

# It's time for reform Trans\* Health Issues in the International Classifications of Diseases

A report on the GATE Experts Meeting

The Hague
November 16-18
2011

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#### Introduction

The International Classification of Diseases (ICD) is a document listing and classifying all disorders, diseases, injuries and other health-related situations, as well as the diagnoses acknowledged and applied by health professionals and systems. The ICD is developed by the World Health Organization (WHO) and adopted by the World Health Assembly. Its tenth edition (known as ICD-10), which was adopted in 1990, is currently in force. The WHO is currently reviewing the Classification with an aim to introduce its eleventh revision, ICD-11, in 2015.

The current ICD-10 includes different diagnoses concerning trans\* persons, listed under Chapter IV, Mental and Behavioral Disorders. The references are included in the subchapters 'Gender Identity Disorders' and 'Disorders of Sexual Preference'. These diagnoses are not only regularly applied to adult trans\* persons but also to children and adolescents. In some countries, ICD-10 diagnoses are used to make trans\* persons' access to health (including transitional health) possible, while in other countries the same codes are used for the opposite effect: denial of health care. They are also a requirement to access legal recognition of gender identities, in most countries where legal recognition of trans\* people's identities is possible. However, those same diagnoses have been criticized by trans\* people, because they pathologize trans\* persons and their bodies, identities, expressions and sexual experiences. At the same time, and as they constitute outdated and biased judgments, the diagnoses concerning trans\* health issues have been criticized for their scarce or null clinical relevance. This is why different sectors of the trans\* community have been insisting on the need for a critical approach both to applying ICD-10 and developing ICD-11.

By mid-2011, GATE decided to make a formal contribution to this collective process by convening spaces for meeting and discussion on two core issues: trans\* depathologization in the context of ICD-11 and trans\* person's full access to healthcare (and to the legal recognition of their gender identities wherever the diagnosis is still a requirement). To this end and as a starting activity, GATE convened a group of experts in different fields – many of them trans\*-identified, and most of them also activists – for an in-depth discussion of ICD-10 and to suggest lines of work towards the development of ICD-11. The document we are sharing today reflects the discussions held during this meeting and we hope it will contribute to promote these and other discussions in different trans\* communities and movements.

The WHO will be developing ICD-11 in the coming two years. Therefore, these must be years in which trans\* activists worldwide get involved in this process – through analysis and discussion, developing and sharing of proposals, etc. The questions raised by the need to combine depathologization and full access to health and legal rights do not have a single answer that can satisfy the needs and



interests of all trans\* persons in every country and public or private health system. This is why GATE calls for committed involvement in this process. For further information, please don't hesitate to contact us at icd@transactivists.org or visit our web site: www.transactivists.org

#### I.1 About this report

www.transactivists.org

This document is aimed at giving an overview of the discussions that were held at the Experts Meeting organized by GATE – Global Action for Trans\* Equality. The content in the following pages was collectively addressed, elaborated and discussed, but GATE assumes full accountability for the selection, exposition and articulation of those contents. Participation in the Experts Meeting does not imply agreement with any or all parts of this report, even though we hope to provide an adequate representation of the discussion and thought process. As the purpose of this document is to offer an overview of the discussions that took place in The Hague, it does not include footnotes or bibliographical references. A suggested list of bibliography can be found at

# I.2 About the ICD reform process

Invited by GATE, a group of more than 20 experts from most parts of the world met at the Dutch Ministry for Education, Culture and Science on November 16-18. The goal of the meeting was to explore alternative concepts to discuss alternative models for trans\* health classifications in the International Classification of Diseases (ICD-10), with the purpose of introducing new perspectives, analysis and references in the WHO process of producing the ICD-11. Participants came from India, Venezuela, New Zealand, Brazil, Spain, Switzerland, Sweden, China, USA, Thailand, Argentina, Great Britain, Lebanon and the Netherlands, and work in the fields of human rights, medicine, advocacy, as well as other related areas. Most experts also self-identify as trans\*.

GATE's involvement in the process of the ICD revision and reform, including the organization of the Experts Meeting in The Hague, the production of this report and follow-up activities, is possible thanks to the support of the Dutch Government, the Open Society Foundations, and an anonymous donor.



#### **Invited Experts**

GATE invited experts on trans\* health issues from all continents, though unfortunately due to scheduling conflicts none of the invited experts from Africa could take part in the meeting.

Following is a list of experts who were able to attend:

- Aitzole Araneta, sexologist, M.A. gender studies (Basque country, Spain)
- Maria Sundin, social worker and counselor (Sweden)
- Paula Machado, anthropologist, professor, Universidad Federal do Rio Grande do Sul/Member of the Latin American Consortium on Intersex Issues (Brazil)
- Berenice Bento, coordinator, Núcleo Tiresias, Universidad Federal do Rio Grande do Norte (Brazil)
- Amitava Sarkar, Solidarity and Action Against the HIV Infection in India (SAATHII) (India)
- Jack Byrne (Aotearoa/New Zealand)
- Sam Winter, associate professor, University of Hong Kong (China)
- Amets Suess, STP 2012, International Stop Trans Pathologization Campaign (Spain)
- Preempreeda Pramoj Na Ayutthaya, social worker (Thailand)
- Alli Jernow, Senior Legal Advisor, Sexual Orientation and Gender Identity Project, International Commission of Jurists (Switzerland)
- Wissam Sheib (Lebanon)
- Satya Rai Nagpaul, trans\* activist (India)
- Randall Ehrbar, psychologist (USA)
- Andre Wilson (USA)
- Tamara Adrian, professor of Law (Venezuela)
- Constantin Cojocariu, lawyer, INTERRIGHTS (UK)
- Manou de Nennie, Policy advisor on LGBT issues, Directory of Gender Equality, Ministry of Education, Culture and Science (The Netherlands)
- Els Veenis, Policy advisor on LGBT issues, Directory of Gender Equality, Ministry of Education, Culture and Science (The Netherlands).
- Experts from The Netherlands and USA who prefer to remain nameless in this report.

# The Meeting was also attended by:

- Dr. Geoffrey Reed, Senior Project Officer, Revision of ICD-10 Mental and Behavioural Disorders, Department of Mental Health and Substance Abuse (MER/MSD), World Health Organization.
- Eszter Kismödi, LLM. JD. Human Rights Adviser Gender, Reproductive Rights, Sexual Health and Adolescence Department of Reproductive Health and Research World Health Organization.



- Mauro Cabral, co-director GATE Global Action for Trans\* Equality (Argentina)
- Justus Eisfeld, co-director GATE Global Action for Trans\* Equality (USA)
- Jane Cottingham, independent consultant on sexual and reproductive health and rights, facilitator of the meeting.

#### Issues at stake

Depathologization, access to health care, and access to legal recognition are three pressing human rights issues for trans\* people.

**Depathologization**: trans\* people's experiences and needs have been historically pathologized, and that ongoing pathologization has extremely negative consequences: it diminishes or denies trans\* people's autonomy, creates and reinforces arbitrary lines between healthy and pathological ways of gendered existences, and limits trans\* people's lives to dependence on a diagnosis, including their access to legal gender recognition.

Access to health care: in most countries of the world, trans\* people require a specific diagnosis in order to have access to health care —including transitional, pre- and post-transitional health care, as well as to transitional harm reduction. Diagnosis has also a decisive influence in circumscribing those health professional fields mainly involved with trans\*-specific health issues. Key aspects of accessing health care are costs and their reimbursement, which are usually and strictly linked to diagnosis and its codification within the ICD. Willingness and technical knowledge on the side of health care professionals are other major factors in trans\* people's ability to access health care.

Access to legal recognition: in the majority of countries with laws and regulations allowing trans people to change their legal gender, trans\* people's access to the legal recognition of their gender identity relies on medical diagnosis and letters from medical providers. Trans\* people must be able to access to these legal provisions, even with a change in the relevant ICD codes. In countries where cross-dressing is punishable, having a medical diagnosis can mean a respite from these laws.

# **Principles**

The Experts' Meeting was guided by the following general principles proposed by GATE:

- Gender variance is a common human feature; therefore, gender identities and gender expressions are not pathologies. They must be respected, not treated, cured, suppressed, persecuted and/or punished.
- All gender identities must be approached holistically and be able to be fully



expressed and realized irrespective of their historic, present or envisioned embodiment.

- Access to health must be approached from a human rights perspective, granting full access for all; therefore any proposal affecting trans\* people globally must grant and protect trans\* access to Health in diverse health systems. Therefore, the right to health and the right to identity are inextricably linked.
- Trans\* diversity must be respected, recognized and included as a key consideration in any proposal affecting trans\* people globally. That includes, for example, diversity at the level of culture, religion, geopolitical location, ethnicity, socioeconomic status, age, body, sexual orientation, gender identity and expression, serologic status, citizenship and migrant status, transitional status, etc.
- Trans\* people's decisional autonomy must be a guiding principle in all actions affecting trans\* people, with a specific emphasis on decisions related to trans\*-specific healthcare. Informed consent, and not differential diagnosis, must be the ground for accessing gender-affirming procedures.
- •Stigma associated with mental health issues is an extended challenge for the trans\* movement; however, any action aimed at facing and dismantling it must neither naturalize stigma nor project it over other communities.

#### **About Trans\***

GATE uses the term trans\* to name those people who identify themselves in a different gender than that assigned to them at birth and/or those people who feel they have to, prefer to or choose to present themselves differently to the expectations associated with the gender role assigned to them at birth - whether by clothing, accessories, cosmetics or body modification. This includes, among many others, people who identify as transsexual and transgender, transvestite, travesti, hijra, cross dresser, fa'afafine, two-spirit, no gender, third sex and genderqueer people.

The term should be understood as a political umbrella term, which encompasses many different and culturally specific experiences of embodiment, identity and expression. The asterisk aims to make its open-ended character explicit.



#### II. Agreements

The group of experts convened in The Hague reached these main agreements: Remove the following codes:

F 64 Gender Identity Disorders

F64.0 Transsexualism

F64.1 Dual-role transvestism

F64.2. Gender identity disorder in childhood

F64.8 Other gender identity disorders

F64.9 Gender identity disorder, unspecified

F65.1 Fetishistic transvestism

F66.0 Sexual maturation disorder

F66.1 Egodystonic sexual orientation

F66.2 Sexual relationship disorder

#### Supporting Arguments

The aforementioned codes:

- Do not provide any clinically relevant information.
- Reflect cultural prejudices against gender diversity and reinforce narrow Western gender stereotypes.
- Have historically had and still have a strong negative impact on trans\* people's lives by pathologizing and stigmatizing their sexualities, identities and expressions.
- Function as gatekeepers to health care.
- Support continuing human rights abuses, for example in countries where excessive and irrelevant testing in psychiatric hospitals is required for any change of ID documents. In some countries, they also promote and justify so-called "reparative therapies".

# III. Ongoing debates

During the Experts' Meeting at The Hague and the weeks that followed the Meeting, debates continued to develop around four main issues: diagnosis as a need; usage of a decentralized model for change; placement of chapters, blocks, codes and diagnoses; how to best serve adolescents and children. In the following pages these contentious issues will be introduced in summary without a final decision.



#### III.1 Trans\* health issues in ICD-11

One of the most challenging issues discussed at the Experts' Meeting is the very need of including trans\* health issues in the ICD-11. According to the principles that guided the meeting, that inclusion must be a reference, or a set of references that is not based in illness and, at the same time, granting access to health care, public or private insurance coverage and legal recognition of trans\* people's identities.

Taking into account this last and seemingly unavoidable connection between diagnosis and health care coverage, other questions arise: what kind of diagnosis would be needed? The group of experts convened in The Hague agreed on this set of references for a possible diagnosis:

- Must not pathologize trans\* people's gender identities, gender expressions, sexualities and, in general, trans\* people's experiences of gender, as they constitute human variations.
- Must focus on trans\* people's true health issues (i.e. distress associated with actual or anticipated self-perceived sex characteristics which are inconsistent with one's gender identity). Must be connected effectively with proper treatment (i.e. gender affirming procedures) and rule out inappropriate and damaging treatments (i.e. 'reparative' therapy, excessive testing/diagnostic procedures).
- Must be recognized by public and private health systems as fully reimbursable.
- Must not have re-pathologizing, re-stigmatizing or other negative effects on trans\* people's lives.
- Must be applicable only to those looking for specific health care and only during the time they need that specific care; it must not work as an universal descriptor applicable to all trans\* people for an indefinite amount of time.
- Must be able to grant access to specific health care in different transitional stages and as requested/needed by the trans\* person.
- Must be accessible to health practitioners, including especially those working in primary health care settings and those with limited clinical training/knowledge of issues faced by trans\* people and, at the same time, promote specialized research and training.
- Must be legally valid in those countries where a specific diagnosis is required to access legal gender identity recognition, and also in those countries where diagnosis is used to avoid criminalization.
- Must be fully respectful of cultural diversity and its articulation in terms of gender identity, gender expression, transitional needs, cultural attributions of gender etc.

Attempting to give answers to these different and pressing diagnostic needs, the experts' group started imagining a classification model able to respond successfully to all of them. This decentralized model was called the Starfish Model, and it is introduced in the following point.



#### III.2 The Starfish Model

After separately considering different codes, blocks and chapters, it was proposed at the Meeting to explore what was called a Starfish Model: a decentralized system of codes, located in several blocks and chapters, which could be used by and for trans\* people to gain access to health care in very different health care settings.

An actual starfish has a decentralized nervous system. While all parts of the starfish work together, a chopped-off leg can exist on its own, and actually grow a new starfish. A spider, for example, has a centralized nervous system where the whole spider dies if the head is injured. At the Experts' Meeting the starfish was used as a metaphoric model that could give answer to differentiated possibilities in terms to access to health care, including its coverage. In this sense, combining different chapters, blocks and codes (the starfishs' legs) could exponentially increase trans\* people opportunities of accessing health care under very different circumstances without recurring to a single and potentially repathologizing diagnosis (a Spider Model). These circumstances include, for instance:

- Public and/or private regulations in regard to transitional care and its coverage, which could require particular codes to work. The Starfish Model would provide those codes and integrate them within a more extended classification.
- Access to specialized or general health care providers according to local availability. The Starfish Model would offer different entry points to guide health care providers with different fields and degrees of specialization on trans\* health needs.
- Access to legal recognition, as well as to diagnostic protections against criminalization. The Starfish Model would provide the different codes necessary to grant access to legal recognition in several countries and those codes used as human rights protections against trans\* people's criminalization.

As the codes, blocks and chapters considered to be potential starfish's legs imply distinct approaches to trans\* health issues, the Starfish Model will protect trans\* people's diversity in regard to health needs.

During the Experts' Meeting and afterwards, debates were focused mainly in the following chapters as possible legs of the trans\* diagnostic starfish:

Chapter IV. Endocrine, nutritional and metabolic diseases (E codes)

Chapter V. Mental and Behavioral disorders (F codes)

Chapter XIV. Diseases of the genitourinary system (N codes)

Chapter XXI. Factors influencing health status and contact with health services (Z codes)



The experts also explored the possibility of creating an entire new ICD Chapter, focused on sexual and reproductive health, and placing a trans\*-specific block there. This possibility has not been explored further at this stage. Due to fears of loss of coverage in various health care systems, the creation of a Z stand-alone block focused on trans\*-specific healthcare was not further developed.

The rest of this report focuses primarily on developing an effective decentralized starfish model for trans\* access to health care. However at this point it is useful to list some outstanding issues that still require further discussion, such as:

- Is there a need for trans\*-specific diagnoses at each leg of the Starfish to make it work?
- If that is not the case, how would general and specific diagnoses work together within the same model? How would they be connected?
- Are all the legs of the Starfish equally relevant? And, if that is not the case, under which principles should they be organized (i.e. according to relevance in regard to treatment, relevance in regard to coverage, etc.)?
- Which ICD chapter/s, block/s, code/s and diagnosis should be part of the Starfish?

#### III.3 ZCodes

One of the most compelling proposals that came out of the Experts' Meeting was the idea of working with the codes included in Chapter XXI: Factors influencing health status and contact with health services (Zoo-Z99). This work could imply the creation of a new code or a new block [(Z)t], or the utilization of already existing codes under Chapter XXI [Z].

# Supporting Arguments

Conceptually, Z codes seems to be the best place to introduce a non-pathologizing definition of those trans\* experiences that intersect with the health system. That introduction would be fully consistent with other blocks and codes already in Chapter XXI.

- Z codes would provide non-illness based references to guide health care providers and research to a depathologizing approach.
- Within a Starfish Model, (Z) or (Z)t could provide a non-pathological core that modifies other blocks or codes. The codes could be used to modify already existing codes to better serve a trans\* person.
- The Z(t) category could be such a factor, making an existing code blend in with trans\* healthcare needs where needed, or make it stand out when it is useful to do so. In this sense, Z codes would counter the assumption that trans\* experiences are radically unique and cannot be related to health needs shared with other



users of health care services.

• Existing Z codes already provide good references for trans\* health care (such as Z60.4 Social exclusion and rejection or Z60.5 Target of perceived adverse discrimination and persecution, Z70 Counseling related to sexual attitude, behavior and orientation and Z71 Persons encountering health services for other counseling and medical advice, not elsewhere classified)

#### **Challenges**

Z Codes are not diagnostic codes, but modifiers. Working solely with Z or Z(t) codes or blocks risks losing access to health coverage in different health systems and countries.

#### Additional Comments

- Some experts proposed to introduce two different (Z)t blocks, one of them focused on transitional health and the other one in trans\*-specific needs in the context of general care (such as access to gender-coded services like cervical or prostate cancer screening or counseling for depression that is influenced by the person's gender identity or expression).
- A Z-block or code could function as a middle relay-node of the starfish (i.e., as "healthcare related to gender identity"), providing trans\*-specific modifiers to standard (or new, but neutral) E, N and F codes

### III.4 E and N Codes

Another strong proposal that came out from the Experts' Meeting was the possibility of working with both Chapter IV: Endocrine, nutritional and metabolic diseases (E 00-99) and Chapter XIV: Diseases of the genitourinary system (Noo-N99). This could imply the use of existing codes and blocks (E) and (N) (or creating new neutral codes that could also be used for trans\*-related issues), or creating new, trans\*-specific, codes and/blocks: (E)t and N(t).

# Supporting Arguments

- E and N codes have an intrinsic relationship with highly successful transitional treatment (i.e. hormonal therapy and/or surgical procedures).
- In the case of E codes, most often the underlying principle would be the concept of hormonal wellbeing or balance. That is the impetus for any medical discussion about inducing or blocking sex hormones.
- •Those health practitioners provide transition-related health care, such as general practitioners, endocrinologists, urologists, gynecologists and plastic surgeons generally apply E and N codes. The medical practitioners are thus already familiar with their use.



- •E and N codes are generally reimbursable.
- •E and N codes already include organic features that can be related to trans\* people's embodiment (such as E34.9 Endocrine disorder, unspecified, N50.9 Disorders of male genital organs, unspecified, N62 Hypertrophy of breast, including Gynaecomastia and Hypertrophy of breast Not Otherwise Specified and Massive pubertal, N64.0 Atrophy of the breast, etc.)

In the particular case of E codes, they provide good examples to follow in the design of the decentralized Starfish Model (i.e. E10-14, Diabetes Mellitus, which includes renal complications, ophthalmic complications, neurological complications etc.) E and N codes better reflect the physical or embodied component of trans\* experiences, something that is not included in a gender identity-based diagnosis.

- E and N codes can be applied without depending upon a mental health diagnosis.
- E and N codes have an intrinsic relationship with health care based on harm reduction (i.e. health consequences of hormonal treatment without professional supervision, or black-market breast augmentation produced with industrial silicone).

#### Challeges

- Undoubtedly, the main challenge associated with E and N codes is how to articulate E(t) and N(t) without reinforcing gender binaries or pathologizing bodily diversity. One example of discussions around this topic is to introduce new blocks and/or new codes focused on "current or anticipated primary and/or secondary sex characteristics selfperceived as inconsistent / incongruent / incoherent with self-perceived gender identity/sense of self/identity" E and N blocks and codes are intrinsically tied to specific organs (e.g. ovaries) and, in some cases, they are gender-specific too. For example E 28 (Ovarian Dysfunction) is available to females only and E 29 (Testicular dysfunction) is available to males only.
- Both also refer to very sex-specific anatomical features. Therefore it would probably be necessary to develop new gender-neutral E and N codes that reflect the sex and bodily diversity of trans people. Creating new blocks and new codes (E)t and N(t) would be a fundamental change to the logic of these chapters.
- For the same organic-based reason, E and N codes do not include any subjective dimension (i.e. gender identity/sense of self). Under the current epistemological understanding of subjectivity within the ICD, that could mean the need of having a cross-reference under Chapter IV. Mental and Behavioural Disorders in order to make E and N codes work.
- The introduction of the aforementioned subjective dimension (i.e. self-perceived gender identity) would challenge treatment reimbursement under E and N codes in some countries. Including E and N codes could reinforce the



current pathologization of body diversity and promote a clinical understanding of trans\* people's health issues as the expression of sex development disorders. This risk applies strongly to children and adolescents. Hence it is crucial to focus on self-perceived hormonal wellbeing as noted above. Any diagnosis should not define "atypical" bodies or sex characteristics as inherently problematic.

#### Additional Comments

- Suggesting the creation of trans\*-specific E and N codes (or block), or the inclusion of trans\*-specific health care in neutral codes do not mean to attribute an endocrine or genitourinary etiology/origin to trans\* identities and experiences.
- While Chapter XVII: Congenital malformations, deformations and chromosomal abnormalities (Q codes) was not formally considered during the Experts Meeting, some codes included in that chapter could play the same role as relevant N codes (i.e. Q52.0 Congenital absence of vagina; Q55.5 Congenital absence and aplasia of penis, etc.). The use of Q codes represent the same risk of reproducing gender binaries and pathologizing body diversity than the use of E and N codes.

#### III.5 F Codes

The group of experts convened in The Hague strongly agreed on the need of removing all existing F codes referring to trans\*-specific issues. However, there was considerable discussion and disagreement, about whether or not a new trans\*-specific code should be ntroduced in the F chapter.

The other crucial debates during and since the Experts Meeting have been around FCodes and what, if any, role they might play in the decentralized Starfish Model.

Particular attention was paid to code F64.0 Transsexualism, and its entire localization: Chapter IV. Mental and Behavioural Disorders, Disorders of adult personality and behaviour (F60-F69), F64 Gender Identity Disorders.

# **Supporting Arguments**

- Its placement under Chapter IV implies that trans\* experiences are, by definition, a Mental and/or a Behavioural Disorder. This definition promotes clinical, legal, bioethical and, in general, social understandings of trans\* individuals as mentally disordered people.
- Its placement under the label of 'Disorders of Adult Personality and Behaviour' implies that there is something intrinsically pathological at the core level of trans\* people's personalities and/or behaviour.



- Its placement under the label of 'Gender Identity Disorders' implies that gender identity is the very phenomenon to be diagnosed every time a person's gender differs from the sex assigned at birth, which implies that a person's identity is a clinical condition to be treated. The normative connection between trans\* experiences and gender identity also ignores the centrality of the physical or bodily issues associated with those experiences.
- Its placement, as well as its definition, leads to more attention being paid to clinically irrelevant information (such as "the desire to live and be accepted as a member of the opposite sex") instead of attending to clinically relevant experiences, such as distress or dysphoria.
- The entire diagnosis is built upon a gender-binary assumption, anticipating only two mutually exclusive gender identities: male and female. This assumption dismisses the fact that many cultures anticipate more than two genders that may or may not be overlapping.

#### **Challenges**

- Some trans\* people have mental health issues that may be linked to their gender identity, for example when somebody develops anxiety or depression as a result of a struggle with their gender identity and/or the way their gender identity is treated in their surroundings.
- Some health systems may rely on the intervention of mental health practitioners for the determination of coverage for trans\*-specific healthcare.
- As trans\*-specific codes have been central to granting access to transitional health care, losing those codes and replacing them with F(z) codes could be difficult or impede future access to that healthcare and its coverage in different countries.
- Removal could negatively impact a health provider's access to specific information if a person's health record does not mention their gender identity in some way.

It ignores the unique nature of trans\* experiences, in particular, distress associated with embodiment.

• The following subsection sets out the main options raised in discussions about the possible role of F codes within a trans\*-specific decentralized Starfish Model.

# III.5.a Using already existent F codes

With the assumption that gender identity is not a mental disease, and having other diagnostic options for physical treatment, there is no need for a specific code in the F chapter. Some trans\* people have mental health issues that are related to their gender identity, for example depression or anxiety that results from their own or society's uneasiness with their gender identity or expression. F-codes in Chapter IV actually include a set of diagnoses that could accommodate trans\* people's mental health needs without introducing a trans\*-



specific diagnosis (i.e. F41. Other anxiety disorders, F43 Reaction to severe stress and F43.2 Adjustment disorders). Instead of creating a new F(t) block and new codes, these and other F codes could be modified with specific Z(t) codes in the context of the decentralized Starfish Model, where this is appropriate without negative repercussions for the trans\* person in question.

#### Supporting Arguments

- Self-identification in a gender different than the sex assigned at birth, and the experiences associated with that self-identification, do not constitute a mental disorder.
- The association between gender diversity and pathology (in this case, a mental disorder) is based on cultural prejudices and investment in the gender binary and its hierarchies.
- There is nothing intrinsically disordered in identifying oneself in a different gender than the sex assigned at birth, adopting a gender expression contrary to cultural expectations associated with that assigned gender, or desiring to modify sex characteristics and demand social and legal recognition.
- Associating gender identity and, in general, trans\* experiences with any trans\*-specific mental health diagnosis will continue to pathologize those experiences and, furthermore, trans\* people.
- If trans\* experiences are rendered primarily as mental disorders, it may become harder for trans\* people to achieve recognition in their own gender identity (i.e. a trans woman is perceived as a mentally disordered man).

# Challenges

- A removal of trans\*-specific F-codes could risk losing access to: transitional health in different countries, including insurance coverage specific mental health services (such as counseling and psychotherapy) and/or legal gender recognition where a specific F code diagnosis is required.
- It will be difficult to make links between trans\* experiences of mental health visible, especially where mental health issues are a result of how a trans\* person is able to live their life in a (transphobic) society.

# III.5.b Creating a new trans\*-specific F block or code/s based on clinically relevant experiences, in particular, distress

During the Experts Meeting another position with regards to F codes was introduced. Acknowledging the negative effects of the current classification and its focus on gender identity and gender expression, this alternative position proposes to change the diagnostic focus to trans\* people's clinically relevant experiences in the realm of mental health, specifically the experience of distress associated with actual or anticipated sex characteristics, as well as to the



concomitant impairment provoked by distress.

According to this proposal, trans\*-specific diagnoses could be introduced in Chapter V, as a differential F code (or block), under the possible name of "gender dysphoria," with the purpose of attending to well defined mental health needs arising from specific issues faced by trans\* people and granting access to insurance coverage where access depends on F-codes.

#### Supporting Arguments

- Proper diagnosis will have a positive impact in granting access to adequate health care and improving health care conditions (i.e. through research focusing on issues facing trans\* people).
- Diagnosis must focus on clinically relevant symptoms. In this case, these symptoms are distress with actual or anticipated sex characteristics or ascribed gender role, accompanied with clinically relevant consequences or significant impairment in relevant areas of function. They can be articulated in a diagnosis such as "gender dysphoria."
- This symptomatic focus will also prevent the diagnosis from being applied to all trans\* people regardless of their specific experiences, and will allow access to proper mental health care to those who truly need it. A symptom-based diagnosis would also help to establish clear criteria (i.e. based on distress thresholds) for treatment. In addition this creates the option for "in-remission clauses" specifying that if that distress has been alleviated (e.g. through access to appropriate health services) then the diagnosis would no longer apply.
- Transitional health care, particularly gender affirming treatments such as hormonal and surgical procedures, have been identified as successful treatments for the distress experienced by many, but not all, trans\* people. Such an F code diagnosis would grant access to such treatments for those who need them.

# Challenges

- The clinical characterization of trans\* experiences as "unique" and, thus, deserving a specific diagnosis, is based on cultural prejudices against those experiences (such as gender-variance).
- A diagnostic emphasis on distress will continue to pathologize specific feelings that some trans\* people experience (i.e. distress).
- Even when distress or dysphoria would become the core notion of the diagnosis, given the historical and current functioning of mental disorders the new diagnosis would continue to pathologize trans\* people and their identities.
- Given the intrinsic connection between diagnosis and access to transitional health care in different countries, a diagnosis built on notions such as distress or dysphoria would promote these notions and the experiences associated with them as the normative version of trans\* identities, forcing people to reproduce narratives of distress or dysphoria or threatening them with exclusion from



transitional care.

- Other conditions with a potentially negative impact on mental health do not require a specific diagnosis (for example, distress associated with oncological diseases).
- F codes have a long history of being used as a tool for gatekeeping and exclusion of trans\* people from the health care they need, be it trans\*specific or not. A continuing linkage of trans\* health care with specific F-codes could continue this practice.
- Even when a diagnosis based on a key symptom -such as distress or dysphoriacould be authentically smaller in its scope, the historical and normative influence of a mental health diagnosis could imply negative consequences for the decentralized Starfish Model. In this sense, "gender dysphoria" could easily work as a stand-alone diagnosis, or become the center of the starfish, constituting the entry point for all trans\* related health care and rendering the other diagnoses superfluous. (For example, if such a diagnosis became unavoidable in order to have access to trans\* specific health care)

#### Children and adolescents

The group of experts convened in The Hague did not propose any specific chapter, block or code recommendation in regard to trans\* adolescents and children, mostly due to time constraints. However, concerns were raised in regard to the following issues:

- The current diagnosis (i.e. F64.2 Gender identity disorder of childhood) pathologizeschildren's gender variance, reinforcing and imposing gender stereotypes. Diagnosing gender variance in childhood has severe negative effects, from stigma to forced reparative therapy, and must be avoided in ICD-11.
- Children and adolescents have the right to have access to information, counseling and trans\*specific health care (i.e. counseling, hormonal blockers in adolescence, etc.). That right could be granted through Z(t) codes.
- Using F.90-98 codes: 'Behavioral and emotional disorders with onset usually occurring in childhood and adolescence' as significant codes for trans\* healthcare could repathologize gender variance in childhood and/or adolescence.
- Z codes seem to provide many of the healthcare needs expressed by trans\* children, adolescents and their families (i.e. codes Z70-z76, Persons encountering health services in other circumstances, including Z70, counseling related to sexual attitude, behaviour and orientation, Z71, Persons encountering health services for other counseling and medical advice, not elsewhere specified, etc., and in general, codes Z80-z99, Persons with potential health hazards related to family and personal history and certain



- conditions influencing health status).
- However, as already noted, a Z code on its own is not a diagnosis and may not be sufficient to access funding for relevant services. If it is necessary to develop specific E codes to enable children and adolescents to access hormone blockers, these codes must not pathologize body diversity, gender expression as inherently problematic, but should focus on the best interests of the child.



#### V. Recommendations and Conclusion

During the past decades, trans\* people from around the world have been asking the same question: how to depathologize their lives while retaining, at the same time, full access to health care and legal recognition? And different answers have been proposed - from deleting all possible references to trans\* issues from clinical manuals to only including the least damaging references. The Experts Meeting organized by GATE was another opportunity to pose these fundamental questions, to explore different answers and to realize, once again, how pressing and challenging correct answers can be.

At this point in the debates around these issues, GATE does not have a formal proposal to submit to the World Health Organization in regard to how trans\* specific and general health care issues should be included in the ICD-11. However, we do have some recommendations in regard to the process of including them:

- **1.** Trans\* people from around the world must be actively involved in the process of defining and including their health care needs in the context of ICD 11. Trans\* people's expertise must not be disregarded, ignored or excluded.
- **2.** ICD-11 references (chapters, blocks, codes) should avoid pathologizing trans\* people's experiences of gender identity, gender expression, body diversity and sexuality. This recommendation applies particularly to those references potentially affecting adolescents and children. Instead the focus should be on the medical needs of trans\* people.
- **3.** Trans\* individuals must be called by their self-perceived gender identity, even in the context of references addressing bio-anatomical features or the gendering of body parts should be removed.
- **4.** ICD-11 references should apply only to those trans\* people that need health care, and only for the time they need it, avoiding any codification of trans\* experiences in general as susceptible or in need of diagnosis.
- **5.** Given its global impact, ICD-11 references must take into account different cultural contexts and avoid any codification of trans\* experiences in Global North / Western terms, especially terms that assume binary, mutually-exclusive genders, such as male/female.
- **6.** Even when the ICD is intrinsically based on a clinical logic, we truly believe that this logic can be expanded to include depathologizing approaches to trans\* health issues and, therefore, we encourage the WHO experts' working group to move in that direction.



#### V. Definitions

In this report, the following concepts are used:

**Gender affirming procedures**: refers to all those procedures - surgical, hormonal, psychological or otherwise - aimed to affirm trans\* people's gender identity and/or to allow them to express it freely and in the way they prefer. Gender affirming procedures must be driven by the desire of the person who seeks them.

**Transitional health care**: refers to health needs and care provision associated with the process of identifying and living in a gender different than the sex assigned at birth, including counseling, hormonal treatments, surgical procedures and other gender affirming procedures, as well as harm reduction measures.

**Legal gender recognition**: refers to the process that trans\* people have to take in order to obtain legal documentation (passport, birth certificate, ID card, tax payer number etc.) that is fully representative of the gender identity of that person.

**Trans\* - specific health care**: it refers to those health care needs directly derived from trans\* people's experiences in regard to their gender identities, gender expressions, sexualities, embodiments, etc. It involves not only gender affirming procedures, but also harm reduction measures and, in general, trans\* health issues. It also includes gendered procedures that may involve body parts generally associated with a different gender (for example cervical exam for a male-identified trans\* person), as well as health care that is needed as a result of living in transphobic societies (such as mental health services).

*Harm reduction*: has become a pressing trans\* health issue. In those contexts where trans\* people do not have access to proper transitional care, body modifications take place through other means, such as unsupervised industrial silicone injections, black market hormonal treatments and surgeries in unlicensed facilities. As these procedures have extremely negative health consequences, addressing them through effective harm reduction policies is a priority in the field of trans\* health care in many countries.



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