

Not So Much a Care Path...

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Introduction

The article at the heart of this paper was first published in July 2006 through *LGBT Health UK* – a Yahoo discussion group set up to continue and build on the professional liaisons and debate fostered by the UK's first national LGBT Health Summit, which took place in June 2006 at Guys Hospital in London.

“*Not so much a care path...*” is part of a running series of publications designed to set the scene for debating the reform of trans health care in Britain, and is intended to mark a distinct turning point in emphasis within that series.

In common with much of my earlier writing, “*Not so much a care path...*” aims to illuminate the extent and nature of the problems that trans people face at every turn; however it does so from the hitherto neglected perspective of how overall care paths are constructed through NHS services at the present time, and how those combine with philosophical problems underlying the services themselves, to create an obstacle course for anyone seeking care in this area.

The Backdrop

“*Not so much a care path...*” is published at a time when a committee under the auspices of the Royal College of Psychiatrists (RCPsych) is preparing to release a draft of its’ planned guidelines for the care of people with gender identity issues, as part of a wide consultation prior to finalisation and adoption.

The RCPsych guidelines (already almost two years overdue) are eagerly awaited by many stakeholders, since they mark a historic opportunity for this area of medicine to move away from an imported system of treatment protocols for protecting US physicians from feared litigation. Many PCT’s have stated their intention to wait for the RCPsych guidelines, for instance, before reviewing their own commissioning policies.

The so-called “*Harry Benjamin Standards of Care*”¹ (relied upon till now) have long been criticised as an ill-conceived anachronism by some observers – not least trans people themselves². The once-in-a-generation chance to design an approach more fitted to the modern *British* vision of a holistic, client-centred, evidence-based public health service therefore ought to be an opportunity for radical reappraisal of concepts and methods in a world that already acknowledges trans people to be far from mentally ill.³

Will the RCPsych proposals meet the hopes of all the stakeholders waiting for publication?

One way to tell will be the extent to which the proposals help to address the kinds of problems illustrated here and evidenced by the 600 plus current and former service users who signed a petition calling for NHS reform⁴. The acid test is whether the new guidelines will help commissioners understand how best to construct respectful and caring, flexible, innovative, safe and cost-effective approaches to the needs of people with gender identity issues.

We must ask this question: If society's vision of trans people has changed so dramatically in the last decade, will the guidelines enable PCT's to mirror that sea change? In turn, can that help lead to better all-round preparedness to welcome tax-paying trans people as equally deserving consumers of a National Health Service that is there for everyone?

The Need for Parallel Reforms

In "*Not so much a care path...*" I have aimed to encapsulate a complex and many-sided problem, with examples and a model that can simply be reduced to a single page. (See Figure 1).

Real life is much more complex than that, of course. The question of commissioning – clearly one of the major problem areas to be tackled – is intricately bound with the question of how care pathways work. That, in turn, is linked to the conceptualisation of what the proper aim of care should be. And, as I've said on several occasions now, the current treatment goal of litigation-proof genital surgery is treating the wrong problem and hence failing the vast majority of an extremely diverse group, many of whom may never ever need or want to get to that stage⁵.

We have to stop the system that thinks only of genitals and preparing trans people for sex. In its place we need a whole start-to-finish vision of treatment that cares for the whole person and equips them for a happily gendered life.

Before we can get there, however, we need a debate that thoroughly exposes the way in which the present system fails and abuses people. Then, with that as the starting point, we can be ready to start with a clean piece of paper, and the contribution of an enormously diverse group of people, to design an approach that serves real trans people properly in the 21st Century.

Not So Much a Care Path ... More a Kind of Steeplechase

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Trans campaigners like myself get an awful lot of correspondence from people having difficulties with practically every aspect of using the NHS – whether that's for the ordinary kind of care we all seek when unwell or injured, or the very specific kind of medical assistance required for us to express our gendered identities through the bodily appearance we present to others.

This latter factor – the need for medical assistance to express one's identity – is a key differentiator between the kinds of need-relationships experienced by LGB people and those who are “T”.

At the risk of being simplistic, nobody needs a doctor or surgeon's assistance to take the first and subsequent steps towards exploring and living their sexual orientation. All you need is someone else of the same sex!

In one sense the same can be true of some trans people – at the start of their transition...

People who know their own minds don't actually need a diagnosis or anyone's permission in order to change gender role. You just go and do it. It's not illegal in the UK. In my own case, all those years ago, I just picked a day, wrote to all the organisations who needed to know I was changing my name and gender, dealt with all the sensitive face to face explanations for family, friends and clients – and then did it. The “should I be out?” question isn't optional in the way it can sometimes be for LGB folk, but you can do quite a lot about getting on the road to honest gender expression without ever needing to go near a doctor, if you're inclined to do it in the old fashioned way of the trans community's pioneers.

The trouble is you can't get any further down the path without the assistance of medicine – and that's where the trouble begins, unless you have the money to define and follow your own care pathway.

Easy if you have the money to pay

Private care for people changing gender role is incredibly sophisticated these days – if you look offshore. A quick trip to look at the two sites below will give a very good idea of the kind of on-demand services available to those with the money – and there are obvious concerns about seeing UK citizens getting on planes to far flung places because they feel they'll get what they want there.

See <http://www.supornclinic.com/> (Thailand)

And <http://www.drdouglasousterhout.com/> (San Francisco)

The best known private service provider closer to home in the UK is currently preparing to mark his retirement with a malpractice hearing at the GMC in the autumn⁶. The case against

him isn't being brought by any of his devoted patients, who would rather see him elevated to sainthood. Instead the complaint comes from a group of four NHS psychiatrists at a single clinic, who heartily disapprove of him having offered a flexibly patient-centred approach, for years before the concept entered the clinical vocabulary.

The complainants, putting forward a public interest case, are rather better known among their NHS patients for an incredibly rigid regime of treatment – so harsh that new patients often complain to me of spending their first consultation being lectured on the rules of the establishment, and all the ways they can be thrown off the clinic's list for non-compliance.

With Dr Russell Reid neatly pinned down in a corner, and his sole private practice successor⁷ still really finding his feet, the range of non-NHS options for trans people in the UK is therefore very constrained. Inevitably, as a result, a lot more attention is being focussed now on why the NHS is considered so bad by many trans people that they would sell all their belongings (if they had many) to get private treatment if they could.

Not so much a care path

The hurdles served up by the NHS to trans people are many. They often start with GPs who are simply not willing to deal with a trans patient⁸, or who lack the basic knowledge of where to turn. It is not uncommon to find that trans people know an awful lot more about the care path, treatment protocols, drugs and surgeries than the doctors they encounter.⁹

Some of the biggest hurdles are created by extremely rigid commissioning policies – some of which are unlawful, but attempted in any case, in the hope that the hapless patient won't know their rights, the case law, and how to respond.¹⁰

Then there is an absence of choice – almost always a solitary tertiary referral route to a single Gender Identity Clinic (GIC) in West London¹¹. Next come the lengthy waiting lists, followed by treatment programmes that can spin things out for years. (The record to date was a patient who had been seeing a psychiatrist for 14 years). If (as in several cases) the relationship between patient and Gender Clinic irretrievably breaks down, PCT's apply their single referral policies to offer the patient the stark option : go back there, or have no treatment.

Visualising how all these factors can literally gang up against a single patient is difficult though. So I've created a simple diagram of the hurdles, based on the ways in which treatment most usually takes place in the UK. See Figure 1¹²

Hurdles and Delays

Trans people seeking help to change their gender role almost always make their first contact with the NHS via their GP – which is where their first shock can occur. A patient in a rural area wrote to me recently and explained how it's not always that simple to follow the dictum “Change your GP” if all the GPs in your village practice and miles around are likely to be of the same religiously-inspired mind.

Assuming your GP is supportive and can find out what to do, the next uncertainty is what will happen next. Some PCT's have policies that amount to a blanket ban on any kind of referral for treatment of trans people at the present – usually based on a policy of funding only in “special cases”, but with no indication of what an “exceptional case” would be¹³. Sometimes that's applied to all aspects of treatment; sometimes (incredibly) a PCT may fund evaluation

and years of hormone treatment – only to then refuse surgeries. The ethics of starting a treatment without any commitment to fund it to the clinically recommended conclusion are debateable of course.

Some PCTs have evolved policies of sending patients first for evaluation by a local psychiatrist. A case can be made for that, given that the main factor in diagnosing someone as transsexual is to establish that they don't have any kind of mental illness that might manifest in similar kinds of expressed wishes. In other words, trans people are characterised by an absence of mental pathology -- somewhat underlining the point that expressing your innate identity isn't a defect or illness, but just another form of normal human diversity.¹⁴

Unfortunately, that's not how local psychiatric referrals usually work though. Some psychiatrists know there is nothing they can do to “cure” trans people of being themselves and simply want nothing to do with such referrals. Some simply declare they're not interested in serving the need – as though that were a valid option for professionals to take. Some have pet ideas about subjecting trans patients to lengthy psychoanalysis – which in fifty years has never produced a validated outcome. If the patient is lucky, they may just find a local psychiatrist knowledgeable enough to take a history and perform a differential diagnosis – but in those cases the patient can then simply find themselves back at square one, with their PCT still unwilling to refer to a “Gender Identity Clinic” (GIC) – or to offer a choice of which GIC the client might wish to attend¹⁵. Private practice options are definitely off the menu – even when considerably cheaper (as they often are). Where there is one choice, the patient may either be faced with a long distance journey of hundreds of miles for consultations – or a waiting list measured in years – or both.

Having got to the GIC, the patient may then be met with the kind of boot camp regime which I described earlier, and a lack of professionalism that generally beggars belief. Patients have described travelling two hundred miles for an appointment only to find that it has been cancelled at short notice beforehand. Notes are lost. People complain of never seeing the same practitioner twice and having to give the same basic history again. Any treatment undertaken with another therapist beforehand is usually denounced, with the stark choice to “stop and go back to square one” or be removed from the list. Patients have even been removed from lists for missing a single appointment, for reasons beyond their control.

And it's as well to remember, when recounting this horrific catalogue of abuses, that the patients in question are often by this point extremely vulnerable. They've lost friends, family, jobs, homes – all because of the discrimination and stigma attaching to being a transsexual person. For them there is no going back. Their bridges are burned and, besides, they wouldn't want to return. It takes a pretty powerful force inside to move people to face all this, knowingly.

Patients face a treatment regime that forces them to undertake an endurance test for a period of at least two years before being “allowed” to the next stage, which is a referral for the genital surgery that the whole regime is centred around¹⁶. And then, again, their troubles can start over with their PCT – haggling over whether their surgery is to be funded. One young trans woman was famously told a few years ago in Sheffield that she was number 15 on the local waiting list for surgery, which was funded at the rate of one procedure a year! In the end, being extremely resourceful, the woman in question mounted a local publicity campaign with the support of her local paper to SHAME her PCT into reviewing their policy¹⁷. Soon enough she got her surgery in a matter of months, plus a promised policy review¹⁸. But it

begs the question of whether healthcare for such vulnerable people should really be based on the principle of the squeaky wheel getting the grease.

Faced with all this as an everyday reality across the country it is little wonder that lots of trans people *do* look wistfully at those pictures of smart waiting rooms and high tech surgeries in Thailand, San Francisco and a growing number of places in-between. Similarly, the Internet has made it remarkably easy for those same people to go online with a credit card and order up the prescription hormones they need, to bypass a health system that is seen by them as abusive and obstructive.

When I was a teenager, the place people would go was Casablanca – because there was literally nothing else closer to home¹⁹. It's sad to think that the options for those with money are still not a lot different these days. It's just a different airport.

The trend of Internet Hormones and offshore surgery is not anything to celebrate. It hasn't happened yet to my knowledge, but sooner or later someone is going to die this way. Cross sex hormones aren't sweets. They can be dangerous when taken without the right precautions and testing. Overseas surgeries are full of risks too – for nobody hears of the treatments that didn't go well – and it's a long way to go back and complain.

But this is where medicine in the UK is pushing people. It's a form of neglect, which should have no place at all in the Health Service we all pay for.

In search of help

Trans people approach medicine looking for no more than the same kind of relationship that a pregnant woman seeks for a safe delivery of her child. Being pregnant isn't an illness, and there is no debate about whether it was a matter of choice or not to be that way. Medicine's role is to help the event to take place safely and comfortably for all concerned, because it's a thing that happens to people.

Unlike pregnancy, having a transgender identity (albeit rarer) is *never* a choice. In common with having a baby, however, the outcome has an unstoppable inevitability of its own. And all that trans people seek from medicine on that journey is some help from the supposedly caring people around them.

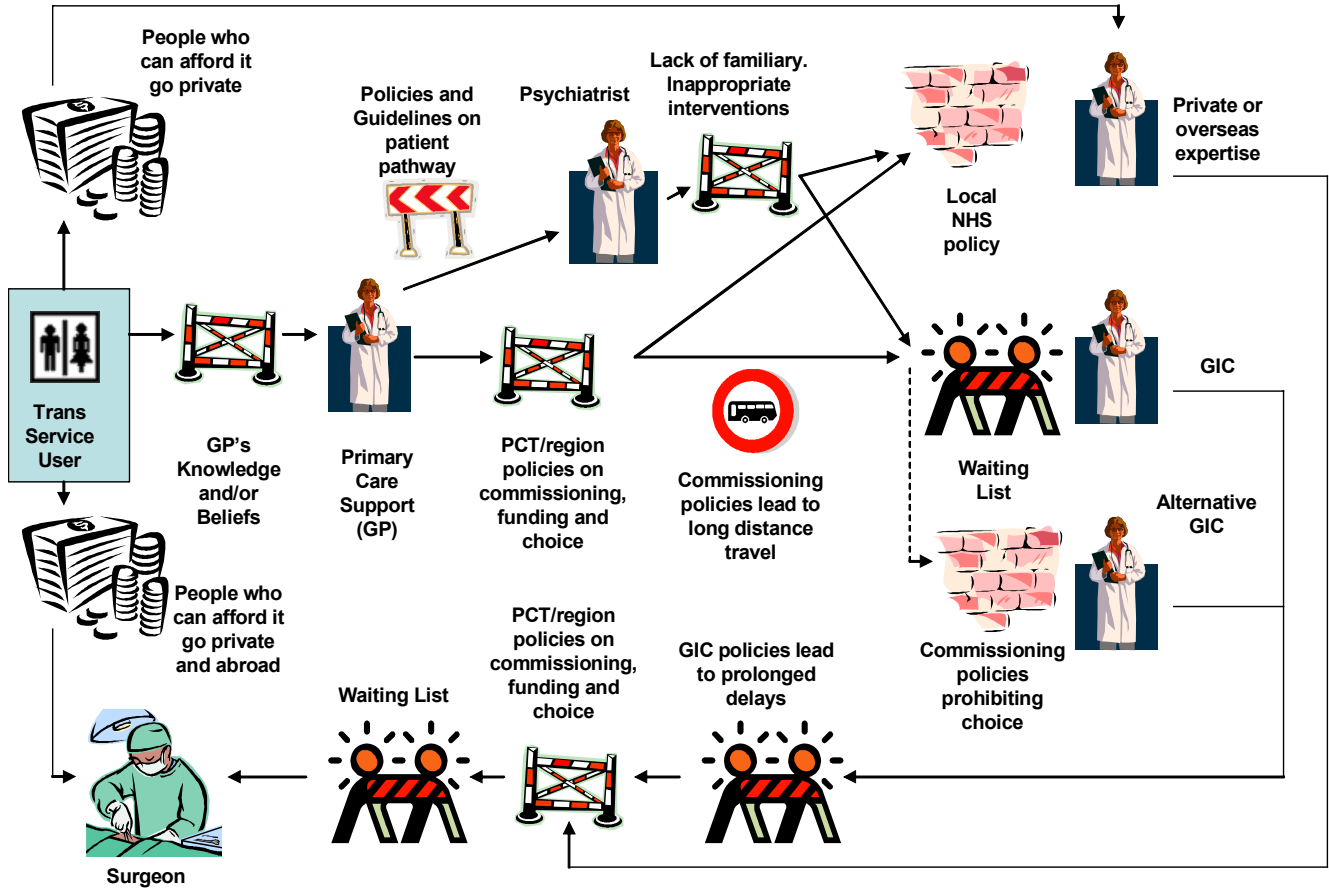
As I've illustrated here, the issue is not an absence of care so much as a quantity of abuse.

It's time the steeplechase season ended. I never advocate for trans people to have any “special” rights. In a public health service that delivers so badly for so many others it would be unfair to expect trans people to have a better ride than anyone else. But if we can achieve a level field – a place where trans people are treated no more abominably than everyone else – that would be a fair starting point for equality.

Christine Burns, July 2006

Figure 1

Gender Treatment Hurdles



Contextual Reading

The edited collection of my earlier works. “*Essays in Trans Healthcare Politics*”²⁰ was intended to set the historical and contemporary backdrop on the tensions between service users and psychiatrists whose views have dominated this field of medicine for fifty years. It explains some of the background to why trans people are viewed and treated as they are by most western clinicians, and the nature of the philosophical divide between those who see gender variance in pathological (mental illness) terms, and those who understand it in the language of human diversity, freedom of expression and the promotion of overall health.

“*Essays in Trans Healthcare Politics*” is presented as it was written, as a series of political essays and news editorials by the author, addressing a world audience of several hundred contemporary trans activists through the “PFC-News” email distribution list²¹. Not only does it therefore provide a contemporary view of the grounds on which trans people challenge and criticise the medical discourse behind their care, it also provides an insight into the reasons why Britain’s dominant public-funded Gender Identity Clinics (GICs) function in the way they do when people expressing gender identity issues are referred into their care.

My separate paper, “*A Basis for Evaluating Care Approaches and Services for Trans People in the UK*”²², published in July 2005, set out from the *opposite* perspective, to define a set of generalised criteria by which care services for transsexual people, and their underlying governance protocols, could be evaluated against contemporary healthcare principles and in terms of acceptability to the client group.

Designed as a sense-checking tool, the document is intended to provide a systematic means by which to appraise both existing services and any new attempts to deliver care in more innovative ways. Because it sets out a user-oriented charter for better, more patient-centred health care, the principles and tests which the paper proposes are often referred-to in short form as the “*Manifesto for Care*”.

A rather damning view of the treatment offered by the Charing Cross Gender Identity Centre is provided by a report commissioned by the Brighton and Hove City PCT in 2004. With evidence from both clients and local GPs, the local “Spectrum” group’s “*Report into the Medical and Related Needs of Transgender People in Brighton and Hove*”²³, pulls no punches in criticising the clinic, to which the PCT currently refers those undergoing gender transition. Eighteen months on, the newly merged Sussex PCTs are now said to be actively considering alternative ways of providing care and treatment for people with gender identity issues, using a higher proportion of locally sourced expertise. If they proceed down this path then they will probably be the first Trust in Britain to take break with the tradition of handing all treatment responsibility to a remote GIC; however, they are unlikely to be the last, as one of the attractions is already thought to be a massive saving in costs.

The Parliamentary Forum on Transsexualism, chaired by Dr Lynne Jones MP, has published a document entitled, “*Guidelines For Health Organisations Commissioning Treatment Services For Those Experiencing Gender Dysphoria And Transsexualism*”²⁴, aimed at helping PCTs to make clinically appropriate decisions in respect of funding all aspects of the treatment of people experiencing any degree of gender dysphoria. This guidance is based on the collected best practice advice of those principally concerned with advising, helping and treating transsexual people and on the personal experience of trans men and trans women.

Footnotes

¹ The Harry Benjamin International Gender Dysphoria Association's Standards Of Care For Gender Identity Disorders, Sixth Version, February, 2001. Orders and History - <http://www.hbigda.org/soc.htm>. Online edition - <http://www.hbigda.org/Documents2/socv6.pdf>. Note that the *Harry Benjamin International Gender Dysphoria Association* (HBIGDA) is in the process of dropping the term "Gender Dysphoria" from its title and is changing its name to the *World Professional Association for Transgender Healthcare* (WPATH).

² Examples of dissent include the publication of an alternative human rights based manifesto for access to medical services by the International Conference on Transgender Law and Employment Policy (ICTLEP) at its second conference in Houston TX, 1993. <http://www.pfc.org.uk/medical/ictlep.htm>. The author's published "Manifesto for Care" echoes similar principles (See "A Basis for Evaluating Care Approaches and Services for Trans People in the UK, Christine Burns, July 2005, <http://www.pfc.org.uk/medical/cb-eval1.pdf> (pp 6-9).

³ At the December 2002 launch of the UK Government's plans to legislate for trans people's legal recognition, the lead Minister (Rosie Winterton MP) introduced a policy that stated: "[Transsexuality] is not a mental illness. It is a condition considered in itself to be free of other pathology (though transsexual people can suffer depression or illnesses like anyone else)". <http://www.dca.gov.uk/constitution/transsex/policy.htm>

⁴ The "Reform of Service Provision of Gender Identity Disorders in the NHS" petition was launched in the summer of 2005 by a group of service users who complain that service provision is "overly obstructive and detrimental" and that the system "often causes patients to see the unsatisfactory care that exists as an obstacle to be overcome rather than as assistance with their condition". As at July 2006 the number of signatories stood at 601. The petition statement can be found at <http://www.petitiononline.com/nhsgidsp/petition.html> and the individual comments of signatories are at http://www.petitiononline.com/mod_perl/signed.cgi?nhsgidsp&1

⁵ GIC practitioners in the UK generally estimate that only 20% of people referred to them will progress to eventual surgery. Although most debate is generally centred around the needs of that fifth of referrals, it is important not to lose sight of the fact that the remainder have care needs too. Indeed it can be argued that neglecting the needs of those four-fifths of patients could lead to regrettable outcomes.

⁶ Dr Russell Reid's case is expected to be considered by the GMC in October 2006. Although he has already now retired from practice, the outcome could see him struck off for malpractice. See "GMC Enquiry Into Gender Change Expert"; *The Guardian*; 20th Jan 2004
http://www.guardian.co.uk/uk_news/story/0,3604,1126835,00.html

⁷ See the website of Dr Richard Curtis at <http://www.transhealth.co.uk/>

⁸ There is a specific problem in the case of prescribing the sex hormones and hormone inhibitors that are needed in order to suppress the development of some secondary sex characteristics and the development of others. At present such drugs are not officially licensed for use in this way and some doctors are therefore understandably concerned about the implications of prescribing them without the backing of a gender specialist. This kind of concern is not unique to trans people (see BMA information and guidance on prescribing in general practice, Sep 2004 - <http://www.bma.org.uk/ap.nsf/Content/InfoOnPrescrib0904~Pats&Prescrib>). It is usually possible to work around this kind of problem, although cases have arisen where a deadlock can occur – for instance if the gender specialist treating the patient is a private service provider and PCT policy rules out dealing with them. The more common problem is that some GPs simply refuse to treat trans people at any stage on grounds of their personal ethical reservations.

⁹ There are several entire Internet sites dedicated to providing education, help and practical advice to trans people – following in a tradition of buddying, mentoring and self-help that has evolved over decades in groups that used to meet discreetly in back rooms and other places of safety. Nowadays the web means that some of these sites have grown to serve an international audience, with pages translated into multiple languages. For examples see the large sites maintained by Professor Lynn Conway (<http://www.lynnconway.com/>) and the "TS Roadmap" site operated as a commercial enterprise by Andrea James at <http://www.tsroadmap.com/>. See also <http://www.trans-health.com/>, and (for an example of a more formal service online) <http://www.vch.ca/transhealth/>

¹⁰ See “No Welcome In The Hillside”, Christine Burns, PFC-News October 2005, <http://www.pfc.org.uk/pfclists/news-arc/2005q4/msg00000.htm> followed by “Still No Welcome In the Hillside”, Tracy Dean, PFC-News, May 2006 <http://www.pfc.org.uk/pfclists/news-arc/2006q2/msg00023.htm>

¹¹ The Claybrook Centre (also known historically as “Charing Cross GIC”) is part of the West London Mental health Trust. For details see <http://www.wlmht.nhs.uk/ourservices/details.asp?id=134>

¹² Also available separately online at <http://www.pfc.org.uk/docs/hurdles.pdf>

¹³ The Court of Appeal ruled in July 1999 that it was unlawful for health authorities (now PCT’s) to operate a policy on funding of treatment for “Gender Dysphoria” that amounted to a blanket ban. See “Blanket ban on treating transsexuals is ruled ‘unlawful’”; British Medical Journal, number 319; 7th August, 1999 (<http://www.pfc.org.uk/news/1999/nwlanca9.htm>). The full ruling may also be consulted via the Press for Change legal library at <http://www.pfc.org.uk/legal/nwl-appl.htm>. Readers should note that whilst this judgement was revisited in some detail by the Court of Appeal in the “Herceptin case” of Rogers v Swindon PCT (<http://www.timesonline.co.uk/article/0,,8122-2132025,00.html>), the finding in that instance specifically differentiates the two different sets of circumstances. [2006] EWCA Civ 392, [2006] All ER (D) 181 (Apr), Para 82.

¹⁴ Although there is a logic in referring people to a local NHS psychiatrist for evaluation before considering a Gender Identity Clinic (GIC), the policies of many GIC’s ignore the local psychiatrist’s findings. GIC’s instead insist in repeating the same basic process to identify or exclude the possibility of a mental illness, as part of their standard and inflexible protocol. The result of this is a frustrating delay for the patient and the inevitable duplication of clinical effort at public expense. It follows that PCT’s considering GICs for inclusion in their referral policies ought to check this and insist on an integrated care approach.

¹⁵ In a recent Parliamentary Written Answer, the Minister of Health explained that Trusts are not obliged to offer trans patients a choice under current Government policy, since their treatment is regarded as a Mental Health condition. (For full Hansard reference see <http://www.pfc.org.uk/pfclists/news-arc/2006q3/msg00009.htm>)

¹⁶ Although this is a subject for a separate article, it is important to keep in mind that the writer is on record for criticising the flawed assumption in current treatment protocols that “prepare GIC patients for sex, rather than for a happily gendered life”. Genital configuration, whilst relevant to sex and reproduction, is arguably *not* the determining characteristic of people’s gender role or a successful transition. Current diagnostic criteria define transsexual people in terms of the desire to change their genitals, and public opinion seems to demand it; however many trans people confirm that it is not their first and overwhelming priority and the Gender Recognition Act recognises that legal recognition can be appropriate even without genital surgery. Many confirm that the most important outcome *for them* is to achieve a happy and stable life in their transitioned role. Therefore it is questionable whether GIC protocols are even centred on the right goal.

¹⁷ See Transsexual wins battle to have operation on the NHS, Sheffield Star, 9th September, 1999. <http://www.pfc.org.uk/news/1999/kh-ss2.htm>. See also Pink Paper feature “Out of the shadows”, <http://www.pfc.org.uk/news/2000/pinkp1.htm> and Guardian coverage at <http://www.pfc.org.uk/news/1999/kh-guar.htm>.

¹⁸ “NHS to review Sex Change operations”, Sheffield Star, 30th July 1999, <http://www.pfc.org.uk/news/1999/kh-ss.htm>

¹⁹ See the autobiographies of trans people who famously transitioned in the 1960’s, such as April Ashley and Jan Morris, whose 1974 classic “Conundrum” is available again in paperback from Amazon.

²⁰ Collected Essays In Trans Healthcare Politics (How Medicine Lost The Trust of Trans People), Christine Burns, May 2006, <http://www.pfc.org.uk/docs/essays-transhealth.pdf>

²¹ PFC-News is fully archived online at <http://www.pfc.org.uk/pfclists/news-arc/index.htm>. With 4750 articles spanning the period since July 1998, plus a dedicated search engine, PFC-News provides an unequalled resource for studying the climate in which trans people live in contemporary Britain, and the way in which trans people have risen to that challenge.

²² “A Basis for Evaluating Care Approaches and Services for Trans People in the UK”, Christine Burns, July 2005, <http://www.pfc.org.uk/medical/cb-eval1.pdf>

²³ “Report into the Medical and Related Needs of Transgender People in Brighton and Hove – The Case For a Local Integrated Service”, Persia West, Brighton and Hove Spectrum group, October 2004 - <http://www.pfc.org.uk/medical/spectrum.pdf>

²⁴ “Guidelines For Health Organisations Commissioning Treatment Services For Those Experiencing Gender Dysphoria And Transsexualism”, Parliamentary Forum on Transsexualism (April 2005) - <http://www.pfc.org.uk/medical/pf-guide.pdf>