

Freedom of Information Act 2000 disclosure log entry

Reference

20-21117

Date sent

30/10/2020

Subject

2005 David Taylor Report

Details of enquiry

Please could I have a copy of the 2005 'David Taylor Report'?

Response Sent

Your request for information has been handled under the Freedom of Information Act.

Please find attached a copy of the report. Please note, some information on pages 9 and 10 has been redacted as it contains personal information and is, therefore, exempt under Section 40(2) of the FOIA.

REPORT ON GIDU REVIEW (MAY - OCT. 2005)

I. Introduction

The GIDU is a service for children and young people who suffer from high levels of distress resulting from their problems with sexual identity and for whom provision is poor nationally. These problems have serious consequences for their psychosocial functioning in their everyday lives at a developmentally crucial time, as well as longer term impacts throughout their lives (e.g. an increased risk of eventual suicide). Inevitably this report will focus upon areas that will benefit from receiving attention. However, it also needs to be read while keeping fully in mind the value of the endeavour of the GIDU's leadership and that of its staff. The head of the Unit Dr Domenico Di Ceglie, since first setting up the GIDU has worked assiduously with its staff so that the service now has an international reputation. The review found that the work of the GIDU has resulted in a set of understandings and a clinical service which is a serious and ethical attempt to mitigate the possible adverse consequences of what can often be a grave disorder.

II. Review Findings

An insufficiently examined and discussed difference of professional opinion about gender identity disorder in children and young people is the primary cause of the difficulties experienced by the GIDU. In what, by their very nature, are always going to be conflictual problems eminently capable of arousing strong feeling there are also differences about the best way of translating theoretical models and clinical understandings into the most effective approaches to assessment, management and treatment.

The problems of the GIDU (and the T&Portman Clinics) have become more evident as the service has grown. In addition changes in social attitudes have increased pressures upon staff to comply with the demands and expectations of patients, and sometimes of their parents, in ways that may not always be in their long-term best interest.

These problems have included:-

1. Lack of place and ownership within the Trust's clinical organisational structures contributing to insufficient management and support of the service overall
2. Lack of clear & authorised development aims and business plan
3. Inadequate home base and provision of accommodation
4. Staffing, seniority and skill mixes, and perhaps selection processes, militating against the development of a staff group in which full team-working and decision making via appropriately detailed case discussion can occur, in a setting guided by clear leadership
5. Differences of clinical viewpoint among the staff of the GIDU have not always been contained, leading to unease, dissatisfaction and some difficulties with staff retention.

All of these problems are to some extent secondary to the underlying differences between the GIDU and the Trust with respect to differing positions re psychic reality

vs. social validation models and to the use of powerful drugs as part of a process to delay or effect changes in physical sexual characteristics and gender.

The secondary practical issues such as the increasing size of the service, accommodation problems, lack of infrastructure and isolation, without a proper place in a directorate of allied clinical services have a reality of their own and require remedy of themselves. This sort of infrastructure difficulty is a familiar feature of almost any innovative service development.

The findings and recommendations of this report seek to describe and address these interlinked problems. Attention to each should produce significant overall benefits to the quality of the service and to its future development.

A. Scientific and Clinical Issues:

The Nature of Gender Identity Disorder

Most informed workers of whatever persuasion consider that GID is a collection of multi-factorial syndromes rather than a single condition with a single aetiology. In the main it is agreed that:-

1. There is usually a combination of contributing causes of a constitutional, biological, psychological and psychosocial nature, all heightened by the context of adolescent mental and physical growth, development and maturation - in other words as part of an enormously active period of re-organisation.
2. In a large proportion of cases, environmental, psychological and psychosocial factors are quite evidently important.
3. Only a small percentage of cases are biological inter-sex conditions. Indeed, the identification of an inter-sex condition precludes the diagnosis of Gender Identify Disorder.
4. In a proportion of cases, the identity disorder shades into other psychosexual development disorders and same-sex sexual preferences.
5. In a proportion of cases, where there have been deprived or injurious upbringings - child abuse, multiple caregivers etc. - the GID seems to be just one expression of a much wider developmental or personality disorder with, for example, borderline features.
6. A proportion express what outwardly appears to be an entirely ego-syntonic wish or conviction of possessing a true identity as that of their non-biological gender.
7. Amongst this group there may be some where there is little sign of disorder in other areas of functioning (or a sense in which any wider disorder is organised and defended against by a gender belief system).

Whilst something is known about the natural history of the syndrome there is also much uncertainty about outcome:-

1. A larger number of younger children than the population currently referred express what may apparently be transitory wishes to be of the other sex
2. There is an impression that boys and girls in this early, pre-pubertal group tend to show more flexibility and responsiveness to therapeutic interventions.

3. A proportion of the smaller number of established cases amongst immediately pre-pubertal children may manifest enduring convictions about their gender.
4. Particularly in relation to this latter group the outcome of different approaches to management is not clearly established.

We found considerable differences of emphasis among clinicians about the aetiology, case management and treatment of gender identity disorder. Conflicts arise out of a lack of resolution of these different ways of understanding the disorder and the values which may lie behind them. The models are:-

The psychological model:-

1. Is that it is an outcome of an enmeshment with and/or a defence against an identification with a primary object with profound depressive anxieties
2. The defence may have the phenomenological character of a delusion, or of an over-valued idea or it may be much more transitory and have an "as if" character.
3. The conative status of this defence probably gives some clue as to outcome; most experienced clinicians suggest a need to recognise the limitation of psychological therapy in terms of change in an established gender identity configuration.
4. While it seems possible that reversion occurs in some instances it is equally clear that in many the condition seems unresponsive (in the narrow terms of reversal at least).
5. In younger children the condition is more often transitory; here a timely and appropriate therapeutic intervention might be particularly helpful in attending to the background out of which the primary symptom arose and which might lead to the emergence of other difficulties subsequently.
6. Therapy may address many of the deeper seated or less obvious expressions of disorder in this patient group. This may improve functioning generally, lessen distress and increase the possibilities of better personal adaptation even while the gender identity configuration appears to be unchanged.
7. As well as current or 'sleeper-effect' * benefits for primary and secondary difficulties some clinicians would argue that it is important for reality-testing, for the long-term health of patients, family networks and for society as a whole that the factuality of biological and 'experience near body-image' gender is affirmed.

The psychosocial model:-

1. Places more emphasis upon social role learning in gender identity development.
2. Therefore gender identity is more likely to be viewed as a matter of personal choice and preference.

* A 'sleeper-effect' refers to a term arising out of research into the effects of psychotherapy particularly psychodynamic therapies. Typically, it refers to the fact that the full benefit of treatment only shows after a latency period of some months or in some cases over a year. This is thought to be connected with a disturbance which typically arises at the end or termination phase of treatment and how this disturbance requires time to resolve for the emergence of the full benefits of the newly internalised capacity.

3. Therapeutic interventions would more likely aim to facilitate gender change transitions and to be sympathetic to this.
4. On this basis there are differences of practice amongst the clinicians as to whether they use the patient's chosen name of their desired gender or adhere to the given name or some reasoned position in between the two.
5. Therapy aims to minimise the impact of what are mainly viewed as adverse social responses causing secondary disabilities like social withdrawal. These are seen as arising from the reaction of family or extra- family networks and include hatred, bullying, teasing, scape-goating, tormenting and all the various forms of social reaction to difference ('stigmatisation').

The genetic or neuro-genetic model may be used either to complement or to supplant the other two:-

1. It concerns early expressions of genetic/ physical aspects of the prenatal/maternal environment, or other neuro-developmental factors. These affect areas of brain development thought to be instrumental in gender identity development (?frontal lobe/hypothalamic connections etc)
2. This view is often held to support therapeutic pessimism or to indicate that treatments need to be physical ones. These arguments are not sound. Many genetic conditions and associated disabilities may be responsive to environmental or psychological interventions.
3. Likewise these putative neuro-developmental difference are held to vindicate patients' feelings of subjective certainty about their 'true nature'

The compatibility of the aetiological and treatment model adopted by the GIDU with the values of 'the Tavistock & Portman Trust approach' ?

Although it is currently only loosely specified our understanding of some of the main components of the T&P approach is that:-

1. It is based upon a serious commitment to identify, to understand and to grapple with the kinds of psychological and psychosocial factors known to be important in mental distress and disturbance.
2. It does not sanction the routine use of mind-altering, brain-altering, development altering or body-altering medications or operations for the treatment of mental disorders save where there are clear and legitimate and well evidenced indications for their value. This caution especially applies if there is a sense of psycho-active medication or physical interventions being resorted to in a misinformed, opportunistic, evasive or perverse way.
3. However, it recognises that there are limits upon the indications for psychological approaches and upon their efficacy
4. It recognises the existence of conditions which are likely to need physical treatments - so the use of medication or other physical interventions is not ruled out in all circumstances.
5. However, physical interventions are used sparingly - especially in those situations where, while they may be the best available option, the understanding of the condition and the treatments that are available are rudimentary or incomplete. This means using good indications based upon a careful weighing of benefits and losses and in a way that is thoughtfully evidence-based.

6. Clinical decisions in these circumstances should be reached on the basis of a detailed consideration of the nature of the condition, previous findings and guidelines, a thorough assessment of the individual case and, in some instances, only after a serious trial of psychological interventions in their various forms – in assessment consultation/ individual therapy/ group therapy/through psychosocial advice and liaison/family therapy in psychoanalytic or systemic form.

The dialogue required in order to arrive at some working solution of these different ingredients is yet to take place.

That it has been so difficult for the Trust to find an appropriate *physical* base for the GIDU may be symptomatic of the unresolved nature of the different points of view listed above. Another expression of this may be the lack of resolution concerning the name of the GIDU. The initials GIDU are variously understood as the “Gender Identity Development Unit”, the “Gender Identity Dysphoria Unit” and finally the “Gender Identity Disorder Unit”.

The Dominant Treatment Model Employed:

Many patients – increasingly it seems – present expressing a wish for hormone treatment and - again increasingly - with parental support.

The express policy of the GIDU is to gain time and space for thinking through. This may involve slowing down some of these demands from patients and sometimes parents as well as the bio psychosocial processes involved in adult maturation. Many factors lie behind the pressures upon clinicians to act so as to provide immediate solutions through physical interventions which may not always, in the long term, prove to be helpful or beneficial. Thus the social process of referral to the hospital (UCLH), the fact of having a physical examination and an assessment and blood test along with being seen by a doctor (a Consultant Paediatric Endocrinologist) becomes a rite of passage underlining the serious reality of what is going on.

The use of endocrine/hypothalamic blocking agents and hormones:-

1. The rationale in the Gender Identity Disorder Unit for using these medications is that they purchase a developmental delay and through this some time to think about what is going on without being so driven by the pace of biological sexual developments.
2. On the basis of a theory that these patients require action and concrete processes rather than abstract thinking (of which they are intolerant), the use of blocking agents and hormones which lead to physiological and anatomical changes are felt to convey acceptance of the intensity of the gender conviction, consolidate an otherwise precarious treatment alliance and may avert, for instance, the threat of suicide.
3. It is by lending physical reality to the patient’s express fantasies and wishes that they offer an opportunity for a kind of reality testing - for the individual to see if this is what they really want.
4. This has been - within the GIDU and within the Trust - one of the practices that have excited most controversy.

5. It should also be noted that there is a range of practice carried out internationally. Mostly these are based upon a consensus concerning the advisability of a “staged approach” which moves first from fully reversible interventions through partially reversible ones to only as a final stage irreversible interventions in adulthood.
6. There are guidelines available from the Royal College of Psychiatrists and also from the Harry Benjamin Gender Dysphoria Association Standards of Care for Gender Identity Disorders (6th version). In addition the British Society of Paediatric Endocrinology and Diabetes has produced, “Guidelines for the management of GID in Adolescents and Children” which sets out a rather different position than that in the Benjamin Gender Dysphoria Association guideline. But there are subtle differences of emphasis in each of the three guidelines. For instance, the Paediatric Endocrinology guideline firmly states that, “we believe that individuals cannot confidently assess whether or not they are genuinely misplaced within their body until they have experienced their own natural pubertal hormonal milieu and consequent physical changes” (page 1 of the guideline).

The rationales underpinning this approach may be valid. However, as far as we could tell they are relatively untested and un-researched. More detailed research should be undertaken into the ideas behind this treatment approach. However, conventional prospective outcome studies based upon the “gold standard” methodology of random allocation control trials would be extremely difficult to mount and may not be practicable or ethical given the nature of the interventions concerned. It is likely that as well as some pooling of data concerning the patient populations of different services and different countries that progress in the understanding of this condition is likely to arise out of a number of more detailed studies/enquires. Not least, there is a need for considerable further work about the type of outcomes that are already encountered in this patient group. This type of observational study concerning what currently happened and what the outcomes currently are is probably a key part of working out what might be the best way of thinking about benefit and improvement in these difficult situations. Protocol development work in this area is already taking place and should be expedited.

There are a number of specific questions. For instance, is it true that hypothalamic blocking agents/endocrine analogues purchase time in the ways proposed? Is empirical information being gathered about what patients do with the extra months and years by which puberty is delayed? Is any information available upon the effect of the temporary and partial cessation of sexual maturation upon the multilevel developmental process involving brain, body, psychology and social role which are going on in adolescence? A key part of the normal psychological adaptive processes of adolescents requires the individual's engagement with these major bodily changes - in part fuelled by sex hormones. A degree of disturbance is often a part of these adaptive processes. This is obviously much increased in this patient group. Are we making sufficient enquiries about the possibility of other ways of responding to this potentially adaptive process?

Although the information we received was not unanimous it is the consistent impression of a number of GIDU staff that the service was coming under pressure to recommend the prescription of drugs more often and more quickly, and that the

independence of professional judgement was also coming under increasing pressure. Young patients may threaten suicide if their anxieties are not immediately addressed. Parents and others may threaten to complain and there are powerful lobbies from older patients pressing for the use of medication, which even more worryingly, is now available without regulation via the internet. Clinicians will differ in their ability to resist the pressure to comply. Currently, there is no overall Trust position to support clinicians and clearly a dialogue needs to take place to address these many and powerful pressures.

B. Recommendations for the Clinical Service:-

1. It is important that underlying issues and models are made explicit. This will be part of an enabling process for staff to re-equip themselves with understandings which can form a basis for clinical decision-making and treatments of the highest possible quality as well as reflecting the degree of uncertainty in the field.
2. In connexion and dialogue with this the Trust should set out its view of the principles and aims of the service so that a shared approach is achieved.
3. The overall aim will be an assessment and treatment service of the highest standard which also advances knowledge of the disorder and its treatment. Given that this is such a difficult and problematic area it is not an option for the Trust to provide a service that is less than the best possible.
4. Recognise the possibility of a connection and similarity between GID, eating disorders and body dismorphic disorder (BDD) as a useful step which will further the organisation of Trust services for patients with these conditions and research into them. The hypothesis essentially is of a family of serious developmental disorders emerging in adolescence
5. Given the diversity of models and the nature of the Trust the process of clinical decision making should take more account of the explicit working through of multiple perspectives held by professionals in this field who have different points of view and *knowledge* bases. The consultant leader of the team will be responsible for and have the authority for the final clinical decision but this will be with reference to the opinion of the multidisciplinary team and with regard to agreed protocols and understandings based upon the clinical model, the assessment and treatment package(s) to be made available and guidelines regarding treatment of choice.
6. Given the variation in responsiveness and flexibility of patients with these conditions it is very likely that there will be no single, obvious treatment of choice. It is likely to be a package comprised of thorough assessment followed by a variety of therapeutic options. Given this complexity and the need for careful clinical judgement the process whereby the eventual clinical decision making is reached is as important as the content of those decisions (within certain limits).
7. The indications for the various treatment approaches will also vary according to the patient group. Thus for the younger group where more flexibility is to be expected and where the possible benefits of intervention are greater more attention than currently should be devoted to providing them with ongoing therapies of various types. The service should consider ways of maximising possibilities of early intervention - although it is recognised that predicting the course of early cases is difficult. Some may 'resolve spontaneously'.

Nevertheless, even in those cases where “spontaneous” resolution occurs this does not mean that there are not deep seated developmental problems which might benefit from a therapeutic intervention.

8. In the patient group with obvious high levels of disturbance - including evidence of a borderline organisation of the personality - long term therapeutic inputs should be offered wherever possible. There will also be a place for long term intermittent interventions with this group.
9. For the patient group who consistently maintain an ego-syntonic wish/conviction re gender reassignment the current policy of purchasing a delay in time - if necessary with the use of hormone blocking agents - should still be available. The indications for this option need to be more searchingly set out including indicative times of cooling off and specifications of the assessment process required and its duration. Serious consideration needs to be given to the individuals capacity to make an informed decision – to give informed consent – on the basis of the best possible awareness not only of potential benefits but also the irreversible effects and the potential hazards both physically and emotionally. In situations where there continues to be serious reservations about the wisdom of this course of action (that is greater than the usual doubts and uncertainty to be expected) then it should be possible for the GIDU to feel that its staff have the clinical authority to decline to provide these physical interventions. This group should be followed up long-term in order to maintain a therapeutic contact and for clinical audit purposes.
10. In order to ensure the best possible liaison with the Paediatric Endocrinology Service at UCLH these arrangements should be reviewed and contact made at a managerial level with the Endocrinologists involved. This relationship needs to be formalised and clear understandings about practices, resources, accommodation, managerial structure and future research need to be reached. This would be of benefit to both aspects of the GIDU Service and also to the Endocrinologists also. One of the issues which require clarity is the location of clinical responsibility for a) the Endocrinological intervention and b) the psychological assessment and treatment.
11. The staff of the Unit undertake a considerable amount of consultation which involves travelling to local services. The model used in this work could be spelt out and its costs, benefits and pricing evaluated
12. The name of the Unit needs to be confirmed. If the title 'Gender Identity Development Unit' is to be retained this aim needs to be more clearly represented in the work of the Unit and in the way this is perceived both within the Trust and without. For instance, parents consult the GIDU in instances where the disorder may be transient or resolved especially with the provision of special preventative work. The existence of this work could be more highlighted and perhaps the amount of it increased. Likewise, in its role in helping the children of transsexual parents in coping with confusion and ambiguity about gender arising from a parent's difficulty there will be many opportunities to facilitate and to understand the factors involved in normal gender identity development and its vicissitudes the greater profiling of this type of work would minimise misapprehension about the aims and purposes of the Unit by studying normal gender development as well as pathological. At the moment this title risks an interpretation of an equivocal attitude to normal

gender development being made. In the long term this will not be helpful although in the short term it may purchase an uneasy peace.

13. The Unit needs to have sufficient expertise and resources for clinical audit of its various patient groups, its assessment and treatment methods. This audit activity should not be undertaken in a tendentious spirit in order to prove one or another position or perspective. Audits need to be objective and searching.
14. Similar issues apply to research which will be facilitated by the service being seen to be part of a family of disorders which develop in full form in adolescence, namely GID, eating disorders and so-called body dismorphic disorder.

Although there are other options which might be considered, if this way forward is thought to be along the right lines, the GIDU will require a range of additional inputs in terms of locating its place in a wider clinical management structure, its staffing, the working relations amongst the team and its physical accommodation. These pre-requisites need to be costed and a business model developed which takes these into account. The subsequent service will be larger, involve more expenditure and will therefore need to generate more income. It is likely that some of the improvements to the service will be resisted by some of the patients hitherto referred to it and by some amongst the patients' organisations even while they are to their long-term benefit. This may reduce referral rates and the risk attached to this needs to be estimated.

These necessary infrastructure inputs are now examined.

III. Practical Measures Re Infrastructure:

A. Locating the service within a clinical directorate.

As the current head of the GIDU service has pointed out the Unit has suffered by virtue of its 'orphan' status with it having no place in the Clinical Directorate structures nor their plans. A tendency towards the isolation of its clinical practice along with a lack of central ownership have inevitably contributed to problems described above.

1. We recommend that the GIDU should be housed within a clinical directorate where the boundaries with other services in the Trust dealing with similar age groups can be more permeable. This will permit the GIDU to become an integrated part of a culture of clinical practice and maintain the compatibility and quality of clinical services (both ways).
2. The GIDU would be best placed in a developing team dealing with gender identity disorders, eating disorders and body dismorphic disorder located in the Adolescent Department and accountable to its Clinical Director.
3. While the capacity of the Adolescent Department has been stretched its new strategy offers a real prospect of this increasing. The issue of physical space is dealt with below.

B. Physical Accommodation:

The current arrangements for the accommodation of the GIDU are not viable-

As pressure on available space has increased a difficult situation

The Portman Clinic with its patient group is not an appropriate location for a service like the GIDU. Since the mooting of the review and the involvement of the new there has been a clearer understanding between the two services and some of the day-to-day problems are much better managed. However, the current arrangement is a temporary, rather than long term solution.

1. We recommend that although the Adolescent Department has no space available additional clinical space adequate for the GIDU should be freed in the Tavistock Clinic building when/if the 2nd additional floor of the 'Finchley Wing' becomes available - on the basis of its allowing some further non-clinical re-locations from T.C. site to F.W.

C. Staffing of the GIDU:

Notionally, the GIDU has a 'clinical establishment' of six paid staff although there have been recent resignations and a further resignation is expected.

The 'establishment' is:-

	WTE	Approx. Salary Cost
Consultant Child & Adolescent Psychiatrist-Director	.5	£61.5k
Consultant Child & Adolescent Psychotherapist	.3	£21.6k
Senior Clinical Lecturer in Social Work	.4	£28.5k
Clinical Psychologist	.2	£10.5k
Clinical Nurse Specialist	.2	£10.5k
Total Clinical staff in WTE	1.6 wte	Total £132.6k
Administrative Staff	1	Total £22k

Paediatric Endocrinology Liaison Clinic:

One Consultant in Paediatric Endocrinology (2 PA's/ term) and one Consultant in Adolescent Medicine & Endocrinology (2 PA's/ term) work unpaid at UCH/ Middlesex ,Department of Endocrinology.

Owing to recent resignations the staff group is not at full complement. There are discrepancies between the GIDU pay budget which gives a total wte of 3.4 and the current staff list which gives a wte of 1.9. Many staff - while working more than the sessions they are contracted for - find that their contribution is fragmented and inefficient because of having small numbers of sessions.

Currently, in connection with both these factors there is an increased tendency for leadership and seniority to be focused solely on the Director. The team needs a senior professional from another discipline to produce a better balance of clinical authority and experience.

Recommendations:

1. To achieve the clinical aims set out in **IIB** the staff group needs to be strengthened
2. No member of staff should have less than 0.4 wte sessions commitment to the Unit.
3. Attention should be given to succession planning particularly at directorate level.
4. The GIDU like other parts of the Trust should have trainees attached from the various disciplines. (Whilst the work of the GIDU is specialist it would provide a valuable experience for trainees who would contribute to the work of the unit. This reduce tendencies towards service seclusion
5. As a specialist unit the GIDU could attract honorary associates as a clinical resource and as a contribution to the scientific life of the Unit.

D. Current Size, Income & Expenditure & Future Size, Income & Expenditure & Business Plan:

In the year 2000/01 there were 28 referrals; by 04/05 this had increased to 50. The increase occurred almost entirely between 01/02 and 02/03; since then the number of referrals has stabilised.

Information on patient flows and movement through the system is imprecise. An idea of the dimensions of the service can be gained from the following:-

1. In 04/05, 50 referrals were received
2. 340 appointments were offered
3. Approx 77 cases were open at any one time. (Currently there are 117 cases open).
4. The average period of treatment was something like 18 months. We do not know how many appointments this means nor how many patients are in regular treatment and how many in intermittent contact.
5. We do not have figures for the mean, median and mode of numbers of appointments, treatment duration, or outcome for the total patient group nor by sub-group. (Although CareNotes data may now be able to give this)
6. We do not have exact figures for the number of patients prescribed hormone therapy nor whether or not the proportion of these is increasing (nor data on trends in their ages) (however, these figures could be calculated with a designated audit).
7. All of these could be established with a service audit.
8. The Unit does a considerable amount of outreach/liaison which involves travel to distant parts of the country.

The current annual income of the service is £250k with budgeted expenditure in the region of £210-220k (approx). The real costs of the service are substantially greater. The clinical costing project might yield some additional precision.

It is clear that for the service to function on the model of enlargement and strengthening outlined above there will be a need for additional clinical sessions. Operating on the principle of no staff working less than 0.4 wte on the GIDU this will mean greater costs and a projected break-even income requirement in the region of £300K-£400K.

Recommendations:

1. A new exact business case needs to be made to establish the viability of the model of enlargement and strengthening as a component part of the Adolescent Directorate, as a service affiliated with other developments as described (i.e. eating disorder and BDD)
2. A second option would be a much smaller scale service again integrated within the Adolescent Directorate.

D. Taylor
Jan 2006