

April 20, 2010

David J. Kupfer, M.D., DSM-5 Task Force Chair
Darrel A. Regier, M.D., M.P.H., DSM-5 Task Force Vice-Chair
American Psychiatric Association
1000 Wilson Boulevard, Suite 1825
Arlington, VA 22209-3901

Re: Proposed Draft Revisions to Diagnostic and Statistical Manual of Disorders and
Criteria

Dear Messrs. Kupfer and Regier:

On behalf of Lambda Legal Defense and Education Fund, Inc. (“Lambda Legal”), we have set forth below initial responses to the Proposed Draft Revisions to the Diagnostic and Statistical Manual of Mental Disorders and Criteria (“the DSM-5 Proposed Revisions”), as requested by the American Psychiatric Association on its website www.dsm-5.org. Lambda Legal urges significant changes to the DSM-5 Proposed Revisions to reflect a positive, nonstigmatizing approach to transgender health care, to assist individuals in achieving legal and social recognition consistent with their gender identity and expression, and to maintain and increase access to transition-related health care.¹

Founded in 1973, Lambda Legal is the nation’s oldest and largest nonprofit legal organization committed to achieving full recognition of the civil rights of lesbians, gay men, bisexual, and transgender (LGBT) people and people living with HIV, through impact litigation, education, and public policy work. Lambda Legal has appeared as counsel or *amicus curiae* in numerous landmark cases in federal and state courts involving the interpretation and application of statutory and constitutional protections for LGBT people. See, e.g., *Lawrence v. Texas*, 539 U.S. 558

¹ See American Psychological Association, Task Force on Gender Identity and Gender Variance. (2009). “Report of the task force on gender identity and gender variance.” Washington, D.C.

(2003) (counsel); *Romer v. Evans*, 517 U.S. 620 (1996) (counsel); *Varnum v. Brien*, 763 N.W.2d 862 (Iowa 2009) (counsel).

Lambda Legal has a particularly strong interest in the DSM-5 Proposed Revisions, because transgender people face widespread discrimination, including barriers to accessing health care, and advancing the rights and freedoms of transgender people is an integral part of Lambda Legal's mission. *See, e.g., Hernandez-Montiel v. INS*, 225 F.3d 1084 (9th Cir. 2000) (amicus); *In re Maloney*, 96 Ohio St. 3d 307, 774 N.E.2d 239 (2002) (amicus); *Brandon v. County of Richardson*, 264 Neb. 1020, 653 N.W.2d 829 (2002) (unanimous holding that Sheriff was liable both for his failure to protect transgender man and separately for his abusive treatment of him) (counsel for plaintiff-appellant); *Fields v. Smith*, No. 06-C-112 (E.D. Wis. Mar. 31, 2010) (holding that state law barring medical treatment for transgender prisoners with Gender Identity Disorder (hereinafter "GID") constitutes deliberate indifference to plaintiffs' serious medical needs in violation of the Eighth Amendment, and violates plaintiffs' right to equal protection) (counsel); *Lopez v. River Oaks Imaging & Diagnostic Group*, 542 F. Supp. 2d 653 (S.D. Tex. 2008) (holding that a transgender employee stated a claim under federal civil rights law for sex discrimination when her employer fired her because she did not conform to her assigned gender role) (counsel); *Glenn v. Brumby*, 632 F. Supp. 1308 (N.D. Ga. 2008) (holding that plaintiff alleged plausible equal protection claims for discrimination on the basis of sex stereotyping and medical condition (GID)) (counsel); *L.P. v. City of Philadelphia*, Nos. HO-9121146 & CO-9120114 (Pa. Human Relations Comm'n Oct. 27, 2009) (pending before Pennsylvania Commission on Human Relations representing transgender girl subjected to verbal and physical abuse because of sexual orientation, gender identity, sex, and disability (GID) while in custody at Philadelphia youth detention facility) (counsel).

I. General Comments on the DSM-5 Proposed Revisions of Gender Identity Disorder

- a. **The APA must prioritize maintaining and increasing access to transition-related healthcare throughout the DSM revision process, according appropriate attention to the significance of “medical necessity” in accessing care**

As a civil rights organization representing the rights of LGBT people for more than three decades, Lambda Legal is acutely aware of the severe and painful consequences of stigmatizing and pathologizing individuals based upon their sexual orientation, gender identity, and gender expression. We laud efforts to remove societal burdens of discrimination, and support reinforcing those efforts through sensitive and accurate revisions to medical texts and manuals, including but not limited to the DSM. Through our legal and policy work, Lambda Legal fights for the civil rights of all people to be free from discrimination based on harmful gender stereotypes. We believe that diversity of human expression, including one’s sexual orientation, gender identity, or gender expression, should not be considered a disorder.

At the same time, we know the success of many of our court cases and much of our legal advocacy on behalf of transgender people has rested upon a medical diagnosis that clearly sets forth the medical necessity for transition-related treatment, including hormones and surgery. Our commitment to increasing access to health care for transgender individuals, particularly with regard to transition-related healthcare, is evidenced by our recent Health Care Fairness Survey, “When Health Care Isn’t Caring,” the first such survey to examine refusal of care and barriers to health care among LGBT and HIV communities on a national scale.² Our survey revealed that transgender people, particularly low-income transgender people and transgender people of color, report higher levels of discrimination in accessing competent and comprehensive health care than others we surveyed.

We support the American Medical Association (AMA), American Psychological Association

² <http://www.lambdalegal.org/publications/when-health-care-isnt-caring/>

(APA), the American Academy of Family Physicians (AAFP), and the World Professional Association for Transgender Health (WPATH) in their recognition of the efficacy, benefit, and medical necessity of gender transition for many transgender people.³ Medical necessity is properly evaluated on an individual basis; being transgender should not in and of itself constitute a diagnosis or disorder, and does not dictate a particular medical need.

We are deeply concerned that the uphill battle many transgender people face in accessing medically necessary healthcare will be made more difficult, if not impossible, without a clear path leading from diagnosis to treatment access. In general, our current medical and legal framework does not sanction public or private insurance coverage for treatment without actual need. One has only to look at our most recent hard-won victory for transgender prisoners in Wisconsin to access treatment. Medical necessity undergirded our success in overturning a statutory ban on treatment for prisoners. See *Fields*, supra. Tellingly, the arguments against our incarcerated clients relied on the assertion that treatment was “merely cosmetic” -- and therefore medically unnecessary. See *id.* As lawyers committed to protecting and advancing the rights of transgender people, including those whose access to medical is dictated by the government due to incarceration, poverty or, in the case of many transgender youth, abuse or abandonment, we do not believe that the DSM can be validly revised in isolation, without prioritizing the mapping out of a clear path to treatment access based upon medical need.

Discrimination rooted in misunderstanding about the medical necessity of transition-related care is far-ranging: Rhiannon O'Donnabhain recently battled the Internal Revenue Service to finally receive a ruling that her transition-related medical procedures were improperly deemed “cosmetic”

³ AMA House of Delegates, Resolution 122: Removing Financial Barriers to Care for Transgender Patients, *available at* http://www.tgender.net/taw/ama_resolutions.pdf; APA Policy Statement: Transgender, Gender Identity, & Gender Expression Non-Discrimination, *available at* <http://www.apa.org/about/governance/council/policy/transgender.aspx>; http://www.hrc.org/issues/patient_rights.htm; WPATH Clarification on Medical Necessity of Treatment, Sex Reassignment, and Insurance Coverage in the U.S.A., *available at*

or “elective.” See *O’Donnabhain v. Commissioner of Internal Revenue*, No. 6402-06, 2010 U.S. Tax Ct. LEXIS 4 (U.S. Tax Ct. 2010). Her successful case alleviated a significant financial burden, and again, it was based upon showing the medical necessity of her surgery.

Absent a wholesale revision of our medical and insurance system to provide routine access to care based on the desire for it, rather than need, we are deeply concerned that without a clear delineation of the full range of what constitutes medical necessity, even more transgender people will face denials of treatment in our current system. The burden will fall most heavily on those who are most marginalized, and the effects are dire: Denial of proper care results in great suffering, including but not limited to harms ranging from multiple documented, horrific incidents of life-threatening self-castration by incarcerated transgender women,⁴ to street purchases of adulterated hormones (administered in ways that increase the risk of contracting HIV),⁵ to debilitating depression and suicide.⁶ These harms in and of themselves attest to the medical necessity for treatment. We believe the DSM revisions must be guided by realistic assessment of transgender people’s health needs and that pathways to access care must be clearly delineated and safeguarded before revisions are finalized.

b. The APA must prioritize increasing access to legal and social gender recognition for transgender people

We also recognize that a diagnosis of GID is currently used to assist individuals in achieving legal and social recognition of gender identity and expression. Lambda Legal fights for the rights of transgender people to access federally- and state-issued documentation that correctly reflects their gender identity, regardless of surgical status. We recognize that in some jurisdictions, transgender

<http://www.wpath.org/documents/Med%20Nec%20on%202008%20Letterhead.pdf>

⁴ See, e.g. “Health Care Policies Addressing Transgender Inmates in Prison Systems in the United States,” *Journal of Correctional Health Care*, Vol. 15, No. 4, 280-291 (2009).

⁵ See Pooja S. Gehi & Gabriel Arkles, *Unraveling Injustice: Race and Class Impact of Medicaid Exclusions of Transition-Related Health Care for Transgender People*, 4 SEXUALITY RES. & SOC. POL’Y 7, 10 (2007).

⁶ See AMA House of Delegates, Resolution 122: Removing Financial Barriers to Care for Transgender Patients, *available*

people are able to access identification that matches their gender identity by providing documentation from a medical provider who can attest that the individual is living full-time in an experienced/expressed gender, rather than the assigned sex.⁷ At times, this documentation has involved a diagnosis of GID. Moreover, a diagnosis of GID has been instrumental in successful advocacy for transition-related healthcare for some people, as well as a basis for legal protection under certain state disability discrimination laws.⁸ Lambda Legal has successfully argued claims on behalf of transgender people in employment and healthcare discrimination cases using the diagnosis of GID. See *Glenn*, 632 F.Supp.2d at 13408; *Lopez*, 542 F. Supp. 2d at 653; *Fields*, supra.

In light of the current vital and practical uses in legal and healthcare contexts for a diagnosis that recognizes the treatment needs of many transgender individuals, and in the interim between any future shift from a mental health diagnosis to a medical diagnosis,⁹ we recommend that any and all DSM-5 provisions relating to transgender healthcare have a clear and unambiguous purpose that is limited to psychological distress or dysphoria, a serious condition that can be treated with medical procedures. The revisions should make clear that a diagnosis is not properly premised simply upon variation of gender identity or expression.

II. Comments on Specific Sections

a. “Typical of the other gender”

We are concerned that the DSM-5 Proposed Revisions sections Gender Incongruence (in Adolescents or Adults), “Indicator 6,” and Gender Incongruence (in children), “Indicator 4” appear

at http://www.tgender.net/taw/ama_resolutions.pdf.

⁷ For a complete list of requirements for DMV gender reclassifications, see Spade, Dean, “Documenting Gender,” *Hastings Law Journal*, Vol. 59, No. 1, 2008.

⁸ See e.g. *Lie v. Sky Publ'g Corp.*, 15 Mass. L. Rptr. 412, 2002 WL 31492397 (Mass. Super. Ct. 2002); *Enriquez v. W. Jersey Health Sys.*, 777 A.2d 365 (N.J. Super. Ct. App. Div.), cert. denied, 785 A.2d 439 (N.J. 2001); *Doe v. Yunits*, 15 Mass. L. Rptr. 278, 2001 WL 664947 (Mass. Super. Ct.); *Jette v. Honey Farms Mini Market*, 2001 WL 1602799, No. 95 SEM 0421 (Mass. Comm'n Against Discrimination 2001); *Jean Doe v. Bell*, 754 N.Y.S.2d 846 (N.Y. Sup. Ct. 2003); *Doe v. Boeing Co.*, 846 P.2d 531, 536 (Wash. 1993); *Smith v. City of Jacksonville Corr. Inst.*, 1991 WL 833882, Order No. 88-5451 (Fla. Div. Admin. Hrgs. 1991); *Jane Doe v. Electro-Craft Corp.*, No. 87-B-132 (N.H. Sup. Ct. 1988).

⁹ See “Comment on Proposal for Gender Incongruence in the DSM-5,” Callen-Lorde, the Lesbian, Gay, Bisexual, and

to reinforce gender stereotypes by referring to “typical feelings and reactions of the other gender.” Promotion of such stereotypes does not support medical treatment goals and in fact may well undermine such goals, by promoting secondary distress due to gender-linked societal judgments that should have no basis in medicine. These indicators are based on a concept of “atypical” gendered behavior that encourages reliance on stereotyped and culturally derived notions of gender, rather than distress. We recommend that the diagnosis be limited to the evaluation of clinical distress or dysphoria caused by incongruence between one’s experienced/expressed gender and one’s assigned sex.

b. Exit Clause

We are concerned that the addition of an “exit clause” in the Gender Incongruence (in Adolescents or Adults) section so that individuals who have transitioned can “lose” the diagnosis may create confusion under existing precedent recognizing that GID is a serious medical condition that warrants medical treatment and legal protections. We are also concerned that an “exit clause” will harm adolescents who face difficulties in accessing treatment for GID, because it might reinforce the notion that one’s experienced/expressed gender is merely a transient phase, rather than a valid medical concern. We recommend that the DSM-5 proposed revision clarify this point to prevent misinterpretation of the medical necessity of transition-related care for some transgender adolescents.

c. “Gender” versus “Sex”

Courts have often looked to the language of the DSM in disability or discrimination cases that involve transgender litigants with GID-related claims. The DSM-5 Proposed Revision’s replacement of the term, “sex” with “gender” will contribute to the confusion in litigation that the legal field already faces. We recommend that the ultimate version maintain current language or

clearly define and standardize language in the DSM in order to maximize understanding of critical legal protections and improve access to medically necessary healthcare treatment for many transgender people.

d. Severity Questions

i. “Legal Sex or Gender”

The term “legal sex or gender” in the Severity questions of the proposed revision is misleading and will create confusion for consumers and the courts. In general, people do not have a single “legal sex.” One’s legal sex is not necessarily determined by the gender marker on identity documents. For example, one’s legal sex for purposes of marriage may be regarded differently from that referenced on a driver’s license or birth certificate. We recommend that the proposed revision replace the term “legal sex or gender” with “sex assigned at birth” in order to prevent confusion and best protect rights.

ii. Inclusion of Sexual Orientation and Age

The proposed revision’s inclusion of “sexual orientation” and “age” within the Severity questions should be rejected. The questions about these characteristics provide no meaningful information relevant to diagnosis and only create the potential for misuse and confusion. We recommend that these factors be removed completely.

e. Transvestic Fetishism

We urge the Committee to eliminate the diagnosis of Transvestic Disorder (TD) in the DSM completely. It appears to be a baseless and harmful diagnosis rooted in nonconformity to gender stereotypes, without any valid medical underpinnings.

III. Additional Consultation and Input Is Required

We submit these comments in compliance with the deadline given by the APA, but we are concerned that the limited outreach to important stakeholders paired with the constrained

timeframe for comment are insufficient to capture input that is vital to the necessary result. Lambda Legal strongly urges additional, ongoing discussions and necessary input from transgender people, legal advocates, and “community providers who serve and are accountable to significant numbers of people affected by this diagnosis.”¹⁰ We join Callen-Lorde, the Lesbian, Gay, Bisexual, and Transgender Community Center of New York City, and their co-signatories in calling for the APA to explore alternative pathways to medically necessary, transgender-specific health care that might rely more significantly upon a medical diagnosis.

On behalf of Lambda Legal, the undersigned attorneys remain actively interested in additional engagement with the DSM revision process. We look forward to a productive, continuing discussion as the process moves forward.

Sincerely,



M. Dru Levasseur
Transgender Rights Attorney
dlevasseur@lambdalegal.org
212-809-8585 extension 224



Hayley Gorenberg
Deputy Legal Director
hgorenberg@lambdalegal.org
212-809-8585 extension 269

¹⁰ “Comment on Proposal for Gender Incongruence in the DSM-5,” Callen-Lorde, the Lesbian, Gay, Bisexual, and Transgender Community Center of New York City, and co-signatories.