

Trans People's Access to Gender Reassignment Services Health Sector Round Table Discussion 27 February 2008

Introductions and Objectives for the Day

The round table discussion was opened by the Human Rights Commission's kaiwhakarite Bill Hamilton, who then introduced the facilitator, Warren Lindberg to outline the objectives for the day. These were focused on a small number of concrete tasks, namely identifying:

- the work required to develop treatment pathways and standards of care / best practice guidelines
- the options for how this work could be done and
- the next steps for progressing this Inquiry recommendation

Warren Lindberg emphasised that participants would not be making decisions, and any minutes would be distributed widely to trans people and others interested in the Inquiry's health recommendations. All participants were then invited to introduce themselves, and to outline their involvement in the Inquiry.

Inquiry overview

Commissioner Joy Liddicoat provided an update of work since the final report of the Inquiry into discrimination experienced by transgender people was released on 18 January. The key activities had been media work, briefings with trans communities and government agencies, and prioritising this health sector round table discussion.

Treatment Pathways overview

Deborah Woodley from the Ministry of Health provided an overview of:

- the components of the NZ health quality framework
- clinical (or treatment) pathways including common features and designs
- guidelines and
- standards of care

Deborah Woodley's PowerPoint presentation and a slightly longer background note distributed by the Ministry of Health are attached as Appendix 1.

Discussion

The key issue raised in the initial group discussion was the limitations arising from treatment pathways that focused on treating symptoms or disease states rather than on supporting people's holistic and complex health needs. Participants then broke into three small groups to discuss the following questions:

- If health services for trans people were working well, what would that look like?
- What is the outcome people want and what do trans people need to achieve their potential?

Report-backs from small group group discussions identified the following key points:

RECOGNITION:

- The importance of language e.g. empowered choice
- Recognise a person's right to self-direction and to identify their own needs
- Recognition rather than diagnosis

RANGE OF OPTIONS

- There is potential bias and discrimination in current decisions about services for trans people
- Structural barriers exist preventing trans people from accessing services
- Ensure there is a range of options and the flexibility to move between them
- The importance of health interventions that enable trans people to live and work in their appropriate sex / gender identity
- We will need to grapple with how much ability trans people should have to pick from the smorgasbord.
- There are likely to be problems if treatment pathways and standards of care aren't aligned
- Some degree of gate-keeping or moderation exists, particularly for safety reasons. As a result, the ability to get a second opinion or to question such decisions is necessary.
- Negotiated consent is important.

NETWORK OF EXCELLENCE:

- There is a need for local teams of health professionals to work together
- Both trans people and professionals need support at a local and regional level
- Establish a decentralised network of excellence (described as a spider web or umbrella), where interested people work together across the country.
- Participants preferred a network of excellence rather than a single centre of excellence because of concerns that the latter option would reduce options for trans people who did not live close to such a centre
- A network of excellence could develop and demonstrate best practice
- The possibility of a Society for Transgender Studies (other examples cited include the NZ Society for the Study of Diabetes, and the Society of Sexology which existed in the 1980s).
- The importance of education for health professionals, including around confusion between gender identity and sexuality

Standards of care / best practice guidelines overview

Judi Strid from the Office of the Health and Disability Commissioner gave a presentation showing how research evidence is the basis for recommended best practice, standards, protocols for particular procedures and individual treatment plans or pathways. This material included clear definitions of clinical guidelines, treatment protocols and treatment / clinical pathways. Judi summarised how this framework could be applied to the issue of gender reassignment services. This presentation is attached as Appendix 2.

Discussion

Participants considered that evidence-based or best-practice guidelines were not feasible in New Zealand. This was because there is insufficient quantitative evidence showing the impact of various procedures on trans people. Therefore the group's general preference was for consensus guidelines (one form of recommended practice) or simply guidance about gender reassignment services.

The issue of a network of excellence was raised including that it could help to cultivate a research culture about trans health issues or gender reassignment services. Participants considered that, in the medium to longer term, such research, particularly consumer-led studies, could improve the evidence base for clinicians working in this area.

A number of participants had been involved in the development of guidelines for other health issues or groups. Their comments are included alongside other key discussion points listed below, in no particular order of importance:

DEVELOPMENT OF GUIDELINES OR GUIDANCE

- The best guidelines have been those that include health professionals from a range of disciplines and a diverse group of consumers, including Māori and Pacific people
- Guidelines include a resource for consumers and one for clinicians
- Guidelines or guidance should not be developed in isolation, but alongside other initiatives such as a network of excellence, and education and training of health professionals (with the involvement of trans people)
- There is a need for checks and balances so that 'standards' are neither used as 'paint by numbers' nor lead to clinicians becoming risk-averse
- Trans people are often more knowledgeable than health practitioners about their specific health issues, therefore it is important they take on a key role in developing and implementing guidelines or guidance
- A national strategy or approach is important
- Ministry of Health support and resources are required to give this work credibility, as well as the support of the Human Rights Commission and the Office of the Health and Disability Commissioner

IMPLEMENTING GUIDELINES OR GUIDANCE

- A network of excellence would be a focal point for modelling these guidelines / guidance and sharing them with others
- Training about using guidelines / guidance is part of an implementation strategy
- Someone has to stick their neck out and use the guidelines / guidance
- Guidelines / guidance are also useful for bodies that receive complaints about health services

Participants then broke into small groups to look at the following questions:

- What is needed in order to:
 - o provide clinicians and trans people with guidance
 - o make informed decisions / choices and
 - o ensure optimal care?

Report-backs from group discussions identified the following key points:

ADAPTING OVERSEAS RESOURCES

- The option of developing and applying the World Professional Association for Transgender Health's guidelines (<http://www.wpath.org/>) to New Zealand
- Base guidance on good practice here and overseas, and ensure it is culturally safe and relevant
- Gather up information from around the world as a starting point, including reviews of the evidence
- There are concerns about the DSM IV diagnosis of Gender Identity Disorder which may need to be addressed in developing any guidance

GUIDANCE

- There is an urgent need to get guidance sorted ASAP, with regular review built into the process
- Guidance is the bigger picture, and particular standards of care can then fall out of that work.
- Guidance identifies what health interventions are required and is a stronger basis for decisions about DHB referrals (inter-district flows), funding and prioritisation of elective surgeries

LINKING PEOPLE, SERVICES AND RESOURCES

- Develop a hub so whatever gateway people enter the health system, they are able to access gender reassignment services
- Research, education and linkages (e.g. an 0800 number and public health database) sit alongside the development of consensus guidelines / guidance
- Potentially, the role of the Human Rights Commission may include brokering relationships with Royal Societies, providing links to the wider network of interested people, and creating a safe space for dialogue and conversations

PROCESS

- Recognise trans people as the consumer experts in this area
- Trans people and health professionals working in this area need to have ownership of the process, because of the sensitivity of the issues involved, and the level of myths and discriminatory attitudes about gender reassignment services
- Trans people and groups wish to retain their individuality but need to work together to have a collective voice on these issues
- There would be concerns if trans people's involvement in a dialogue process had any negative implications on their individual access to treatment
- Buy-in from the Ministry of Health is also very important.
- A funded advisory group is required to progress this work

Next Steps

Commissioner Joy Liddicoat summarised the issues that had emerged through the day, thanked Warren Lindberg for his facilitation and all those who had participated, including presenters.

The final group session looked at the next steps required to progress the Inquiry's recommendation to develop treatment pathways and standards of care for gender reassignment services. The preceding discussions had clarified that the immediate priority is the development of guidance for clinicians and trans people on a wide range of gender reassignment services.

Participants were asked what should happen next and made the following proposal:

PROPOSAL:

That the Ministry of Health support a Working Group to develop guidance for the provision of appropriate health services for trans people

Further discussion identified the option that this could be a joint proposal from the Human Rights Commission and the Office of the Health and Disability Commissioner to the Ministry of Health. It was also stressed that any Working Group would require collaboration between trans people and health professionals.

Criteria (for who needs to be involved)

Participants were asked for their ideas about the criteria for choosing people to be involved in such a Working Group, and ways to ensure a broader group of trans people and health professionals were also involved.

Initial comments made at the round table discussion were:

- There is a need for all involved to work from a position of mutual respect, sharing a common sense of purpose

- Participation in this ongoing work should be based on skills, expertise and experience
- Mix and match the people involved, based on specific tasks required at any given time
- Information skills are required, in order to manage background reading
- The group needs to be broad but also a workable size
- It should include both people receiving and delivering treatment
- Involve decision- makers/ stakeholders
- Overall, there is a need for both individual and organisational representation (e.g. to ensure buy-in, diversity and a mix of skills)
- It was suggested that health professional bodies could be asked to put forward someone to be involved
- Some trans people commented that democratic representation can be harder in trans communities because there are a wide range of groups and networks, yet many trans people are scattered and don't belong to any groups. Therefore asking groups to put forward individual nominees may not be representative of the wider community or necessarily result in the right overall skills mix. As a result, some trans participants suggested it was preferable for the Human Rights Commission to continue to choose trans participants, based on clear criteria including ensuring that the diversity of trans people and communities are represented.
- Briefings with trans communities are one opportunity to discuss trans people's participation in this ongoing work, seeking people's views
- The Human Rights Commission's responsibility should be transparent and includes communicating with the wider group of people involved in the Inquiry

Acknowledgements

- Respect for the process today, as a model for the way forward
- Congratulate Human Rights Commission on the wonderful final report and trans people on the courageous stories that came forward
- The report has been received well, the timing is right to move forward, collaboratively.

Resources

Some background resources were on display at the round table discussion and electronic copies were offered to participants. A list of those resources is attached to these minutes as Appendix 3.

Actions

The first task was to circulate the notes of this meeting so that others interested in this Inquiry recommendation can provide any comments about the issues discussed and the proposal outlined above.

- Circulate first draft of minutes to participants, to correct any errors
- Finalise and circulate minutes, including presentations and background paper

Appendix 1: Ministry of Health Handout and PowerPoint Overview

DISCUSSION

Human Rights Commission health sector roundtable discussion on improving the health of trans people.

Background

The Ministry of Health was asked to provide notes on the range of processes that could be used to develop “treatment pathways/standards of care” for trans people. The wider health quality framework has been included to remind all participants that there are already generic standards that operate for all health services.

What are the components of the New Zealand health quality framework?

Providers of health services operate within several statutes and national standards, which together make up the components of the New Zealand health quality framework. These include:

- the New Zealand Health and Disability Act 2000
- the Health Information Privacy Code 1994
- the Health Practitioners Competence Assurance Act 2002, and
- quality and safety requirements for district health boards outlined in the ‘*Service Cover and Operation Policy Framework*’.

An important mechanism within the quality system is the Health and Disability Services (Safety) Act 2001. This Act requires providers of health facilities to be certified against the generic Health and Disability Sector Standards. The generic Health and Disability Sector Standards cover:

- consumer rights
- organisational management
- pre-entry and entry to services
- service delivery
- managing service delivery
- safe and appropriate environments

All health providers need to meet the standards of the Health and Disability (Safety) Act 2001 (certification) in order to continue to operate. These standards are audited three yearly or more often if needed.

Health of trans people

The Report of Inquiry into Discrimination Experienced by Transgender People recommends: developing treatment pathways and agreed standards of care for trans people. The roundtable discussion needs to clarify and define the type of process that would best provide an acceptable clinical pathway that could to be implemented.

There are several processes that may be used, as part of taking a systematic approach, to improving care. These include:

1. Clinical pathway

A 'road-map' outlining a course of care provided to a person. It is a combination of clinical practices that result in the most effective, resource efficient, appropriate treatment for a specific condition, procedure or symptom. Clinical pathways are a 'point of service' tool used to disseminate and implement clinical guidelines. They are also known by a variety of terms such as practice guidelines and clinical protocols.

Clinical pathways are evidence-based multidisciplinary plans of care. They may be for people who have been diagnosed with a specific condition (diagnosis based), who are having a particular procedure (procedure based), or who are presenting with a particular symptom (symptom based).

It is essential that sufficient flexibility be built into the pathway format so that it can be tailored to an individual person's needs.

2. Evidence based guidelines

Clinical practice guidelines have a very specific meaning in modern medical language. These are evidence-based statements to help clinicians and consumers make decisions about appropriate health care in certain circumstances. A guideline provides an evidence-based summary of the benefits, risks and contraindications for investigation, treatment and ongoing management of a particular condition. At a service delivery level a guideline is used as a tool to close the gap between how we currently practise (and the outcomes associated with current practice) and other alternative practices (and the outcomes associated with those practices). It informs decisions for individual people and for organisations by making clear the benefits, harm and costs of different treatment options.

An evidence-based guideline may be considered for an aspect of trans people's health such as hormone therapy.

Developing guidelines

In some cases, guidelines may already exist within New Zealand; and overseas¹ guidelines could be updated for the New Zealand situation. Guideline development requires a large commitment of resources including literature searches and evaluation, guideline development, leadership of a small group and information management.

¹ Good Practice Guidelines for the Assessment and Treatment of Gender Dysphoria (consultation closed February 2007) Royal College of Psychiatrists

Implementing a new guideline in a service needs planning. It is not sufficient to issue the guideline to all potential users; it needs to be 'marketed' in order to gain acceptance. Guidelines have a limited shelf life. Regular evaluation and review of guidelines are essential and ongoing.

3. Standard

A measurable statement about performance describing the quality of care to be achieved based on the best available evidence. New Zealand health care is governed by a number of standards as described in the above framework.

Criteria are the key measurable components of a standard. Criteria specify what is to be measured in a clinical audit, such as the appropriateness of specific health care decisions, the effectiveness of specific processes of care, or the acceptability of specific outcomes.

Anecdotally, we know that some health professionals in New Zealand refer to The Harry Benjamin International Gender Dysphoria Association's Standards of Care for Gender Identity Disorders, Sixth Version (February 2001). These standards are not formally a part of any quality system for trans people health services in New Zealand.

4. Protocols

Protocols are local tools that set out what should happen, when and by whom in the care process. They are often seen as the local definition or a particular care process derived from a more complete guideline. They are tools that assist in quality and reducing inequalities.

Setting up a quality process

The Ministry of Health has experience of working with the health sector and consumers to develop all of the above. It is usual practise for the Ministry to set up a governance/advisory group from across the sector to oversee this type of work. The Ministry policy for the Purchase of Goods and Services relates to proceeding with any of the above processes. All these activities take time and resource commitment.

Slide 1 + 2

Components of New Zealand health quality framework

NZ Health and Disability Act 2000
Health Information Privacy Code 1994
Health Practitioners Competence Assurance Act 2002
Quality and safety requirements for DHBs outlined in Service Cover and Operation Policy Framework
Health and Disability Services (Safety) Act 2001

Clinical and Treatment Pathways

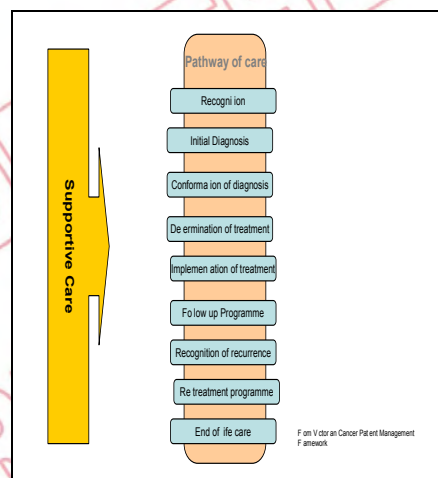
- A road map outlining a course of care provided to a person
- Evidence based multidisciplinary plans of care
 - Diagnosis based
 - Procedure based
 - Symptom based

Slides 3 + 4

Clinical and Treatment Pathways contd

Features of pathways:

- time- and stage-orientated tools
- used to:
 - synchronise the activities of every member of the health care team
 - achieve predetermined patient outcomes
 - provide a continuum of care for those patients whose outcomes are predictable 60 to 75 percent of the time



Slides 5 + 6

Clinical and Treatment Pathways contd

Two common designs:

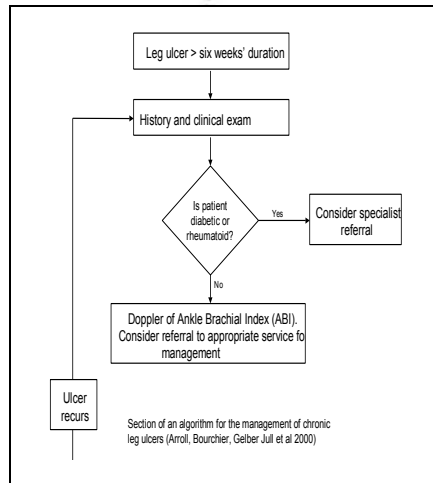
- Text
- Algorithms

Example of clinical pathway excerpt (text)

Assessment of leg ulcers:

- » Assessment and clinical investigations should be undertaken by a health care professional trained in ulcer management (Strength of Evidence III).
- » A full clinical history and physical exam should be conducted for a patient presenting with either their first or recurrent leg ulcer and should be ongoing thereafter (Strength of Evidence III).

Slides 7 + 8



Guidelines

- Evidence-based statements to help clinicians and consumers make decisions
- Summarises risks, benefits and contraindications for investigation, treatment and ongoing management
- Guideline development requires a large commitment of resources
- Implementation needs careful planning

Slide 9

Standards of care

- A measurable statement about performance based on the best available evidence
- Criteria specify what is to be measured eg appropriateness of specific health care decisions

Appendix 2: Office of the Health and Disability Commission's Overview

The journey of evidence from studies to individual patient pathways

Research Studies (includes a range of methodologies involving individual participants)	Synthesis of the research	Recommended practice based on the evidence (population based)	Standards	Protocols for particular procedures	Individual pathways and care plans
<ul style="list-style-type: none"> ▪ Randomised controlled trials (RCTs) ▪ Clinical controlled trials ▪ Qualitative research ▪ Cohort studies ▪ Observational studies ▪ Case control studies ▪ Economic evaluation studies ▪ Diagnostic test studies 	<ul style="list-style-type: none"> ▪ Review of the literature (NZHTA) ▪ Systematic reviews (eg Cochrane Collaboration reviews) 	<ul style="list-style-type: none"> ▪ Evidence-based guidelines with graded levels of evidence (to enable reliability of the guidance to be assessed) ▪ Best-practice guidelines (includes some evidence but lacks the rigor of an EB guideline) ▪ Consensus guidelines (often resorted to when evidence is lacking) 	<p>Standards are generally used as requirements to ensure specific obligations, outcomes and/or standards of care are met. They usually include specific criterion and sometimes targets or indicators that can be measured, reported on and audited for compliance.</p>	<p>Treatment protocols are usually specific to a particular condition or procedure. They are essentially the rules and requirements for a particular treatment or procedure.</p>	<p>Tailored to the individual, treatment plans and pathways should reflect the evidence from guidelines and protocols</p>

Helpful evidence web sites

<http://www.nzgg.org.nz>

<http://www.discern.org.uk/>

<http://www.dipex.org>

<http://www.phru.nhs.uk/Pages/PHD/resources.htm> (critical appraisal tools)

<http://www.cochrane.org/>

<http://www.cebmh.com/> (Centre for Evidence Based Mental health)

clinical guidelines:

are the recommended best practice in responding appropriately to the condition or need based on the most up-to-date evidence. This can include expert opinion where there are gaps in the evidence (Consumer experiences are included as a dimension of expert opinion)

Guidelines cover the general overall approach to a condition which is why they are viewed as recommendations, rather than the very specific and detailed approach outlined in a treatment protocol (usually about one procedure eg IV infusion, administration of anaesthesia) or pathway (designed for a specific person).

The most desirable guidelines are evidence-based guidelines with specific levels of evidence so the reliability and applicability of the guidance is more explicit. For instance you would know whether a procedure had been tested in a randomised way to assess how effective it was and what the risks are. You would also know whether any studies had looked specifically at the effect on the day-to-day lives of people who had had the treatment.

treatment protocols:

are usually specific to a particular condition or procedure

They are essentially the rules and requirements for a particular treatment or procedure.

A practitioner can be taken to task and may have to justify a deviation to a standard treatment protocol.

treatment pathway:

Also known as a clinical pathway or care plan, this is specific to an individual person.

Example of applying the evidence

So if you were looking at a flow chart for gender reassignment you would start with a review of the evidence/literature review. This would enable you to develop clinical guidelines of the best approach based on the evidence of best outcomes for this group of people.

Within this best approach there would be specific procedures such as hormone treatment which may have a treatment protocol. The pathway would be the individualised plan for a person wishing to achieve gender reassignment, outlining their particular options/course of action.

Making Sense of the Evidence

(or the need for caution when interpreting data)

Facts:

- A) The Japanese eat very little fat and suffer fewer heart attacks than the British or Americans.
- B) On the other hand, the French eat a lot of fat and also suffer fewer heart attacks than the British or Americans.
- C) The Japanese drink very little red wine and suffer fewer heart attacks than the British or Americans.
- D) The French drink lots of red wine and suffer fewer heart attacks than the British or Americans.

Conclusion: Eat & drink what you like. It's speaking English that kills you.

Appendix 3: Some Selected Trans Health Resources

Most of the resources below were available to participants at the health sector round table discussion. The British Columbia protocols were circulated by one of the health professionals shortly afterwards.

INTERNATIONAL

The World Professional Association for Transgender Health's Standards of Care – this organisation's professional consensus about the psychiatric, psychological, medical, and surgical management of gender identity disorders: <http://wpath.org/Documents2/socv6.pdf>

UNITED KINGDOM:

UK Guidelines for Health Organisations Commissioning Treatment Services for those Experiencing Gender Dysphoria and Transsexualism (April 2005): <http://www.pfc.org.uk/files/medical/pf-guide.pdf>

These guidelines have been produced by the Parliamentary Forum on Transsexualism (<http://www.lynnejones.org.uk/transsex.htm#forum>) to assist purchasers 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:

The University of Sheffield's research on Evidence-based Commissioning Collaboration: Gender Reassignment Surgery: <http://www.pfc.org.uk/files/ScHARR.pdf>

Royal College of Psychiatrists' Consultation on Draft Good Practice Guidelines for the Assessment & Treatment of Gender Dysphoria (closed 16 February 2007): <http://www.pfc.org.uk/node/1430>. This website also includes a range of trans individual and group responses to that consultation process: <http://www.pfc.org.uk/node/1454>

These and a wider range of resources can be found on the UK Press for Change website under the following headings:

Good Practice: <http://www.pfc.org.uk/node/613#good>

Standards of Care: <http://www.pfc.org.uk/node/613#standards>

Overseas guidelines: <http://www.pfc.org.uk/node/613#lit>

Evidence-based medicine and research:

<http://www.pfc.org.uk/node/613#evidence>

Department of Health publications:

<http://www.pfc.org.uk/node/613#equality>

IRELAND

The Irish Equality Authority's 2004 report *Access to Health Services for Transsexual People* (2004) - This report combines findings from a small scale qualitative study of the views of transsexual people with an examination of

current healthcare policy and practice in Ireland.
<http://www.equality.ie/index.asp?locID=105&docID=254>

CANADA

The Ontario Public Health Association's Trans Health Project – A position paper and resolution adopted by the Ontario Public Health Association:
http://www.opha.on.ca/ppres/2004-06_pp.pdf

Trans Care Project, British Columbia (BC) – Local and international clinicians, expert in transgender care, worked with transgender community members to co-create these seven sets of detailed practice protocols for clinicians in BC. They include separate guidelines covering:

- Transgender Primary Medical Care
- Counselling and Mental Health Care of Transgender Adults and Loved Ones
- Social and Medical Advocacy with Transgender Adults and Loved Ones
- Caring for Transgender Adolescents
- Endocrine Therapy
- Transgender Speech Feminization / Masculinization and
- Care of the Patient Undergoing Sex Reassignment Surgery

They are all available from
<http://www.vch.ca/transhealth/resources/careguidelines.html> This Vancouver Coastal Health website also includes a large number of consumer guides.

UNITED STATES

Links to some US guidelines for those working with trans youth can be found on the Press For Change website here - <http://www.pfc.org.uk/node/613#lit>

This is a 30 March 2008 interview from the Boston Globe with Dr Norman Spack, paediatric endocrinologist at Children's Hospital Boston:
http://www.boston.com/bostonglobe/ideas/articles/2008/03/30/qa_with_norman_spack/

NEW ZEALAND

A February 2002 Tech Brief commissioned by the Ministry of Health to determine the level of evidence supporting the effectiveness of gender reassignment surgery:
http://nzhta.chmeds.ac.nz/publications/trans_gender.pdf