgical reassignment.

This continues today despite the 1999 judgement which simply held that transsexualism was an illness and entitled to treatment under the auspices of the National Health Service Act(s).[11] Yet, it is

VII. King, D (1993) and King D (2002)

VIII. Interview with psychiatrist

IX. Walsh PC, Scott WW. (1979)

X. Corbett v Corbett [1970] 2 All E.R. 33, 48; [1970] 2 W.L.R. 1306-1324

XI. R v North West Lancashire HA Ex p. A, D and G, (1999) QBD

clear from the list of 'expert' doctors entitled to assess and approve transsexual people in order for them to obtain legal recognition of their acquired gender, that not only are psychologists (rather than psychiatrists) actively involved in assessment, diagnosis and treatment, but also many non-psycho-therapeutic doctors.

With this diverse range of services and a growing number of patients we have reviewed and mapped current clinical provision as best we could within the limitations explained in our methodology. We have endeavoured to let clinicians speak for themselves about the services they provide in order to build up as accurate a view as we can.

In this report we review the current clinical services available for trans people in the UK. Some findings have surprised us and made us aware of how difficult a practitioner's job can be in this field. Whist writing this, Health Care Wales effectively shut down clinical services in Wales by refusing to fund any treatment for transsexual people, including initial assessments, leaving the very few practitioners to look elsewhere for patients to fill their clinical time. Similarly many other Primary Care Trusts are refusing funding for surgery for transsexual people. Generally, the view from the patient experience is one of doom and gloom[12] yet by the middle of 2008 over 2200 people had successfully obtained legal recognition in their preferred gender, and on average there are still upwards of 300 people applying for such recognition each year.[13] Each one of these must have been assessed, and many will have started if not completed treatment and possibly surgery.

We want to stress that this report is not an evaluation of clinics, or the clinicians working in them, but rather it is a 'snapshot' of service provision including where the provision is geographically, what they can provide and what clinicians themselves think is helping or hindering them with their work. We hope that this information will facilitate planning and help improve the provision of these services.

The many conclusions and recommendations we make are intended to be signposts through this very problematic service. In our opinion, they are ways of improving the lot for both doctors and patients, and creating a happy, dynamic and responsive service.

Prof. Dr. Stephen Whittle, OBE,
Head of the Mapping Project team
28 September 2008

XII. Eastwood (2007)

XIII. Figures obtained from the Gender Recognition Panel, September 2008





Executive Summary

This report is an enquiry into the current state of the provision of services for gender dysphoria from the perspective of frontline service providers

1. Methodology

This report is based on qualitative data collected from interviews with healthcare professionals working in the field of gender reassignment, between November of 2007 to March of 2008 in England and Scotland. . During the interviews, participants discussed:

- the services that they provide,
- the types and locations of patients to whom they provide services,
- the principles underpinning clinic governance,
- their perspectives on the current state of service provision
- what constrained the delivery of services to their satisfaction

Our sample included eight clinical leads of both small and large clinics in the UK. Due to time constraints and problems gaining access to participants, this sample does not cover all clinics. However, due to the consistency of the perspectives of participants on current service provision we suggest that our sample is sufficient to draw the conclusions that we have.

2. Interview findings

Practitioners were deeply committed to assisting individuals who experienced gender dysphoria, yet many expressed their dissatisfaction regarding the wider systemic, clinical, political and professional environments in which they worked. These are summarised as follows:

2.1. The commissioning process

Participants expressed strong views about the process of commissioning funding for individual patients and described how it encroached on their workload. They cited lack of clarity in the process; the volume of paperwork and the judgements of funding providers as deeply problematic.

➲ **We recommend that the commissioning process should be clarified to reduce paperwork and expedite the funding process. Commissioning decisions should be based on practitioner opinion and previous legal judgements.**

2.2. The politics of funding gender reassignment

Problems in the commissioning process were regarded as a systemic but also politically influenced. Commissioning bodies viewed gender reassignment treatment - described by one practitioner as ‘life-threatening, as a low priority and/or did not want to be publicly known as

funding such treatment. It was suggested by some participants that funding decisions may be influenced by politics, with decision makers avoiding being publicly seen to be supporting or 'advocating' gender reassignment.

➲ **Funding bodies need educating in the clinical needs of those with gender dysphoria as well as their legal obligations.**

2.3. The politics of being a gender reassignment practitioner

Participants suggested that the political environment of gender reassignment implicitly affected the way that the field was viewed by other health care professionals. This 'image problem' meant that they found it difficult to find new people to specialise in the field. Some felt that there was little knowledge in mainstream medicine about the work that they did and that their work was not sufficiently legitimised. Practitioners were also aware of the criticisms of pressure groups.

➲ **We recommend improved support for clinicians with a training program or mentoring scheme to bring more specialists into the field.**

2.4. Professional relationships

The field of gender dysphoria is a marginalised one, with many participants stating that they worked in professional isolation. There is a lack of meaningful communication between practitioners and little professional support for practitioners and clinical directors. This means that the provision of gender reassignment treatment is not uniform across clinics or indeed across England.

➲ **We recommend more communication between individual practitioners and clinics and to set up a national organisation or fellowship of practitioners who treat gender dysphoria.**

2.5. Great expectations of gender reassignment

The barriers to providing care to practitioners' satisfaction detailed in this report have a bearing on the relationship between practitioners and service users. The delays caused by the current process of funding, coupled with long waiting times for treatment means that many service users, having experienced barriers to their care pathway may regard practitioners as further 'gatekeepers' in the process. Practitioners stated they were uncomfortable with the power dynamics that this entailed.

➲ **We recommend that practitioners should develop collaborative relationships with patients as much as possible. If our other recommendations are acted upon, this relationship may become easier.**

2.6. Local v National services

The current national clinical arrangements have come about in an ad-hoc fashion, where gender clinics have been established in response to practitioner interest and local need. This

means that some areas provide services locally or regionally, whilst others prefer to use services commissioned from outside of their area. Some practitioners expressed the desire for development of clinics to be further regionalised. However, large national clinics were keen to emphasise that their experience and expertise with a wide range of patients are of value when treating gender dysphoria, particularly those with complex needs.

- **We recommend that local, regional and national services need to be further developed in line with patient needs**

2.7. Systemic problems: waiting lists

Long waiting lists for assessments, specialist appointments and surgery continue to be a significant problem. This was not limited to particular clinics or areas; it was found repeatedly in interviews taking place across England. This problem is compounded by clinics experiencing financial uncertainties, retirements and closures.

- **National strategies and coordination must be put in place to cope with the realities of future higher demand for the services. Funding should be provisionally approved for an entire treatment of one patient from the outset, thus eliminating roadblocks in further stages of treatment.**

2.8. Clinical challenges

Practitioners stated that there could be improved coordination between the numerous clinicians needed to treat a patient. Many interviewees desired the creation or expansion of linkages with other practitioners in their area, particularly surgeons, endocrinologists and therapists

- **Clinics need to be expanded and clinicians need teamwork in order to provide comprehensive services.**

3. The need for future research

This research has limitations, which are outlined in the Methodology section of this report. Further research is needed in a number of areas for a comprehensive review of current provision including in-depth investigation of the following:

- **The contentious yet important question of whether or not gender dysphoria should continue to be a considered a mental health condition.**
- **The views of the patient group on service provision.**
- **A thorough review of current service provision with a robust action plan on how the service can meet the growing need.**



FOR YEARS WE'VE BEEN SHOUTING 'THIS IS A PROPER PART OF MEDICINE'
(2008 UK GIC PSYCHIATRIST)

Chapter 1: Introduction and Literature Review

1.1. About Trans People and Gender Dysphoria

Gender dysphoria is a condition whereby individuals have strong feelings of discomfort and disconnection with their birth sex. There are a number of variations along the wide range of cross-gender identity and behaviour amongst people. Among the most common of these identities are those who feel transgender and transsexual. Transgender people are generally understood to be those who are unhappy with their birth sex and live in their preferred gender, but do not seek medical intervention to achieve this social transition. Transsexual people however, may require medical treatment to facilitate a physical transition from one sex to another. There are also others who struggle with having uncomfortable feelings about their gender but are unsure as to the path they want to take. Often, the descriptor 'trans' is used to describe people who fall within a diverse range of incongruent gender identities.

1.1. How many Trans People are there?

There has been considerable work on estimating the number of transgender and transsexual people within the UK population (see the discussion in Witten et al, 2003) and the conclusion must be that there is simply no publicly available statistical data on which to make firm estimates. In 2000, after informal consultations with the Passport Section of the Home Office, Press for Change estimated there were around 5,000 transsexual people in the UK, based upon numbers of those who had changed their passports (Home Office 2000), though a Scottish Needs Assessment Survey in 2004 would indicate half that number (Scottish Needs Assessment Programme 2001). As of September 2008, 2201 people had already been awarded a Gender Recognition Certificate (GRC).[14] Nevertheless, there is no substantive knowledge of how many people in the UK identify as transgender or transvestite, or use any other gender identity descriptor. Estimates vary considerably, with a quick internet search suggesting figures from about 1 in 100 to as many as 1 in 20 in the male population.

1. Correspondence between Press for Change and the Gender Recognition Panel Secretariat, November 2006.

Recent estimates placing the number of transsexual people residing in the United Kingdom at around 5,000 people [15] are clearly a very low.[16] There are currently no accurate estimates as to the number of trans people in the UK in total, as the above figure does not include an unknown number of transgender people, cross-dressers and others who may well face dysphoria about their gender but for whom there is currently very little clinical support. Recent research suggests that the trans population is growing on an exponential scale.[17]

In **A, D & G v North West Lancashire AHA** (1999), court held that Gender Dysphoria was classed as an Illness under the National Health Service Acts 1948

The Court Held: Commissioning bodies for health care CAN NOT impose a Policy of a Blanket Administrative Ban on Gender

Many aspects of trans identity formation are presently unknown, including its cause and origin. Some disciplines suggest a congenital basis, but debates about this are contentious and no single cause has been proven. The condition is classified as a mental health issue in DSM IV-TR and ICD 10 due to the harmful effects that it can have on an individual's psychological well being. At present, it is classed by the National Health Service as an illness following the case of A, D & G v North West Lancashire AHA, (December 21st 1998)[18].

There are a number of organisations that connect trans people for the purposes of support, education and advocacy. The largest of which, Press for Change (PFC), is a political lobbying and educational group for in the UK. In the process of their work over the past sixteen years, PFC has accrued over 2500 contacts with people around the country who identify as trans. Due to the stigma and potential social repercussions of expressing cross-gender feelings, a great deal of support is required for a successful social transition. In response, a number of small local and regional peer support groups have developed around the country, along with a growing number of online resources. Although these sources of information have multiplied over recent years, most people with gender dysphoria are 'coming out' in isolation and do not have the strong social networks to assist them during this time. Some people struggle with

2. Home Office (2000) The statistics from the Interdepartmental Working group drew upon figures on gender changes on Passports and Driving Licenses.

3. Recent research by Press for Change suggests that the figure is more likely to be around 20,000 (Whittle et al, 2008 and Whittle et al t 2007').

4. The Transgender Euro Study 2008 found that the majority of survey respondents (n 2575) had transitioned in the last 5 years.

5. North West Lancashire Health Authority v A, D, & G, QBC 1999/0226/4; 0228/4; 0230/4

their gender identities for many years before approaching the health service, especially when faced with opposition from friends or family.[19]

1.2. Gender Dysphoria

People who struggle with the effects of gender dysphoria, are a small but significant population. They have very particular medical and psychological care needs. These needs require a multidisciplinary approach, meaning that a single individual is very likely to require appointments with multiple health care professionals to treat the condition. It should be emphasised at this point that there is no single treatment pathway for people who present with gender dysphoria, but rather, there are multiple ways in which their journey can be facilitated. These journeys differ according to the commissioning policies of individual Primary Care Trusts (PCTs), if such policies exist.

When viewed comprehensively, treatments for gender dysphoria are intended to support the person's psychological, social and physical well being. They can help determine a strategy that is most suitable for the individual and assist them in pursuing the right course of action. In the majority of cases, this is determined to be a medical and social transition from the patient's birth gender to the more appropriate gender of the patient's identity. Several significant research reviews have found that whilst long term studies are very thin on the ground, the overall view is that gender reassignment is very successful, with considerable benefits in terms of quality of life for people with gender dysphoria. (Pfafflin and Junge 1998). [20]

For the purposes of this report, it may be useful to outline the range of service provision that may be required to facilitate a social and/or medical gender transition for those people who are transsexual. Each case of gender dysphoria is unique, but one common pathway is as follows.

1.3. Service Route ways

The first port of call for most people who approach the National Health Service for assistance with gender dysphoria is often a conversation with their General Practitioner (GP). Due to the small number of patients with this particular condition, GPs do not often have a great deal of experience, if any, from which to draw. If the GP approaches the PCT at this point, it is common for people to be referred to a local psychiatrist for evaluation. Those who are referred at this stage will include people who identify as transgender, transsexual, cross-dresser, confused and questioning as well as those who, in the GP's opinion, present similar symptoms to gender dysphoria but who are ultimately determined to have a different diagnosis or no diagnosis at all.

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6. Whittle et al. (2007)

7. Pflafflin and Junge's (1998) review of gender reassignment examined over 70 studies of 2000 patients in 13 countries

A GP, a local psychologist or psychiatrist, or even a nursing-led service such as Sexual Health provider determines whether it is appropriate for them to be referred to a gender clinic or other specialist professional. The possible referrers can be determined by the Gender Identity Clinics or by local PCT policies. Often the clinic that is chosen is a considerable distance away from the individual's local area and will normally be pre-determined by the patient's PCT contractual agreements, assuming that Trust has a policy in place for the condition. Local psychiatrists (and some other providers depending on area) can usually refer the patient to the clinic directly, but the trust must approve funding for this visit before the first appointment is given. Often the wait for funding approval takes a considerable period of time.

1.4. Current Commissioning in the UK

> Several significant research reviews have found that whilst long term studies are very thin on the ground, the overall view is that gender reassignment is very successful, with considerable benefits in terms of quality of life for people with gender dysphoria

Treatment for gender dysphoria is currently considered a specialised service, where the commissioning decision-making is usually undertaken primarily at the Primary Care Trust (PCT) level at present. Each Primary Care Trust receives a budget from the department of health and determines resource allocation in line with local needs. Following their formation in April 2002, PCTs continued to carry out many functions that were previously undertaken by health authorities including the commissioning of services.[21] Under the PCT system, the among conditions requiring treatment is determined at the local level. PCTs commission the services by assessing the needs of patients and procuring the treatment determined to be required.[22] In the case of gender dysphoria, PCTs often have to purchase services outside of their local area due to the low volume of specialist practitioners that are available.

However we are now in another period of change in the treatment of gender dysphoria and the direction of specialised commissioning is moving towards a regionalisation of treatment arrangements.[23] Ten Specialist Commissioning Groups (SCGs) have been created nationally. These groups, aligning themselves with the ten Strategic Health Authorities (SHAs), will co-ordinate PCTs within a region to collaborate on matters of specialised services. The intention

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8. Department of Health (1999) Primary care trusts: establishing better services

9. Farrar (1999)

10. For further information see: 'Background to Specialised Services acc. 01/09/08 :at http://www.dh.gov.uk/en/Managingyourorganisation/Commissioning/Commissioningspecialisedservices/DH_080938

is that commissioning groups will pool resources and standardise treatment across a region by developing consistent policies and entering into contractual agreements with gender identity clinics, surgeons and, if necessary, other specialists.[24] The National Specialised Commissioning Group (NSCG), created in April of 2007, has an advisory role in specialised commissioning on the national level.[25] These new commissioning arrangements will almost certainly change the ways in which treatment for gender dysphoria is provided in England. As commissioning choices are taken by each of the ten Specialist Commissioning Groups to determine where treatment is provided for entire regions, the effect of such contractual arrangements on existing gender clinics is yet to be determined.

There are currently regional anomalies in the commissioning of gender reassignment services – as this report will detail. Health Care Wales, for example, had a blanket ban up until very recently on funding for gender reassignment. Since the ban has been lifted there is now a considerable backlog of patients waiting to be treated.

Within current NHS provision, a small number of gender clinics (>20) have developed in areas where firstly, clinicians have shown interest and secondly, where a clinical need has been established. The concept of the 'gender clinic' can refer to a wide variety of very different clinical arrangements. It is common for gender dysphoria services to be provided in outpatient clinics within the hospital setting.

In the UK, the term 'gender clinic' has been used to denote one specialist or a group of specialists who provide a service for those who may have gender dysphoria. However, as a formal specialty in gender dysphoria does not exist at this time, specialism in the subject tends to be determined primarily by experience in the field. This being the case, practitioners come from a mixture of professional backgrounds and perspectives. Depending on the approach that is taken, practitioners with an expertise in gender dysphoria come from a sexual health, psychology, psychiatry, or other medical background.

People who are undergoing physical transition from female-to-male (FTM) and male-to-female (MTF) both require diagnosis from professionals. After the decision is made that it is appropriate to proceed with a medical transition, there are many options available. Most transsexuals require lifelong hormone therapy, with testosterone or oestrogen and possibly a hormone blocker. There are some complimentary therapies such as speech therapy and hair removal that are thought to be particularly useful to male-to-female trans people. For female to male (FTM) patients, mastectomy is often a top priority, along with hysterectomy and genital surgery such as phalloplasty, scrotoplasy or metoidioplasty. Male to female (MTF)

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11. And Department of Health (2008)

12. For further information see: 'National Specialised Commissioning Group' acc. 02/09/08 at http://www.dh.gov.uk/en/Managingyourorganisation/Commissioning/Commissioningspecialisedservices/DH_080944

patients may require breast augmentation, facial feminisation surgery, voice surgery, tracheal shave, and genital surgery such as orchidectomy, penectomy, vaginoplasty or labiaplasty. Many patients benefit from counselling or other psychological support. Very few gender clinics are fully comprehensive and most rely on linkages with outside professionals to provide at least some of their services. This list is not conclusive, nor does it intend to indicate that a single individual will require all of the above treatments. Moreover, some treatments are rarely funded by the NHS (for example hair removal or full facial feminisation surgery).

There are no overarching rules on the treatment of this condition within the UK. Most Gender Clinic practitioners refer to the World Professional Association of Transgender Health (WPATH) Standards of Care or the recently compiled Royal College of Psychiatry Draft Guidelines for direction. Also, in 2005, the Parliamentary Forum on Transsexualism produced a document for purchasers entitled 'Guidelines For Health Organisations Commissioning Treatment Services For Trans People'[26]. Lynne Jones, MP and Chair of the Parliamentary Forum on Transsexualism, explains in her introduction that these guidelines were drafted in response to the dearth of clear guidance from the Department of Health and the National Institute of Clinical Excellence (NICE) about treatment for gender dysphoria. This document outlines in detail which treatments should be offered to people in this patient group. It also provides funding bodies with authoritative guidelines on how to take 'clinically appropriate decisions' in relation to care for people with gender dysphoria, as well as clarifying their legal responsibilities and obligations. It may prove to be a valuable resource for commissioners and practitioners alike.

The following is a summary of the Parliamentary Forum's recommendations on good practice[27]:

- Clinicians should strive to 'co-operate in a multidisciplinary approach'.
- The goal of treatment is for the patient to achieve harmony between their gender identity and their body. They should also have access to appropriate medical treatment for their biological characteristics (An example that they give is that trans women should have access to screening for prostate cancer).
- Treatment that is individualised, patient-centred and non-prescriptive is more likely to successful than an 'imposed regime'. Working with support from a relevant specialist, patients should have a major role in deciding what treatments are right for them.
- Typical treatment involves a psychological assessment, hormone therapy, psychological support and, if necessary, surgery. This approach 'leads to favourable outcomes'. Informed consent is necessary at every stage.

Finally, the Parliamentary Forum on Transsexualism also highlights another important consideration from the point of view of the patient:

> ***Some individuals will have struggled with this condition for many years, so every effort should be made to provide their treatment as soon as it is consistent with clinical safety.***[28]

From their evaluation, we can see that the considerations for the well-being and empowerment of the patient are paramount in achieving a good treatment outcome.



1.5. North West Lancashire Health Authority v A, D, & G

The case of North West Lancashire Health Authority v A, D, & G [29] was significant because it forced individual trusts to think differently about the policies covering the services for gender dysphoria. In 1998, three transsexuals took their health authority to court after it had refused funding for surgical treatment, arguing that there was 'no overriding clinical need'. [30] The courts ruled in 1998, and held in 1999, that it was unlawful to impose blanket bans on gender reassignment treatment, as was the case in North West Lancashire. In the ruling, treatment for gender dysphoria was considered by Lord Justice Buxton to be '…supported by respectable

15. Ibid. (Section 8: Referral, 8.4)
16. North West Lancashire Health Authority v A, D, & G, QBC 1999/0226/4; 0228/4; 0230/4
17. Clare Dyer, 7 August, 1999

clinicians and psychiatrists, which is said to be necessary in certain cases to relieve extreme mental distress'. [31]

In response to the ruling, many PCTs developed policies to facilitate a transition pathway for individuals for whom a clinical determination deemed it appropriate. Some PCTs, however, do not have policies for this condition, causing delays when a person approaches them to obtain funding. Other PCTs require that all individuals take their case to exceptional circumstances panels, where all panel applications are then rejected.[32] Indeed many trusts consider gender dysphoria to be a low priority treatment. It can be argued that these examples go against the spirit of the A, D & G rulings by prolonging the process of obtaining a treatment that is considered essential for the trans person's well being.

18. Ibid.

19. Clinician Interview

1.6. Why write this report?

This report follows a period in recent years where legal rights among transsexual people in the UK have been expanded and strong social movements have developed around issues of equality and respect for gender differences.[33] It also comes at a time when the NHS is striving to be more patient-centred and proactive about meeting the needs of marginalized communities.[34] The report has been informed by the perspective of the clinical leads and practitioners in the field, many of whom regard their work with gender dysphoria patients as 'life saving'.

Over the course of the research, it became clear how dedicated the specialists in this field are to their work with this marginalized community. However, the multitudes of pressures that are faced in this role make it difficult at times to provide a service that they feel is ideal to meet the needs of the patients. Common themes emerged in our discussions with stakeholders. This report discusses the concerns that have been raised and the challenges that have been encountered by both patients and practitioners.

The authors of this report are greatly indebted to the professionals who generously shared their time and expertise to make this project possible.



20. Gender Recognition Act (2004) at http://www.opsi.gov.uk/acts/acts2004/ukpga_20040007_en_1

21. See also: Department of Health (2005)

Chapter 2: Methodology

The objective of the project was twofold: to map the existing models of provision of services for individuals undergoing gender reassignment in England and to assess the advantages and disadvantages of the current models of service for the treatment of gender dysphoria from the perspectives of a range of key stakeholders. In this section we detail some of the problems we encountered in carrying out the research and how we had to adapt the methodology in order to proceed successfully.

2.1. Original plan

The original plan for this report was to produce a comprehensive, large-scale piece of work conducting interviews with key stakeholders ranging from commissioners to service users. From the beginning of the project, the researchers faced challenges in achieving the original aims in the time allotted for a number of reasons. These challenges are outlined as follows:

Firstly, information about the clinicians in this area of healthcare is not well known. Many practitioners often see patients only part-time and sometimes work in professional isolation. An e-mail survey of trans people was conducted to determine details about the clinics that have been attended. However the response rate was low and necessary information was lacking. In early 2007, researchers contacted a selection of clinics from the list of specialists associated with the Gender Recognition Panel. However this list, especially prior to recent updates, contained names of practitioners who are no longer practicing to our knowledge.[35] Relevant practitioners were difficult to contact and some had not been in their positions for a number of years. In the beginning, very few practitioners responded to our call for participants, with only one positive response received by the summer of 2007. We continued to receive very low response rates until winter of 2007, following the implementation of our updated plan as discussed in the next section.

Secondly, this area of provision is considered politically charged and controversial - as will be explored later in the report. As a result, some practitioners were very cautious of researchers and protective of their work. Clinicians working in the field of gender dysphoria often feel competing pressures from commissioners, the public, and the service users themselves (as we detail in this report). A few participants agreed to be interviewed only following considerable correspondence to determine the project's authenticity.

Thirdly, because of the political nature of gender reassignment treatment, there was an issue of confidentiality. Clinical leads were reluctant to divulge specific information about their funding arrangements, meaning that we did not have access to commissioning bodies as

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22. Gender Recognition Panel, List of specialists in the field of Gender Dysphoria (Last updated: 16 June 2008)

outlined in the original plan. Some clinicians were unwilling to contribute to the project without assurances about the types of research that we would be producing. This project did not have the type of ethical clearance that is required to gain access to this user group via the various clinics themselves, so we had to approach trans community leaders to investigate some perspectives about their experiences of healthcare.

Finally, the time allotted for this research was unrealistic for this type of qualitative work. The research was originally intended to take only three months. This timescale was unrealistic due to the time that it would take to gain access to clinicians and service users, arrange meetings, travel to and conduct the interviews, and transcribe and analyse the large volumes of data. The large workloads of the various professionals meant that we had to meet with them around their schedules in order to gain access for the purposes of an hour-long interview. This sometimes meant setting an appointment weeks or months in advance. The original timeframe was not realistic for the size and scale of project and we could not possibly deliver in the amount of time designated.

2.2. Revised plan

The revised plan for this report was to conduct a more realistic enquiry into the current state of the provision of services for gender dysphoria from the perspective of frontline service providers and other key stakeholders who were willing to participate. We decided to overcome the problems gaining access to practitioners by using existing connections and relying on a 'snowball effect' of recruiting participants. Using this technique, we were able to access clinicians who were willing to speak with us. We also employed multiple means of contact with clinicians via e-mail, phone calls and letters.

This report used qualitative methods interviewing a number of professionals from multiple locations in England as well as representatives from clinics in Scotland. In one-to-one interviews, we asked each clinician a set of questions covering a range of issues including, but not limited to:

- the services that they provide,
- the types and locations of patients to whom they provide services,
- the principles underpinning clinic governance,
- their perspectives on the current state of service provision
- what constrained the delivery of services to their satisfaction

The interviews lasted between 40 minutes and 1 ½ hours. At two of the clinics, we interviewed multiple practitioners to get a fuller picture of the range of clinical configurations and approaches that were being employed. The interviews were then transcribed and themes were extracted. A systematic analysis of these interviews was undertaken and themes emerged which are outlined in the following section.

This report is based on qualitative data collected from interviews that took place from November of 2007 to March of 2008. Participants were healthcare professionals and staff involved in gender reassignment service commissioning and provision of services. Key stakeholders came from a wide variety of professional backgrounds - from clinicians who are among the UK's most experienced in the treatment of gender dysphoria, to those who have taken their appointments in recent years. The range of professionals who were interviewed in relation to this project varied greatly. They included four psychiatrists, one psychologist, two general practitioners, two specialists in sexual health, a speech therapist and a specialised services manager. Some of these professionals maintained more than one role and specialty. A few of these professionals worked with gender dysphoria patients full time, whilst others worked with patients on a part-time basis.

Our sample included eight clinical leads of both small and large clinics in the UK. The clinics range in size from serving only a handful of people to having over 2000 patients on the books (see Appendix for table of full details of clinics). We also conducted background interviews with the coordinator of a large gender clinic in the Netherlands and organised informal conversations with service users by holding a meeting with transsexual and transgender community group leaders in London in January 2008. Although this sample does not cover all clinics and may appear partial due to the constraints detailed above, we suggest that it is sufficient to draw our conclusions. Indeed when doing the analysis of interviews we were impressed by the consistency of the perspectives of participants on current healthcare provision for gender reassignment.

2.3. Ethics and confidentiality

Participation in this research was entirely voluntary and names and identifying information has been changed to preserve practitioner confidentiality.

Chapter 3: The Report: Interviews with professionals

Throughout the interviewing process it was clear that practitioners were deeply committed to assisting individuals who experienced gender dysphoria, yet many expressed their dissatisfaction regarding the wider systemic, clinical, political and professional environments in which they worked. The process of commissioning funding for individual patients featured very highly in interviews. This was partly a systemic problem but also part of the political environment of gender reassignment. From the interview material, what emerged was that those making funding decisions may not understand the medical necessity of gender reassignment treatment and/or were influenced by the politically charged issue of gender reassignment in the media and public.

Following on from this theme, participants suggested that the political environment of gender reassignment implicitly affected the way that the field was viewed by other health care professionals – which meant that it was difficult to find people to specialise in the field. Indeed it would seem that the field of gender dysphoria is a marginalised one, with many participants stating that they worked in professional isolation. Moreover, many participants suggested that the political pressures of their work were not restricted within the profession, but came from pressure groups as well as service users who had expectations of their role as practitioners. These themes are developed in more detail below.

3.1. The commissioning process

Many specialist clinicians interviewed detailed the problems they encountered with the different systems of funding for patients. Clinic directors discussed how they had to battle with Commissioners and Primary Care Trusts (PCTs) for approval for every individual treatment for each patient. They also raised the issue about the lack of clarity, with the commissioning process, which created problems for patients and practitioners alike. Others bemoaned the administrative burden that the process created. The issue that clearly emerged from the interviews was that the problems with the commissioning process impeded their clinical work:

> *It's the paperwork that's difficult because the job generates its own load of paperwork. And we try not to get into long correspondences but you often do battle with PCT.*

> *It's just a nightmare. It's a lack of clarity in the commissioning process, in its entirety. It desperately needs to be sorted.*

> *The real issue, I think, is about commissioning. That's the block that I think that prohibits sensible progress of a clinic like this. It's very clear.*

> *…the commissioning arrangements have changed very considerably and they constantly change so some of our effort goes into just trying to sort out the commissioning arrangements for the individual person.*

What also emerged was the issue of gender reassignment being a low priority for decision makers in PCTs. This was in direct contradiction to the practitioners' judgement of the appropriate treatment for those with gender dysphoria. One practitioner described gender dysphoria as a 'life-threatening problem'. Many participants described how the refusal for funding reassignment surgery was based on the grounds that it was a 'cosmetic' or 'obscure' procedure. In a way, this de-legitimised the treatment recommended by the clinicians in their expert opinion as well as suggesting that gender reassignment was a 'lifestyle choice'. Some practitioners suggested that the low prioritization of gender reassignment was simply a strategy for refusal of funding:

Most of the PCTs place this on a low priority system. So compared to child health or treatments for cancer, it does not get priority. However, one or two of the PCTs consider low priority to be equivalent to no priority. They'll say, okay, if you go to an individual panel, the panel will consider your case and if you're somehow exceptional, then we'll fund it. However, the panels would not define what will be exceptional. And indeed in the case of gender reassignment, I don't see how anything could not be exceptional… I mean how could you possibly make a case that this person should be funded and that person shouldn't. It is ethically and practically impossible. So things then get stuck in the panel. And it seems to me to be utterly inappropriate.

> *We did have problems in the past with a director of public health who said that no one is going to get gender reassignment surgery funded while I remain director of public health… It takes an awful lot of time and aggro… It's taken me a long time to convince them [PCTs] that breast reduction, breast augmentation, laser depilation are not cosmetic procedures in this patient group. This is not an aesthetic surgery. This is treatment for a serious, life-threatening mental health problem.*

It would seem that in order to secure contracts with the PCTs, negotiations sometimes resulted in key treatments being excluded. Some clinicians stated that the level of care funded by PCTs varied dramatically and that the 'postcode lottery' was especially strong in relation to this condition. Although Wales was not included in this study, more than one practitioner pointed out that it was notoriously poor when it comes to providing care because of a blanket refusal to treat the condition. On the other hand, an interviewee said that some PCTs are especially good from the patients' point of view.

3.2. The politics of funding gender reassignment

The issue of gender reassignment treatment has a political background which appears to be factored into the decision-making process for commissioners. Some PCTs are aware of the

political controversy surrounding the condition and do not want to find themselves under the spotlight of the media for funding 'sex changes'.

Indeed, one practitioner told us that in order to provide this level of service, a PCT had to 'ignore' the number of people being treated as it exceeded the capped figures. It would seem that there was an arrangement of 'don't' ask don't tell' in order that treatment be commissioned. The reason for adopting this policy was because they were keen to avoid political and media repercussions. One practitioner told us:

> *They fear that if they are seen funding patient for reassignment surgical procedures, that they are going to be criticized for doing it... And that means at the open sessions of their board, public sessions of their board, in the local press. As we know, if you are transsexual, you are still considered fair game by the Daily Express.*

It would seem that the political issues relating to treating gender dysphoria influence the decision making process for gender reassignment. This suggests that the decision makers are uncomfortable to be publicly seen to be supporting or 'advocating' gender reassignment. Rather than treatment being based upon clinical need then, it may be implicitly based upon the political temperature of the media and general public regarding gender reassignment.

3.3. The Politics of being a Gender Reassignment practitioner

The politics of gender reassignment treatment not only seems to affect the decisions of funders. Practitioners also highlighted how gender dysphoria is negatively viewed beyond the clinical setting and the effect it had on the image of the field of gender reassignment treatment. Some discussed how the marginalisation and political image of the field had impacted on the numbers of people taking up a specialism. Others also discussed how the negative and stigmatising label of transsexualism also affected how practitioners were viewed by other health care professionals:

> *It's not a very popular field, and I don't know why. There are some people who have very strong prejudices against the service still and they do not approve of operating on a healthy body… To have mastectomies or hysterectomies, it's something they can't cope with, I'm talking about clinicians. We had a plastic surgeon who came to one of our meetings and went away looking green, he didn't want anything more to do with it.*

> *What would be more helpful is if it wasn't down to a handful of individuals being very reliant on a handful of specialists to do all the various operations. If there are more surgeons trained and more surgeons interested in being trained, not even just from a competition side but from a pure numbers side, it would be helpful to us, yes.*

The lack of new practitioners in the field because of the negative image of gender reassignment treatment can affect the delivery of the service as the small numbers of practitioners in the field have an increased burden and can treat less patients. The field of gender reassignment treatment then, is marginalised and unpopular within the healthcare professions.

Some spoke about society's negative view of transsexualism and the stigmatising affect that has on patients and practitioners alike. One specialist also discussed the pressure from all sides of the political spectrum – not only the stigma of gender reassignment services within healthcare, but also from the media as well as pressure groups:

"For years we've been shouting, this is a proper part of medicine"

> *It's made scary for some people, because there's a lot of noise around sometimes. Some of its appropriate noise… for most services, people, doctors, nurses, move into an area and expect that their work will be supported, recognized, and not criticized. One of the things I find quite hard when I trained and when I opened this clinic was a torrent of criticism and complaints against medicine generally and about provision of gender services.*

> *For years we've been shouting, this is a proper part of medicine - there is work with both psychological and organic it needs to be addressed. And now we have international societies for sexual medicine, we've got journals of sexual medicine. But when I started working in this people were asking, what is sexual medicine? And why are you doing that and what does that have to do with anything?*

This suggests that practitioners have considerable lack of recognition within the health service as well as without the clinical setting. Some practitioners also feel that there may be hostility towards them from some representatives of their client group as well. It would seem that gender reassignment treatment has an 'image problem' within the NHS and that practitioners within the field may be tainted with the same stigma that their client group is. However, one practitioner suggested that as the image of trans people in society improved, then the service may be more accepted:

> *Society's changed in 10 years. That's the thing that I've been most impressed by that people are not coming with quite the same extreme problems. I mean yes… there's always going to be someone shouting in the street, but anyone can walk down the wrong street. The important thing is that overall society is very different. And I think if people see that happening than it will be accepted as more mainstream medicine.*

It would seem then, that many professionals in the field experience political pressures regarding their work within the health service and lack recognition for the valuable service that they provide. The political 'noise' (as one participant put it) and criticism of their work comes from healthcare professions working in other disciplines as well as the client group.

3.4. Professional relationships

Many participants discussed the professional isolation of their work – not only in terms of working in a minority specialised field – but also having lack of contact with other practitioners. Some expressed the desire to communicate more with others who worked in gender reassignment. (box a)

It would be very easy to imagine that those working in a minority specialist field within healthcare may be a coherent group with strong networks and support. However, there is not a great deal of professional support for practitioners and clinical directors in most cases. There are a couple of professional organisations working in this field - at present, the World Professional Organization for Transgender Health (WPATH) and the Royal College of Psychiatry group that is continuing to draft UK standards and occasional partnerships between clinics. There is however, not a great deal of coordination among practitioners. This has left many working in isolation and may contribute to the differential procedures in providing treatment. Indeed on practitioner alluded to some practitioners 'going their own way' suggesting that the issue of professional isolation contributed to the variety of care pathways. Many of the practitioners interviewed would welcome more communication with others, such as a national conference, clinical meetings, or other forms of support.

3.5. Great expectations of gender reassignment

All the practitioners demonstrated deep empathy for their client group and wanted to assist as much as they could in the process of gender reassignment. Many went to great lengths focusing on the importance of social reassignment as well as hormonal and surgical changes. Participants discussed the expectations that the client group had of what the service could provide. One practitioner described the role of the media influence on these expectations; focusing too much on surgery and not on other aspects of gender reassignment:

> *I suppose what we emphasize more than anything is social transition, which tends to get a bit forgotten in the mix sometimes. I think largely because of the media portrayals; documentaries tend to focus disproportionately on surgical and endocrinological changes, because that's the most dramatic 'makeover' aspect… To some extent, we put the dampers on things and I guess we do emphasize the social aspect in a slightly wet blanket way sometimes.*
>
> *People come more often to get surgery because*

Box a.

Many of us are quite professionally isolated. There are a handful of people in the UK to work in this field, and we get to talk and we meet up at conferences occasionally. But it is really, how to improve the patient experience and get more positive outcomes we do need to be working more closely as a group to agree on what is an appropriate outcome measure.

> *they believe all their problems will be solved. I am a real killjoy in that respect….There is a level of confidence that comes with having the right thing inside your pants. But, it doesn't make you into a sociable person who has a lot of friends if you haven't got them already. It doesn't make you into a successful career person if you don't have a career path to go down.*

Many stated that although the media representation of transsexual people had helped develop an understanding of the issues for the public, focusing on bodily transition alone was a simplistic account of the process which ultimately misled the client group as well as other practitioners not working in the field.

To put these issues into context it is worth pointing out that service users may have had to wait a long time to see a practitioner. By the time of their first meeting, not only will they be feeling frustrated, they will probably have also been suffering personally, socially and economically. Some may also have pre-conceived ideas about the role of practitioners in the process –possibly through 'folk stories' from others in the trans community. Indeed one theme regarding the expectations of the client group which many discussed was their role being implicitly seen by patients as 'gatekeepers' or 'judges'. The practitioners were not comfortable with this role at all:

> *… it is enormous anxiety provoking coming to see me; I am a gatekeeper for a lot of people. Although I try to take that away that image, and I try and say that I don't have expectation as to how they dress and how they behave or what their interests are, and you might be a guy wanting to be a woman but still being fascinated by football or whatever. I try not to have stereotypes like that, but people come expecting you to have stereotypes.*

> *Most of the people who I see have read enough histories and looked at enough on the internet that they know what they say to me. I usually spend the first session letting them know that they don't have to play the game… it's a huge power thing that I have that I don't particularly like having because I don't want to be seen in that way, but that is what I am in reality to them.*

> *Of course its right for campaign groups to shout loud, but you can't be battered by it. And I think that that's something that I've been sensitive to and I've tried to pay attention to it…*

These comments suggest that there may be pre-determined barriers between the client group and practitioners, with some being aware of the view of campaign groups regarding practitioners' role in gender reassignment treatment. Many practitioners then, were not comfortable with the power as 'gatekeepers' of the process, with some finding that they had to work hard to unpick the pre-conceived expectations of individual clients.

In summary; the nature of the work of gender reassignment is politically charged in many areas; from the decisions of commissioners in providing funding, to pressure groups and

service users. The field as a whole has an 'image problem', lacking legitimation and recognition from other health professionals. What is clear is that all the factors regarding the marginalisation and political nature of gender reassignment treatment must implicitly affect service delivery. Time spent doing clinical work may be lost by engaging in long correspondence with funding providers; the political image also means a shortage of new people to specialise in the field which must put more pressure on existing professionals and service provision. Finally, working in isolation with a lack of peer support must be compounded by working in a marginalised field. It would therefore be very beneficial for practitioners working in this multi-layered milieu to have more communication with each other and formal support.

3.6. Local vs National Services

As has been discussed in the introduction and literature review, national clinical arrangements have come about in an ad hoc fashion, where gender clinics have been established in response to practitioner interest and local need. The result of this spontaneous development is that some areas provide services locally or regionally, whilst others prefer to use services commissioned from outside of their area. Some practitioners commented on the nature of these arrangements and expressed the desire for development of clinics to be further regionalized. One practitioner expressed astonishment that large metropolitan areas like Manchester and Birmingham do not have gender clinics. Another suggested that the largest clinics might be developed as specialist centres but that further regionalization should take place. Others suggested that more local and regional coordination might provide practical benefits, such as lower costs and easier access for patients:

... it should be regional service. There's no question.

> *I think that there should be regional services... I don't think that there should be one main centre. I do think that there should maybe be one main centre where people who were having major problems went, like a tertiary referral.*

> *There have been a lot of enquiries from other PCTs about the service that we provide, I think that we're seen as being local and cost effective compared with going to London, for obvious reasons because of the transportation costs as much as anything else.*

From the patient point of view, those presently living in areas that commission services from larger clinics outside of the local area often have to travel long distances to attend specialist appointments, presumably causing some degree of disruption with their employment or home lives as well as considerable travelling costs. In general many patients tolerate this well, but others have difficulty as one participant explains:

> *People with gender dysphoria are usually fairly accepting of and fairly able to travel because they have been used to that and have had to do that. But there are*

also other people who perhaps for various reasons, who are less confident, who don't wish to travel, who would rather have a localized service. And I think that people are prepared to travel and accept that they have to travel for big things like the surgery. But if it's for a weekly counselling or weekly speech and language therapy, I think it would end up very costly of their time and also travel costs… I am in favour of a more localized model.

Local, community-based services were championed by one participant who has been convinced by her experience that this was the most desirable form of service provision:

… we are not hospital-based but we are very firmly a community-based service. That is the key. In fact, these are individuals who are living in the community. They are not sick – okay, some of them have other problems to be dealt with – so the community is where they should be… the more I do it the more convinced I am that this the right way to provide the service.

However, large national clinics were keen to emphasise that their experience and expertise with a wide range of patients are of value when treating gender dysphoria, particularly those with complex needs such as learning difficulties or co-existing conditions. They also benefit from historically established services that have remained relative stable through periods where other clinics have opened and closed. The largest clinic in the country plays a particularly key role in English service provision as it takes patients from areas that have no local services to offer, or for whom the wait for local services is inexhaustibly long. There is a need for a more detailed investigation into the merits of regional or national gender reassignment services in terms of treatment costs and level of patient care.

3.7. Systemic Problems: waiting lists

Long waiting lists for assessments, specialist appointments and surgery continue to be a significant problem according to many practitioners. Extended waiting times were attributed to slow PCT financial approval and very high demand for the services. Whilst some clinicians felt comfortable with their current waiting lists, others expressed the feeling that there was not enough appointment time spent with each patient. Also, low 'do not attend' rates for the service were said to have taken away some of the natural flexibility that clinicians are afforded in other clinics. Waiting lists were found to be a strong theme in the clinician interviews:

At the moment, because demand outstrips supply, there is a backlog, and we certainly have a waiting list, which is why the trust has decided to increase my hours. It can take several months during which time they continue to see a therapist, but they've reached a block because without the medical input they can't progress

I think that people wouldn't mind the timescales involved in the service if it wasn't for the additional admin, PCT, bureaucratic stuff that gets added to it.

This situation seemed to be compounded by clinics experiencing financial uncertainties, retirements and closures. Some interviewees told us about situations where these issues resulted in delays, complaints and patient frustration:

> *[The former clinic lead] retired, and basically the service was disbanded. Obviously that left a huge gap for people who needed the service, and there were a lot of complaints about there not being a service and there was a big reaction to that.*

> *The clinic... was closed for three years, which is quite a long time. And when we opened, we took priority those who have been assessed but were still on the waiting list. And we're still having the odd patient coming through that has been hanging around an awful long time. [The patients reacted with] Anger. Frustration. Horrid. And the fact that they hadn't always seen the right person. It was all very piecemeal, it was horrid. So hopefully we are just about through that...*

> *Last year people were waiting ages for second opinions because the person [at a regional clinic] retired and it took them months to replace somebody, and there was a backlog of work. And at the moment, some were still needing second opinions for everybody to go to surgery, that just has a knock on effect...*

Extensive waiting lists seemed to add extra anxiety onto clinicians who already found themselves under a great deal of pressure. Some had extremely long waiting lists or even closed their lists in an attempt to fully treat all of their patients. This theme not limited to particular clinics or areas; it was found repeatedly in interviews taking place across England.

3.8. Clinical Challenges

On the whole, practitioners were comfortable with how they carried out their own clinical work and felt that they provided the best service to patients that they could under difficult circumstances. All agreed that the condition was successfully treatable in the majority of cases. The key to providing a high level of service according to practitioners was the development of strong relationships with the patients and other practitioners, providing a smooth treatment pathway and mitigating the systemic issues that are faced. However there seemed to be roadblocks that prevented this from being realised fully. Cooperation between GPs and the gender clinics was generally felt to be good, but practitioners suggested that progress could be made by improving coordination between the numerous clinicians needed to treat a patient. Many interviewees desired the creation or expansion of linkages with other practitioners in their area, particularly surgeons, endocrinologists and therapists:

> *So what we've actually asked for is one session of endocrinologists time, within our contracts, so we can have that endocrinology advice and guidance and monitoring, because obviously it's a big part of the treatment and it needs to be done right.*

> *In terms of a service, if I had my way, I'd have a therapist or preferably a psychologist or psychiatrist...*

Sadly we do not have an endocrinologist now, I think that's the biggest loss because hopefully this patient group will not need any of the other services long-term. And they are going to need hormones for the rest of their lives, and I think having an endocrinologist there is very important. We are always having queries, and that's something we definitely need in our service that we had that we don't have now.

...there's only one place that I know of, certainly one place that we link with and one surgeon, who will do the operation. So even if there was not a hold up in the commissioning process, that surgeon is obviously going to have a huge waiting list.

More complete and efficient provision was of great importance to many of the interviewees. They emphasised the value of working within a team in delivering a successful service. The final theme that arose from the interviews was the value and importance of partnership and teamwork:

I think that teamwork within speech therapy is very important and I think that multidisciplinary team is essential. I'm very keen on this idea of working with a patient as a whole, not as a patient with a voice who needs proper help with their voice. It's a total thing and I'm fortunate that I've been a member of a gender panel, team, whatever you like to call it for a long time so I've got quite, as you say, a holistic view.

Working in isolation is never good. You tend to go your own way.

And no decisions about patients are made without a team discussion so we meet monthly... It's very important that we share our expertise. I think we're very lucky because I think that other services in the country don't have that regular contact, sometimes it's just by letter. I've always been very fortunate because I work closely with other members of the team and that's absolutely vital.

Linking in with the previous section on professional relationships, this provides further evidence that working in isolation may be difficult and unbeneficial. Teamwork provides support for the practitioners and promotes a well rounded service with improved pathways of communication.

3.9. Summary

This section has discussed the themes, which consistently emerged from the interviews. Practitioners have described the systemic, clinical, political and professional environments in which they worked. The commissioning process as it currently stands, with practitioners often having to engage in long correspondence with funding providers is unsatisfactory. Moreover, the politics of gender reassignment services implicitly has a bearing on the commissioning process from the different systems of funding to the low priority given to gender reassignment treatment. Indeed rather than funding decisions being based solely upon clinical need, the

political temperature regarding gender reassignment with the media and general public seems to be a consideration. The image of gender reassignment treatment within the health service impacts the uptake of new practitioners, with lack of new specialists affecting the provision of service. Many practitioners work in isolation with other healthcare practitioners either lacking knowledge of their field or not recognising it as a legitimate or 'worthy' one. This isolation is compounded by lack of networking with other practitioners working in the field.

Not only have we found that the funding for gender reassignment is a 'postcode lottery', but there is lack of consistency in services with local provision in some areas and other areas referring patients to a larger clinic some distance away. There are advantages and disadvantages to both with local and regional coordination providing practical benefits, such as lower costs and easier access for patients and larger centralised provision having experience and expertise – particularly for those with complex needs. Centralised services, through being more established are also relatively stable through periods where other clinics have closed. The systemic problems we found were extensive waiting lists for assessments, specialist appointments and surgery which put additional pressures onto clinicians. In turn, this appears to set up a difficult relationship with service users who are frustrated and disappointed with the service and regard practitioners as 'gatekeepers' to their care pathway. In the next section we detail our conclusions and recommendations.

Chapter 4: Results: Clinical Provision at-a-glance

Table 1. English Clinics at a glance

Clinic or Region	PCT AREAS COVERED	TOTAL PATIENT NUMBERS	RELATED NHS TRUSTS	REFERRAL PROCESSES	LOCALLY PROVIDED SERVICES	LOCAL SURGERY PROVISION	SERVICES NOT PROVIDED
Devon (correct at time of interview)	➢ South West of England: Somerset, Dorset, Devon and Cornwall	➢ 40 (at max capacity) ➢ 5-6 new per month	➢ Devon Partnership Trust ➢ Individual PCTs	➢ GP's ➢ Psychiatrist ➢ Psychologist	➢ Gender Identity clinic ➢ Psychological assessment ➢ Psychotherapy ➢ Counselling ➢ Hormone therapy ➢ Referral for Gender reassignment surgeries (other than genital). ➢ Endocrinology	➢ None	➢ Genital surgery is referred to London ➢ Other services are referred back to local providers
Leeds	➢ A wide area in the North of England. ➢	➢ Around 100 ➢ 16 on waiting list.	➢ Have a service level agreement with West Yorkshire ➢ Other cases funded by individual PCT's.	➢ Require GP and local sector Psychiatry team referral	➢ Gender Identity clinic ➢ Psychiatric Assessment, ➢ Hormonal therapy ➢ Support through transition ➢ Referral for Gender reassignment surgeries. ➢ Voice assessment and	➢ Refer clients for 2nd opinions which take place in Sheffield or Leicester	➢ Gender Reassignment surgery, incl. Genital surgery are referred to Leicester or London

					training group ➢ Occupational therapy ➢ Up to one year post operative support.		
Leicester	➢ Did not wish to participate to participate						
Liverpool [36]	➢ Liverpool, ➢ Merseyside, ➢ Cheshire, ➢ Manchester ➢ Wales	➢ 40 ➢ Closed to new patients	➢ Merseycare NHS Trust ➢ Some from other area PCTs	➢ GP, ➢ another colleague, ➢ Psychosexual services.	➢ Gender Identity clinic ➢ Psychological Assessment ➢ Hormone therapy	➢ None	➢ No Surgery onsite ➢ Gender Reassignment surgeries referred to London, If patient's PCT has contract with Charing Cross (otherwise there is a problem) ➢ No Voice assessment and training ➢ Referred for local Endocrinology and Haematology

23. Correct at time of interview

London	➢ Anywhere in the UK, including Channel Islands, Isle of Man.	➢ 2,500 (at max capacity) ➢ 750 new per year	➢ Individual patient's PCT ➢ West London Mental Health Trust	➢ Psychiatrist ➢ Psychologist	➢ Two Gender Identity clinics ➢ Psychiatric assessment ➢ Hormone therapy ➢ Referral for Gender reassignment surgeries. ➢ Endocrinology Voice assessment and training ➢ One clinic sees adolescents	➢ Can provide all services in London ➢ Chest surgery wherever PCT agree to fund – often local to patient.	
Nottingham	➢ Majority of East Midlands	➢ Approx. 70 ➢ 60 on the waiting list	➢ Local Mental Health Trust and individual PCTs	➢ GPs mostly, ➢ Consultant Psychiatrists	➢ Gender Identity clinic ➢ Psychiatric assessment ➢ Psychological assessment ➢ Hormone therapy ➢ Referral for Gender reassignment surgeries. ➢ Referral for surgery. ➢ Endocrinology	➢ None	➢ No Voice assessment and training, ➢ Surgery referred to Leicester
Services in the North East **Newcastle** (voice assessment &	➢ North East region	➢ 135	➢ Northern Regional Commissioners (through individual PCTs)	➢ GPs ➢ local Psychiatrists; ➢ Gender Identity services in	➢ Psychiatric assessment, ➢ Psychotherapy ➢ Psychosexual counselling at various locations,	➢ Some local Chest Reconstructive and Mammoplasty	➢ Endocrinology referred locally ➢ Gender Reassignment surgery, incl. Genital surgery are referred

deportment advice); **Sunderland** (psychiatry & psychotherapy)				other regions	➢ Hormone therapy ➢ Referral for Gender reassignment surgeries. ➢ Referral for surgery. ➢ Voice assessment and training, ➢ Assessment and advice on deportment and presentation		elsewhere (usually Leeds or London).
Sheffield	➢ Majority ➢ Sheffield ➢ Chesterfield ➢ Rotherham, ➢ Barnsley, ➢ Doncaster	➢ 70-75 (not at max capacity) ➢ 25-50 new per year	➢ Norcom (North Derbyshire, South Yorkshire and Bassetlaw commissioning consortium) ➢ Individual patient PCTs, ➢ Sheffield Health and Social Care	➢ GP referral	➢ Gender Identity clinic ➢ Psychiatric assessment ➢ Sexual medicine ➢ Hormone therapy ➢ Endocrinology ➢ Psychotherapy ➢ Speech therapy ➢ Peer group, ➢ Image consultant	➢ Refers to some local surgeons (ENT and Breast & Chest surgery)	➢ Some Genital surgery to Leicester and London ➢ Referred for local Endocrinology and Haematology as required

Table 2. Scottish Clinics at a glance

Clinic or Region	PCT AREAS COVERED	TOTAL PATIENT NUMBERS	RELATED NHS TRUSTS	REFERRAL PROCESSES	LOCALLY PROVIDED SERVICES	LOCAL SURGERY PROVISION	SERVICES NOT PROVIDED
Edinburgh	➢ Anywhere in Scotland	➢ 100 (at max capacity) ➢ 1 new per week	➢ Lothian Health	➢ Self referral, ➢ GP referral, ➢ Psychiatrists , ➢ LGBT agencies	➢ Psychiatric Assessment, ➢ Hormonal therapy ➢ Support through transition ➢ Referral for Gender reassignment surgeries ➢ Family support, ➢ Endocrinology, speech therapy ➢ Adolescents are seen	➢ None	➢ Gender Reassignment surgeries are referred elsewhere
Glasgow	➢ Anywhere in Scotland	➢ 400-500 ➢ 73 new per year	➢ NHS Scotland; ➢ Greater Glasgow and Clyde health board,	➢ Self referral; GP referral, hospital referral	➢ General assessment ➢ Psychiatric Assessment, ➢ Hormonal therapy ➢ Support through transition ➢ Referral for Gender reassignment surgeries ➢ Adolescents are seen in clinic	➢ None	➢ Gender Reassignment surgeries are referred elsewhere

Table 3. The Amsterdam Free University Clinic at a glance

Clinic or Region	AREAS COVERED	TOTAL PATIENT NUMBERS	RELATED NHS TRUSTS	REFERRAL PROCESSES	SERVICES PROVIDED LOCALLY	LOCAL SURGERY PROVISION	SERVICES NOT PROVIDED
Amsterdam	➢ Netherlands	➢ 2000 (at max capacity) ➢ 100 – 150 new per year	➢ Referrals from the Netherlands only	➢ Psychiatrist ➢ Psychologist ➢ GP referral	➢ Two Gender Identity clinics ➢ Psychiatric assessment ➢ Hormone therapy ➢ Referral for Gender reassignment surgeries. ➢ Endocrinology ➢ Voice assessment and training ➢ Assessment; Endocrinology; Speech therapy; Surgery	➢ Can provide all services ➢ Chest surgery wherever PCT agree to fund – often local to patient.	➢ Adolescents are referred to Utrecht Clinic

Chapter 5: Conclusions and Recommendations

5.1. Broad Thematic Overview

This research has examined gender dysphoria services in the UK from the perspective of practitioners at a time where the National Health Service is aiming to become more patient-centred. The research has confirmed that organisation and delivery of treatment for gender dysphoria under the NHS needs further expansion and improvement. Our findings should be taken into consideration for the development of services for the future, especially as the decision-making power moves from local PCTs to the regional Specialised Commissioning Groups.

We have found that practitioners in the field of gender dysphoria face a number of systemic and professional challenges in carrying out their work. We suggest that the politically-charged nature of the condition can contribute to the barriers that practitioners face in providing satisfactory services for trans people as a marginalised group. The report confirms that long waiting lists due to very high demand coupled with administrative delays and the low priority that PCTs place on gender dysphoria treatment, contribute to problems in providing a smooth and efficient treatment pathway for patients. The administrative and financial stresses of running a gender clinic are a burden to practitioners and cause blockages in treatment.

The research found that people pursuing treatment for gender dysphoria in different areas of the country may have dissimilar experiences due to different PCT and gender clinic policies. Gender clinics have developed in areas where there is practitioner interest rather than strategically, and the composition of clinicians varies significantly from place to place. The ad hoc development of gender clinics has resulted in arrangements based on locations rather than organised and deliberate national planning. Major metropolitan areas such as Birmingham and Manchester are without local or regional provision for gender dysphoria and rely on purchasing services elsewhere. Regionalisation is recommended as the way forward by many, but practitioners in larger clinics emphasise their experience and expertise, particularly in dealing with more complex cases.

People with gender dysphoria have specific medical needs which require a multidisciplinary approach to treatment in order to support the person's psychological, social and physical well-being. Following the legal case of North West Lancashire Health Authority v A, D, & G, where it was held that it was unlawful to impose blanket bans on gender reassignment treatment, many PCTs developed policies to facilitate transition, however some neglected to do so, and others required all cases to be directed to special circumstances panels. Funding for gender dysphoria services, which is considered a specialised service, presently lies with the Primary Care Trust in most areas. However, specialist commissioning is currently undergoing a period of change.

5.2. Major Points

We have found that a complex, unclear and administratively-intensive commissioning process has caused many problems in treating gender dysphoria (5.1). There was a strong sense that the clinicians had to undergo lengthy correspondence with the PCTs in order to secure funding for their patients. Some PCTs even went so far as to impose de facto bans on funding for the condition. The low priority that most PCTs put on gender dysphoria contradicted the importance that practitioners put on the treatment, and clinicians often had exclude important treatments in their negotiations to secure funding, as further explained in 5.1. It would seem that the political pressure of public opinion and the media on gender reassignment treatment is seen to have some bearing on how PCT take decisions about funding, moving the focus away from clinical need. In 5.3, it is explained that this political pressure also extends to the practitioners who felt that their field is viewed negatively, resulting in fewer professionals available to do the work and causing harmful effects on service delivery. Practitioners sometimes felt unrecognised, criticised and unsupported (5.3).

The finding that professionals felt unsupported continued in section 5.4, where many clinicians felt professionally isolated and out of touch with others in their field. Though there is a national (Royal College of Psychiatry) and an international organisation (WPATH) working on the development of protocols, the coordination of practitioners within the NHS was felt to be lacking (5.4).

The delays caused by the current process of requesting funding from PCTs, coupled with the lack of professionals in the field – inevitably leading to longer waiting times for treatment, has a bearing on the relationship between practitioners and service users. By the time that many service users meet for the first time with practitioners, they may have pre-conceptions about barriers to their treatment pathway. Many practitioners told us they were unhappy with being positioned as 'gatekeepers' to further treatment and the power dynamics that this entailed (5.5). It would seem then, that many practitioners are embattled on many fronts: having to engage with protracted correspondence to secure funding; lack of professional legitimation from other areas of the health service due to the image of gender reassignment treatment lack of new specialists entering the field, thus longer waiting lists and ultimately more difficulties in providing the service which they feel is needed for service users.

We found that some services were provided locally, whilst in other areas, services were commissioned regionally or nationally. Many practitioners argued for more localisation or regionalization of services due to cost, travel, and community-based considerations. Others recognised the expertise that larger, national clinics have in treating unusual or complex cases and filling gaps in national provision (5.6). Section 5.7 showed that long waiting lists due to slow PCT financial approval and very high demand for the services were seen by many as a significant problem. This was compounded by extra workloads on existing clinicians caused by the closure of other clinics (5.7). Finally, in section 5.8 we can see that practitioners felt that the key to providing a good service was creating strong relationships with patients and other practitioners, providing a smooth treatment pathway and reducing the systemic issues that are faced. Many wanted additional members to their teams, especially therapists,

endocrinologists and surgeons. Working within a team was championed and working in isolation was seen to be difficult and unbeneficial (5.8).

5.3. Key Recommendations

Commissioning pathways need to be simplified and the importance of care for gender variant patients appropriately contextualized

- **Every effort needs to be made to clarify and simplify the commissioning process and funders should work with clinics to negotiate mutually beneficial solutions to reduce paperwork and to expedite the funding process.**
- **Clinics should be provided with a dedicated financial officer who is responsible for funding applications. This would help to relieve pressure from the practitioner and free up time that can be used for treatment.**
- **The low priority that many funding bodies have for gender dysphoria treatment needs to be reconsidered in response to the practitioner opinion presented in this research and previous legal judgements.**
- **Each funding body should evaluate their policies regarding treatment for gender reassignment.**
- **Treatment packages need to be more uniform nationwide and to be decided in line with optimal practice.**

Funding bodies need educating in the clinical needs of those with gender dysphoria as well as their legal obligations

- **Funding bodies need to develop a clear understanding of the clinical care pathway for gender dysphoria and if necessary, actively advocate on behalf of the patient group to fight inequality within and outside of the NHS.**
- **Each funding body should evaluate their policies to ensure that it adheres to both the letter of the law *and* the spirit of the legal rulings. Therefore, no unnecessary barriers to treatment should be created**
- **All areas of the NHS should develop strategies on how to actively assist gender variant patients make their way through the system, including appointing liaisons between patient and the funding body.**

Support for clinicians needs to be improved

- Trans people are growing in number and a training program or mentoring scheme needs to be created to bring more specialists into the field. These careers can be made a more attractive option by providing promotional opportunities.

- Careers in this area of medicine should also be actively promoted on a national scale. In doing this, strategic planning should be undertaken in an attempt to provide a wide range of services to patients in all areas.

- The Department of Health should support gender clinics by raising awareness of the recent published guidelines for GPs who are treating gender dysphoria. [37]

Better communication needs to be facilitated.

- More opportunities should to be created for coordination among individual practitioners and gender clinics. There is a distinct need for a national organisation or fellowship of practitioners who treat gender dysphoria. This organisation could arrange meetings and provide other methods of communication.

- Clinics should actively keep in contact with others working in the field in order to avoid isolation. Efforts should be made to build relationships with other practitioners and overcome any potential adversarial relationships that may be due to competition for contracts or differences in clinical opinion.

Comprehensive treatment needs to be provided.

- Funding bodies should ensure that they provide a flexible and comprehensive treatment package according to the patient's needs as recommended by specialists.

- Funding bodies should ensure that therapy is offered as a matter of course, especially during the long waiting periods.

- In order to de-emphasise status of gatekeeper, practitioners should develop collaborative relationships with patients as much as possible. They may benefit from cooperation with local community groups.

Local, regional and national services need to be developed in line with patient needs.

- Future services should be developed on a more regionalised basis with clinics available to provide complete treatment services. However, this should not override the principle of patient choice, especially in relation to surgical options.

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24. Department of Health 2008.

- **A great deal of support should be provided to area practitioners to begin setting up clinics in the larger cities of Manchester and Birmingham.**

- **GPs should play an active role in determining which services require clinical intervention. Local services should be provided wherever possible, especially for regular or routine appointments. The exception to this should be circumstances where further expertise is required.**

- **Larger clinics could be developed as specialist centres that can provide expertise and experience to patients with exceptional needs throughout the country.**

- **There is a need for a more detailed investigation into the merits of regional or national gender reassignment services in terms of treatment costs and level of patient care.**

- **Flexibility in service provision is key in order that gender clinics in England adhere to the standards of care. Patients should have a choice as to the practitioner who they choose to see insofar as this is possible.**

Better national planning and coordination is required.

- **Waiting lists must be reduced dramatically and resources need to be allocated that will provide the means to do so. Strategies must be put in place to cope with the realities of future higher demand for the services. The effects of major events such as funding cuts or practitioner retirements must be mitigated so that additional pressure is not put onto already strained service providers.**

- **Smoother treatment pathways should be provided. Funding should be provisionally approved for an entire treatment package upon initial request by the patient and the practitioner thus eliminating roadblocks in further stages of treatment, most notably surgery.**

- **Information leaflets about the funding process should be provided to the patient in order to make the process and prospective waiting times more clear.**

Clinics need to be expanded and clinicians need teamwork in order to provide comprehensive services.

Linkages with more endocrinologists, therapists and surgeons are desirable to round out the services that are available to patients. Attempts should be made on the regional or national level to identify practitioners who would be willing to see patients undergoing gender reassignment.

5.4. What remains to be learned – Directions for future research

This research has presented a picture of the difficulties that practitioners working in the field face in providing the treatment that they recommend for people with gender dysphoria. The findings should be used to support proposals for further assistance from the Department of Health as well as inform guidance for funding bodies.

Further research is needed in a number of areas to truly get an adequate picture of provision. This research has not identified what specific treatment or treatments are essential to meet the needs of gender dysphoria patients. It has not dealt with the contentious yet important question of whether or not gender dysphoria should continue to be a considered a mental health condition. These are questions that largely require larger scale more comprehensive research. This report has also not fully explored the necessary and significant input of the marginalised patient group and this data needs to be compiled on a national scale. Research in these areas is absolutely necessary in order to ensure that the people with gender dysphoria are provided with a comprehensive service that truly meets their needs.

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