# Just Plain Sense

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Equality, Diversity and plain good sense for the 21st Century

## Monday, February 18, 2013

## San Francisco Consensus Augurs Well for ICD Revision

An important meeting of minds took place in San Francisco earlier this month, with encouraging signs for revising trans related classifications in the forthcoming 11th Edition of the International Classification of Diseases (ICD).

I was there to participate and influence the discussions as an international adviser to the World Professional Association for Transgender Health (WPATH).

### International gathering

With me were the WPATH Board of Directors and members of WPATH's ICD working group from countries around the world. We were also joined by representatives from the World Health Organisation's project team responsible for this section of the revision effort, including one of their senior Human Rights lawyers.

People were taking part from countries as far apart as Canada, China, Venezuela, Bahrain, Argentina, Cuba, Australia, South Africa and Turkey … some via video links from their home countries, but most in the room.

The UK and Europe contingent included contributors from Belgium, Sweden, the Netherlands, Norway, and Spain. Dr Walter Bouman (lead clinician at the Nottingham Gender Clinic) and Professor Kevan Wylie (lead clinician at the Porterbrook Clinic in Sheffield) were there as UK clinicians.

Overall there were just over 30 of us taking part in the day and a half of sessions, which took place over Sunday 3rd to Monday 4th February.

**About the ICD**

The International Classification of Diseases (ICD) is the standard set of definitions of diseases and health interventions used throughout most of the world except the United States. It is published by the World Health Organisation (a specialised agency of the United Nations) and has to be ratified by the health ministers of all 193 WHO signatories (the 'World Health Assembly') before each new revision is published.

In order to ensure the World Health Assembly ratification goes smoothly an immensely rigorous process is followed, gathering consensus worldwide, before a draft is submitted for ratification. For this reason, the process currently underway is expected to run until late 2015. It is not considered likely that the new ICD-11 will be published earlier than 2016.

Unlike the US Diagnostic and Statistical Manual (DSM), which many trans readers will be familiar with, the ICD covers the full range of everything that clinicians concern themselves with, including acute and chronic medical conditions, health prevention and wellbeing interventions, mental health conditions, and supportive therapies.

For trans people this broader scope opens opportunities that are not present in the DSM, which is concerned only with defining Mental Health conditions.

In the DSM, a condition is either a mental health condition (hence included) or not (in which case it is excluded, with possible implications for funding care).

With the ICD there is more breadth of possibility, since trans classifications have the potential to be moved into other chapters of the publication (out of 'Mental and Behavioural Disorders') whilst still being within the scope of health classification as a whole.

The present edition (ICD-10) has been in use since 1992. Transgender-related classifications have been included for almost 50 years.

A classification for 'Transvestism' was first included in a chapter on 'Sexual Deviations' in the ICD-8, published in 1965.

Transsexualism was added to the same chapter in the ICD-9, published in 1975.

The ICD-10 (prepared in 1990) then added a whole raft of additional categories, including 'Dual-role transvestism' and 'Gender identity disorder of childhood' all under the new parent category 'Gender Identity Disorders'.

These long intervals between updates, during times of massive social change, underline why the present revision process is significantly overdue, and especially important to get right. The next chance may not be for another generation.

**The Change Process**

It is vitally important to stress that WPATH doesn't get to determine what will appear in the new edition; nor is the WHO open to lobbying from any single quarter. However, the significance of WPATH's involvement is that it represents a global community of over 800 clinicians with direct specialism in helping and supporting trans people.

The experience of that community is unequalled. The meeting which the organisation convened this month is part of a progressive process of achieving an effective international consensus among its own members, and enabling those members to participate in the WHO's own open consultation process looking for an even wider consensus.

WPATH will be writing more themselves in the coming months about the consultation process from their members' point of view. I will also try and publish some details soon for how non-WPATH members, including stakeholders, can get involved.

**Clinical Utility**

The watchword of the whole ICD-11 revision process is clinical utility. This means that classifications are judged according to their usefulness to clinicians in being able to support and treat people seeking care. A classification which fails this test doesn't make it into the next ICD.

The WHO teams are also aware of the social and political implications of what they publish. In conversation with them it is clear they understand the potential for classifications to have stigmatising effects (or even support criminalisation in some countries) with careless positioning or wording. These possibilities were particularly discussed when we came to the question of whether it was helpful or damaging to include a classification for children exhibiting gender non-conforming behaviours. Indeed, this was the only topic which divided us. It is something which clinicians with narrow parochial interests of practice in their own countries need to get their heads around.

The proposed classifications are not simply imposed without evidence. The process which will take place over the next two years includes organised 'field testing' … a form of consultation … where the WHO pose questions to thousands of participating practitioners about proposed classifications and whether they will be effective in clinical practice. This is why it is so

important for gender specialists to be involved, and why the formulation of the questions put to the field trial groups is of vital interest too.

**Setting the scene**

The proceedings were opened by Dr Lin Fraser, the President of WPATH, who was also the local host for the conference. In turn she introduced members of the board, including the co-chairs of WPATH's ICD working group, Dr Gail Knudson from British Columbia and Dr Griet De Cuypere from Belgium.

To set the scene on our day and a half of discussions, four of us from different interest areas were asked to speak about how the ICD influenced clinical practice and outcomes in our own countries. Besides myself there were Mauro Cabral, a co-director of Global Action for Trans* Equality (GATE) from Argentina; Eszter Kismodie, an international Human Rights lawyer specialising in sexuality, sexual and reproductive health - advising WHO; and Dr Jamison Green, WPATH's president-elect. Jamison becomes the next president of WPATH in February 2014.

Kicking off our session I first explained the history of work towards social and legal change for trans people from around the same time as the ICD-10 had been published in 1992. I mentioned the long tradition of working collaboratively (and critically) with clinicians over that interval, starting with the Gendys conferences which began in 1990. I pointed out the number of revisions which WPATH's own guidelines had undergone in those 20+ years. And I listed the key legal and social changes for trans people in that time. I also reflected how even the ICD-10 definition of transsexualism was little different to the ICD-9 one … hence all these massive social and legal changes had occurred whilst we were still working on international classification that had remained essentially unaltered since 1975.

These reasons, I explained, were why ICD revision could not be incremental … change had to be radical simply to catch up with almost 40 years of major social change, and to create something which would be fit for purpose for anything up to another 25 years. I invited everyone present to approach their task with that in mind.

I expressed my view that unless the ICD genuinely fulfilled the WHO's aim of 'utility' in this area then countries would continue to do what had long since begun to happen … simply paying lip service to the classification system whilst working around it. It was important, I said, for the language and positioning of categories to reflect where we already are in practice (and where we are clearly going). Classification should be an enabler for care. It should not add to the burden felt by either the patient or practitioners who want to see a continuation of evolving best practice.

Mauro Cabral followed with an inspiring contribution, reminding everyone that counties such as Argentina were in some ways far ahead of the curve in conceptualising how to support trans people intelligently. He also tied this to previous work by international Human Rights lawyers developing the so-called Yogyakarta Principles.

Mauro's presentation dovetailed well into Eszter Kismodie's presentation, which provided a broader Human Rights context and referred to a casebook of national court decisions from around the world, gathered by the International Commission of Jurists.

Jamison Green then rounded off the session, pointing out that clinicians in the United States are among the few in the world without access to the ICD-10 (still referring to the ICD-9), but explaining how, even so, WPATH (as an international organisation with widening membership) had a major stake in the revision process. He also explained how trans people in the US are severely marginalised, and consequently are penalised, by the US's high political status when it comes to participation in international discussions, so the ability to participate in these discussions through WPATH, he said, was both unprecedented and crucial to trans people in the US.

Following our presentations, Geoffrey Reed, the project officer responsible for the revision of the contents in the present ICD-10's 'Mental and Behavioural Disorders' section, explained in considerable detail where the WHO and ICD sit within the scheme of things in the United Nations, and how the consensual revision process is being approached, including the involvement of almost 10,000 clinicians interested in contributing views.

**Revision Possibilities**

The starting point for revising the ICD-10 is to consider the classifications which it currently contains. As explained above, the original Transvestism (1965) and Transsexualism (1975) classifications had been added to considerably when the ICD-10 was drafted in 1990. The trans and related classifications included:

F 64.0 - Transsexualism
F 66.1 - Egodystonic Sexual Orientation
F 66.2 - Sexual Relationship Disorder
F 64.2 - Gender Identity of Childhood
F 66.0 - Sexual Maturation Disorder
F 64.8 – Other Gender Identity Disorders
F 64.9 – Gender Identity Disorder, unspecified
F 66.8 – Other Psychosexual Development Disorders
F 66.9 – Psychosexual Development Disorder, Unspecified
F 65.1 – Fetishistic Transvestism
F 64.1 – Dual – Role Transvestism

Well over a year ago WPATH's own ICD Working Group, led by Drs Griet De Cuypere (Belgium) and Gail Knudson (Canada), had come up with a set of evidence-based recommendations for the WHO to delete the vast majority of these classifications … simply because research in national health databases showed many were simply not used in any case.

Those of us who volunteer as WPATH's external advisers concurred with that rationale via online discussion. What that left to discuss was:

F 64.0 - Transsexualism
F 64.2 - Gender Identity of Childhood
F 65.1 – Fetishistic Transvestism

As these three categories required more interactive face-to-face discussion, the main purpose of the meeting in San Francisco was to attempt to reach a consensus that the WHO representatives could see and understand.

The essential points for discussion were:

**1. Whether the F64.0 'Transsexualism' category should be renamed and moved to another (non-mental health) section in the ICD-11 and, if so, where (if anywhere at all).**

The consensus was that there was utility in keeping, renaming and moving the diagnostic category to a non mental health section … although there was dissenting opinion that, if the prime reason for retention was to facilitate access to health funding, then it would be better to fix such a system rather than creating health categories to collude with such distortions. Taking account of the needs expressed by non-western countries, however, the view in the room was that classification is needed but should not be in mental health. The ICD working group will have further work to refine the naming and positioning proposals.

**2. Whether the F64.2 'Gender Identity of Childhood' category should be retained and, if so, whether it should be renamed and moved to a another (non-mental health) section in the ICD-11**

This proved to be a far more divided discussion, bearing in mind that the patient group was (by definition) pre-pubertal children for whom no actual clinical interventions are carried out. All that clinicians do is observe and support … and this is actually support for families to care for their child more than any diagnosis on the child. The later clinical interventions required by adolescents are classified under the previous heading (expanded to cover adolescents and adults together) and it was noted that, among the children, the majority of patients seen resolve as gay or lesbian by the time puberty commences. It was argued that, if it is already considered inappropriate to classify and treat homosexuality as a disorder, then a category such as this would be classifying pre-homosexual cases by another name, as well as providing a license for the practice of 'reparative' therapies. One attendee presented letters from clinicians around the world arguing against classification whereas another, from a European gender team, argued strongly for the benefits of having a classification in their own country. Eventually a vote was taken and opinions turned out to be split exactly down the middle: 50/50. Much more discussion and consideration of evidence will therefore be needed in this area.

**3. Whether to take a position on deleting F65.1 'Fetishistic Transvestism' or to retain it in a more specific form.**

The overwhelming majority in this case argued for recommending deletion, on the grounds that any distress felt by people about their cross dressing behaviour could be addressed through more general categories of the type where people seek help without having a specific condition (so-

called 'Z-codes'). There was no appetite for pathologising a harmless behaviour that is largely cultural in nature. The WHO's threshold for including anything of this nature is where a behaviour may be of specific harm to others. That threshold was not achieved here. One attendee argued that they would like to keep a specific category for helping patients in the extreme instances where the degree of cross dressing becomes out of control and the individual becomes afraid of compromising their job or family life, or getting into trouble with authorities. The majority argued that patients with this kind of need could be helped under broader classifications dealing with obsessional behaviours that reach clinically significant levels.

**What happens now**

As I said before, WPATH's views are not definitive. They are just one constituency listened to by the World Health Organisation … albeit an expert and influential group in this field.

The 'votes' taken around the table on these three issues are not the final say either. In each case the consensus (or division of opinion) informs the work which the organisation needs to do to consult with its wider membership before submitting definitive recommendations to the WHO. The degree of international consensus is indicative of the direction of travel though.

**In summary**

Overall, it was an immensely productive meeting, with a considerable meeting of minds on the topics for discussion, and respectful hearing of the opposite sides of the debate in the one case where there remains a clear division.

I made a case for WPATH to ensure that, as well as now updating their 800+ membership they should also reach out transparently to stakeholders and their organisations too, to ensure that all views are taken into account and balanced as well as possible. It is likely, for instance, that trans stakeholders may have divided views on a world level too. That is the challenge of the ICD … to come up with consistent medical classification that works in all cultures without running the risk of disadvantaging patients in some cultures for the advantage of those in others. It underlines why trans people need to continue working internationally too.