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Controversies in Gender Diagnoses

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Abstract

This article presents the author's thoughts on gender diagnosis controversies during his tenure at the DSM-5 Workgroup on Sexual and Gender Identity Disorders and the ICD-11 Working Group on the Classification of Sexual Disorders and Sexual Health. The work summarizes some of the published conclusions of the *DSM-5* and ICD-11 revision processes regarding three particular controversies: (1) stigma versus access to care; (2) the retention of a child gender diagnosis; and (3) the treatment of prepubescent transgender children. Both the DSM and ICD work groups decided that despite the stigma associated with a diagnosis, retaining an adolescent and adult gender diagnosis is necessary to maintain access to care. As for the child gender diagnosis, given the heterogeneity of this clinical population and that gender dysphoria does not persist in most children, a child diagnosis of Gender Dysphoria (*DSM*) and Gender Incongruence (ICD) should be retained to facilitate ongoing evaluation and management in childhood while acknowledging the uncertainty of the outcome. The treatment of extremely gender variant prepubescent children remains a controversial subject since some underlying assumptions of the treating clinicians are a matter of opinion rather than of empirical data.

Key words: diagnosis, *DSM*, gender dysphoria, gender identity, gender identity disorder, gender incongruence, ICD, transgender, transsexual.

Introduction

In 2007, I was appointed by the American Psychiatric Association's (APA) Board of Trustees to serve as a member of the DSM-5 Workgroup on Sexual and Gender Identity Disorders. Most of my work took place in the Subworkgroup on Gender Identity Disorders. As editor of the *Journal of Gay and Lesbian Psychotherapy* (now the *Journal of Gay and Lesbian Mental Health*), I had done some academic work in this area. I had sought out and published articles about trans issues,[1–4] and the journal devoted an entire double issue to the subject as well.[5] I also coedited a special issue of the *Journal of Psychology and Human Sexuality*, which focused on the question of retaining or removing the sexual and gender diagnoses of the *DSM*.[6] Most recently, I coedited a volume on the treatment of transgender children and adolescents.[7]

As a spokesperson for the American Psychiatric Association (APA) on LGBT issues, I often spoke to the media regarding culture war issues from a mental health perspective,[8] particularly sexual orientation change efforts (SOCE, or so-called reparative therapies).[9,10] Yet despite years of sensationalistic media stories about SOCE, I was startled by some of the responses in the LGBT community when, in May 2008, APA formally announced the make-up of its entire Work Group on Sexual and Gender Identity Disorders (WGSGID). Controversies related to both the diagnosis of Gender Identity Disorder (GID) of Adolescence and Adulthood and the diagnosis of GID of Childhood (GIDC) were first taken up by the LGBT press[11,12] and, shortly thereafter, by the mainstream media as well.[13] Soon after, I summarized several of the more controversial views as follows:[14]

1. As in the case of homosexuality in the 1970s, it is wrong for psychiatrists and other mental health professionals to label expressions of gender variance** as symptoms of a mental disorder, and perpetuating *DSM-IV-TR*'s GID diagnoses in the *DSM-5* would further stigmatize and cause harm to transgender individuals, who are already a highly vulnerable and stigmatized population.
2. Alternatively, other members and advocates of the trans community expressed concern that deleting GID from

**The term "gender variance" is a nonpathologizing alternative to psychiatric diagnoses like gender identity disorder.

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the *DSM* would lead third party payers to deny access to care for those transgender adults already struggling with inadequate private and public sources of healthcare funding for medical and surgical care.[†]

3. Clinical efforts with gender variant children aimed at getting them to reject their felt gender identity and to accept their natal sex were unscientific, unethical, and misguided. Activists labeled such efforts a form of "reparative therapy."

In 2011, I was appointed to another committee dealing with gender diagnoses: The Working Group on the Classification of Sexual Disorders and Sexual Health (WGSDSH) of the World Health Organization (WHO). WHO is presently revising the *International Classification of Diseases* (ICD-10),[15] and ICD-11 has an anticipated publication date of 2015. The WGSDSH is charged with evaluating clinical and research data to inform the revision of diagnostic categories related to sexuality and gender identity currently in the Mental and Behavioral Disorders chapter of ICD-10 and making recommendations regarding whether and how these categories should be represented in ICD-11. The members of this working group summarized some controversies surrounding the ICD's gender diagnoses from the perspective of a United Nations component:[16]

1. The ICD-10 diagnosis of *Transsexualism* has been framed as a *human rights issue* about which WHO received substantial communication and interest from various stakeholders. Many advocates, several countries, the Council of Europe Commissioner for Human Rights[17] and the European Parliament[18] took strong positions that issues related to transgender identity should not be classified as mental disorders in the ICD-11. The latter "calls on the Commission and the World Health Organisation to withdraw gender identity disorders from the list of mental and behavioural disorders, and to ensure a non-pathologising reclassification in the negotiations on the 11th version of the International Classification of Diseases (ICD-11)."
2. While mental disorders are stigmatizing, the combined stigmatization of being transgender and of having a mental disorder diagnosis creates a doubly burdensome situation for members of this population that contributes adversely to their health status as well as to their enjoyment and attainment of human rights. For example, transgender people are much more likely to be denied care in general medical or community-based settings given the perception that they must be treated by psychiatric specialists, even for conditions that have nothing to do with being transgender.[19]
3. From a historical perspective, the classification of gender identity diagnoses as mental disorders seems serendipitous, based more on prevailing social attitudes of the mid-20th century than on available scientific evidence. The etiology of the condition was unknown when placement decisions (i.e., mental vs. somatic vs. neurological disorder/variation) were made in the past and remains unknown now. Further, the extant scientific database cannot empirically answer the question of whether this diagnosis is purely a "mental disorder" or whether any distress is secondary to a physical cause (e.g., an emotional reaction or adjustment disorder due to the incongruence between one's experienced gender and the physical attributes of their natal sex). Further complicating matters, the criteria of distress and impairment that are often required for mental disorders in the *DSM* and ICD are not universally applicable, as there are individuals who present for gender reassignment who may be neither distressed nor impaired.[‡]
4. Given that the research since the mid-20th century has distinguished between sexual orientation and gender identity, the continued bundling of gender diagnoses with paraphilias and diagnoses of sexual dysfunction in the ICD appears to be both outdated and inappropriate.[§]
5. Even among groups that support inclusion of an adolescent and adult diagnosis, there is significant opposition to retaining a diagnosis that applies to prepubescent children.**

Despite (or perhaps because of) these controversies, working on *DSM-5* and ICD-11 has been both rewarding and challenging. These projects have forced me to think about many of my own starting assumptions and constantly left me with the feeling that I was unable to see a larger overview of the subject under study. As making sense of gender cuts across many different areas of our lives and cultures, the closest I have come to an overview of the subject is the image of six blindfolded scientists in white coats trying to describe an elephant. Each of them, touching only one of six parts (trunk, horn, tail, ear, leg, flank), understandably mistakes the part for the whole.[14] I have come to appreciate that any understanding of this subject requires a capacity to "hold complexity"[††] and tolerate the anxiety of uncertainty.

With that mind, what follows is a summary of my present thoughts on three controversial issues surrounding gender diagnoses: (1) stigma versus access to care; (2) the retention of a child diagnosis; and (3) the treatment of prepubescent transgender children.

Stigma Versus Access to Care

Both the DSM-5 work group and the ICD-11 working group wrestled with the challenges of reducing stigma (which underlies the call for removal of the gender diagnoses) and maintaining access to care (which requires the existence of a diagnosis in order to obtain needed medical treatment

[†]The existence of a GID diagnosis has also been a potent legal tool in making medically necessary treatment available to transgender individuals who are wards of the state, such as incarcerated inmates (e.g., Fields vs. Smith; details available online at www.lambdalegal.org/in-court/cases/fields-v-smith) and older adolescents in foster care (available online at www.lambdalegal.org/publications/youth-in-the-margins).

[‡]Although, some have suggested that distress is implicit in the desire for medically assisted gender reassignment (Cohen-Kettenis PT, Pfäfflin F: The DSM diagnostic criteria for gender identity disorder in adolescents and adults. Archives of Sexual Behavior 2010;39:499–513).

[§]In the *DSM-5*, the section on Gender Dysphoria is in a separate section and no longer included in the section containing chapters on Paraphilias and Sexual Dysfunction.

**Geoffrey Reed (personal communication) following the presentation of ICD-11 proposed criteria at a March 2011 meeting of WPATH.

[††]Thanks to Susan Coates, PhD, for providing me with this term so many years ago.

covered by third party payers). This is no simple task as it is difficult to find reconciling language that removes the stigma of having a mental disorder diagnosis while maintaining access to medical care. Those seeking removal aim to frame gender variance as a narrative of normal variation, yet access to medical treatment for any condition usually requires a narrative of pathology.[14,‡‡] Finding a resolution to these contradictory narratives was a more difficult challenge for the DSM work group than for the ICD group (see below), as the *DSM* contains only mental disorders, with the exception of V-codes (usually nonreimbursable by third party payers). Therefore, other than the option of complete removal, there was no other place to situate the gender diagnoses in the *DSM*. Consequently, the working group came up with the following suggestions, all of which have been incorporated into the *DSM-5*.[20]

- Retention of the gender diagnoses (to maintain access to care), both in children and in adolescents and adults;
- Name change from Gender Identity Disorder to Gender Dysphoria (to reduce stigma);
- Separate chapter for Gender Dysphoria which is no longer bundled with the Paraphilias and Sexual Dysfunction (to reduce stigma);
- The addition of a post-transition specifier to be used in the context of continuing treatment procedures that serve to support the new gender assignment (a kind of "exit clause" from the diagnosis, which reduces stigma, when the post-transition individual is no longer gender dysphoric but still requires access to care for ongoing hormone treatment); and
- Narrower diagnostic criteria to reduce false positives (to reduce stigma).

In addition to the above changes, and acting upon recommendations that emerged from the work group,[14] APA issued two position statements. The first opposes any form of discrimination against transgender individuals.[21] The second supports access to care and coverage by third party payers for individuals seeking medically necessary treatment.[22]

In the case of the ICD working group, its recommendations to WHO have yet to be decided upon definitively, although a preliminary version has been published by several working group members.[16] Unlike the *DSM*, here there is a possibility of retaining the gender diagnoses but moving them out of the mental disorder section into some other part of the ICD that would be less stigmatizing:

- Retention of gender diagnoses (to facilitate access to care);
- Name changes from Transsexualism and Gender Identity Disorder of Childhood to Gender Incongruence (GI) of Adolescence and Adulthood and GI of Childhood (to reduce stigma; also "incongruence" focuses less on the mental state of "dysphoria")
- Move Gender Incongruence out of the section on mental and behavior disorders; three alternatives were proposed, all intended to reduce stigma while maintaining access to care:
  1. A chapter of its own outside both the section on mental and behavioral disorders (to treat GI as a unique medical condition);
  2. A proposed new chapter on sexual disorders and sexual health that contains both pathological and nonpathological conditions (diagnoses in this proposed chapter would include normal conditions, medical illnesses, and mental disorders, and it would remain ambiguous into which of these three categories the gender diagnoses would fall);
  3. A medical or surgical diagnosis (problematic in that some transitioning individuals do not have surgery and not all who transition socially desire medical treatment).

In summary, neither the DSM nor the ICD work groups could completely reconcile a narrative of normality (no stigma attached to phenomenon) with one of pathology (the phenomenon receives a diagnosis, a diagnostic code, and facilitates access to care). The psychosocial context for evaluating gender variance is rapidly changing, with increasing social acceptance of both trans children and adults. However as a practical concern, both work groups felt it would be difficult to presently make the case to the wider world that transition from one gender to another, like uncomplicated pregnancy, is a normal life phenomenon that requires medical treatment.

Diagnosing Prepubescent Children

In both the DSM and ICD processes, objections have been raised about diagnosing children with a stigmatizing mental disorder, known in both manuals as "Gender Identity Disorder of Childhood." "Researchers and clinicians disagree whether this category should exist at all, whether it should be applied to children, and what diagnostic criteria should be applied.[23]

Bartlett and colleagues,[24] in recommending removal of the GIDC diagnosis from the *DSM*, argued "children who experience a sense of inappropriateness in the culturally prescribed gender role of their sex but do not experience discomfort with their biological sex should not be considered to have GID. Because of flaws in the *DSM-IV* definition of mental disorder, and limitations of the current research base, there is insufficient evidence to make any conclusive statement regarding children who experience discomfort with their biological sex" (p. 753). Hill and colleagues[25] make similar criticisms, "Overall, there is deepening discomfort with pathologizing children and youth for extreme gender variance. Since this is a highly contentious diagnosis–with little established reliability and validity and problematic assessment and treatment approaches–researchers and clinicians need to establish that GID is validly diagnosed with nonbiased assessments and treated effectively in accordance with current standards" (p. 57).

Although gender atypical behavior alone never established a GIDC diagnosis, Isay[26] claims it "implicitly labels homosexual boys as mentally disordered," (p. 9) since research indicates that a certain degree of gender atypical behavior was common in many of the adult gay men he treated. In a similar vein, Richardson[27] warns of the slippery slope between GIDC's pathologizing "extreme" gender atypical behavior and the "normal" childhood gender atypical behavior of many "proto-gay" men and women who do not meet diagnostic criteria for GIDC and never came to clinical attention.

‡‡Two exceptions are normal pregnancy and normal menopause, both of which have been "medicalized" to a certain degree.

Arguments for retention of the diagnosis include:[20,28–30] (1) the need for children with Gender Dysphoria to have access to care, which is often complex and involves treatment of both the family and social environment; (2) increased efforts to narrow clinical criteria to exclude gender atypical behavior unrelated to a diagnosis of Gender Dysphoria; and (3) the need to make it clear to clinicians that the gender diagnoses of childhood do not progress directly into the gender diagnoses of adolescence and adulthood. In fact, most children who meet criteria for a gender diagnosis grow up to be gay rather than transgender.

It should be further underscored that clinicians working from a variety of perspectives (see below) are unable to differentiate between those children whose gender dysphoria will persist into adolescence and adulthood and those in which it will desist. Given the heterogeneity of this clinical population, and that gender dysphoria does not persist in most children, both the DSM and the majority of the ICD work groups felt it would be irresponsible to eliminate the child diagnoses and create the erroneous impression that most trans children become trans adolescents and adults. Instead, a more conservative approach should use a child diagnosis to facilitate ongoing evaluation and management in childhood while acknowledging the uncertainty of the outcome.[7,31]

Treatment of Prepubescent Children

Little is actually known about the origins of a gender identity, whether cisgender or transgender, or about the long-term outcomes of the various treatments currently offered to children. Where there are gaps in the empirical database, experts often fall back on their opinions. As noted in a recent APA Task Force report, "Opinions vary widely among experts and are influenced by theoretical orientation as well as assumptions and beliefs (including religious) regarding the origins, meanings, and perceived fixity or malleability of gender identity. Primary caregivers may, therefore, seek out providers for their children who mirror their own world views, believing that goals consistent with their views are in the best interest of their children" (pp. 762–763).[32]

The APA Task Force further noted, "The overarching goal of psychotherapeutic treatment for childhood GID is to optimize the psychological adjustment and well-being of the child. What is viewed as essential for promoting the well-being of the child, however, differs, as does the selection and prioritization of goals of treatment. In particular, opinions differ regarding the questions of whether or not minimization of gender atypical behaviors and prevention of adult transsexualism are acceptable goals of therapy" (p. 763). The Task Force outlined three general approaches to child treatments in the professional literature:

1. Working with the child and caregivers to lessen gender dysphoria and to decrease cross-gender behaviors and identification. The assumption is that this approach decreases the likelihood GID will persist into adolescence and culminate in adult transsexualism. For various reasons (e.g., social stigma, likelihood of hormonal and surgical procedures with their associated risks and costs), persistence is considered to be an undesirable outcome by some but not all clinicians who work in this area of practice. Critics of this approach have likened it to "reparative therapy," a term more commonly used to describe efforts to change homosexuality in gay adults or "pre-homosexual" children.[33]
2. No direct effort to lessen gender dysphoria or gender atypical behaviors. This approach is premised on evidence that GID diagnosed in childhood usually does not persist into adolescence and beyond and on the lack of reliable markers to predict in whom it will or will not persist. A variation of this approach is to have no therapeutic target with respect to gender identity outcome. The goal is to allow the developmental trajectory of gender identity to unfold naturally without pursuing or encouraging a specific outcome. This approach entails combined child, parent, and community-based interventions to support the child in navigating the potential social risks.
3. Affirmation of the child's cross-gender identification by mental health professionals and family members. The child is supported in transitioning to a cross-gendered role, with the option of endocrine treatment to suspend puberty in order to suppress the development of unwanted secondary sex characteristics if the cross-gendered identification persists into puberty. The rationale for supporting transition before puberty is the belief that a transgender outcome is to be expected in some children, and that these children can be identified so that primary caregivers and clinicians may opt to support early social transition. A supporting argument is that children who transition this way can revert to their originally assigned gender if necessary since the transition is done solely at a social level and without medical intervention.[34] Critics of this approach believe supporting gender transition in childhood can increase the likelihood of persistence and a lifetime of medical treatment.

Treatment of extremely gender variant children will continue to remain controversial since some underlying assumptions of the clinicians are a matter of opinion rather than of empirical data and empirical studies (e.g., clinical trials with random treatment assignment) are neither feasible nor ethical. I wish to conclude by raising some points for the clinicians treating these children to consider:

1. There is no empirical evidence (i.e., controlled study) demonstrating that discouraging childhood cross-gender interests reduces the frequency of persistence into adolescence and adulthood.
2. Since no clinician can accurately predict the future gender identity of any particular child, efforts to discourage cross-gender identifications may be experienced as hurtful and possibly even traumatic by children who do persist into adolescence and adulthood.
3. There is no empirical evidence demonstrating that a prepubescent child who is permitted to transition gender role but then desists can simply and harmlessly transition back to the natal gender.
4. Since no clinician can accurately predict the future gender identity of any particular child, efforts to encourage public early childhood cross-gender roles may be experienced as hurtful and possibly even traumatic by children who do not persist into adolescence and adulthood.

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