LGBT Task Force

Feb. 2, 2015

Katharine Ceroalo
DOH Bureau of House Counsel, Regulatory Affairs Unit
Tower Building, Room 2438
Albany, NY 12237

Re: ID No. HLT-50-14-00001-P; Medicaid proposed rulemaking regarding transgender-related care and services

Dear Ms. Ceroalo:

We write on behalf of the LGBT Task Force of Health Care For All New York (HCFANY) and allies to offer comments on proposed rulemaking concerning Medicaid coverage of transgender-related care and services (ID No. HLT-50-14-00001-P). HCFANY is a statewide coalition of more than 170 organizations working to improve health coverage and access for all New Yorkers. The LGBT Task Force of HCFANY encompasses 50 organizations dedicated to the health and rights of LGBT New Yorkers.

HCFANY's LGBT Task Force commends the NYS Department of Health (DOH) for taking an important first step toward lifting discriminatory exclusions of coverage for transgender-related care through the Medicaid program. Ensuring access to medically necessary care for the treatment of gender dysphoria is critical for transgender people, many of whom have suffered considerable health care discrimination[1] and social stigma-

[1] Surveyed transgender consumers report refusal of care, harassment and violence in medical settings, and lack of cultural competency by providers related to their transgender or gender non-conforming status, see National Transgender Discrimination Survey Report on Health and Health Care. National Center for Transgender Equality. http://transequality.org/PDFs/NTDSReportonHealth_final.pdf

related violence from early ages,[2] in addition to being disproportionately likely to be unemployed and live under the poverty level. [3]

Lifting these exclusions should, at minimum, bring Medicaid coverage rules into conformance with the guidance for private health plans recently issued by the NYS Department of Financial Services.[4] Ideally, Medicaid coverage of medically-necessary transgender health care should be *more* comprehensive than private health insurance coverage because Medicaid enrollees have limited incomes and are unable to afford to pay for health care services out of pocket. Medicaid recipients have a right to payment for services that are medically necessary.

Appoint a DOH Oversight Committee

HCFANY proposes that DOH appoint an Oversight Committee to ensure smooth and appropriate implementation of coverage changes that will be brought about by the final version of this rule. We suggest that this committee include not only DOH staff members knowledgeable about transgender care and Medicaid coverage, but also clinicians competent in gender transition care, representatives of LGBT health advocacy groups and consumers who are transgender. The Oversight Committee should ensure:

1) the provision of training about the coverage changes to DOH staff responsible for administering the Medicaid program and staff of health plans serving Medicaid enrollees, as well as to clinicians who participate in Medicaid and all staff of health centers and hospitals that receive Medicaid payments and who interact with patients;
2) the creation and distribution of fact sheets and instructions about pre-qualification to providers and Medicaid plans;
3) verification that Medicaid plans have provider networks that include clinicians capable of providing the gender transition services that are now covered and writing the letters required for provision of surgical services; and
4) ongoing monitoring and evaluation of the implementation of this rule.

This oversight is of the utmost importance in order to ensure that patients are able to obtain covered care from qualified clinicians in a timely manner.

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[2] In a US study of 402 transgender persons, 56% reported experiencing verbal harassment; 37%, employment discrimination; and 19%, physical violence. Bockting, Miner, Swinburne Romine, Hamilton, and Coleman. Stigma, Mental Health, and Resilience in an Online Sample of the US Transgender Population. American Journal of Public Health: May 2013, Vol. 103, No. 5, pp. 943-951.

[3] See Conron, K. J., Scott, G., Stowell, G. S., & Landers, S. J. (2012). Transgender health in Massachusetts: Results from a household probability sample of adults. American Journal of Public Health, 102(1), 118-122.

[4] Department of Financial Services. Re: Health Insurance Coverage for the Treatment of Gender Dysphoria. December 11, 2014.

In addition, HCFANY recommends several recommended changes in the proposed rule to ensure alignment with existing nationally and internationally-recognized standards of care for the treatment of gender dysphoria, and to allow NYS Medicaid policy to reflect the evolution of these standards in future years, without requiring periodic regulatory changes.

505.2(l)(2) ***Limitation of coverage of hormone therapy to people 18 and over***

The proposal to limit coverage for hormone therapy to individuals 18 or older is inconsistent with medical standards of care and would deprive some younger individuals of the care they desperately need. The World Professional Association for Transgender Health (WPATH)[5] and the Endocrine Society[6], internationally recognized experts on this topic, both agree that hormone therapy can be safely started at 16 years of age. Additionally, delaying appropriate treatment for transgender youth may be dangerous, as transgender youth are at higher risk for depression, self-harm and suicidality than their cisgender counterparts (people who are aligned with their assigned gender at birth).[7] HCFANY urges DOH to remove the reference to a threshold of 18 years for coverage eligibility, and instead substitute language referring to the WPATH and Endocrine Society standards of care.

Requested addition of coverage for puberty-suppressing therapy

HCFANY notes the omission of any mention of coverage for puberty-suppressing therapy for patients deemed medically eligible prior to the onset of puberty and strongly recommends the addition of provisions for Medicaid coverage of such therapy. WPATH and the Endocrine Society outline the provisions of puberty-suppressing therapy. The Endocrine Society, for example, states that:

We recommend that adolescents who fulfill eligibility and readiness criteria for gender reassignment initially undergo treatment to suppress pubertal development. We recommend that suppression of pubertal hormones start when girls and boys first exhibit physical changes of puberty (confirmed by pubertal levels of estradiol and testosterone, respectively), but no earlier than Tanner stages 2–3.[8] We recommend that GnRH analogs be used to achieve suppression of pubertal hormones.[9]

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[5] World Professional Association for Transgender Health. Standards of Care: Version 7. Updated 2012. P. 20

[6] The Endocrine Society: Clinical Guidelines. Endocrine Treatment of Transsexual Persons: An Endocrine Society Clinical Practice Guideline. Updated 2009. P 4

[7] Reisner, Vetters, Leclerc, Zaslow, Wolfrum, Shumer, and Mimiaga. Stigma, Mental Health of Transgender Youth in Care at an Adolescent Urban Community Health Center: A Matched Retrospective Cohort Study. *Journal of Adolescent Health*: January 2015, pp. 1-6 [epub ahead of print]. http://www.jahonline.org/pb/assets/raw/Health%20Advance/journals/jah/feature.pdf..

[8] The Tanner Scale shows stages of physical development in children, adolescents, and adults. Due to natural variation, children pass through the Tanner stages at different time, depending on the timing of puberty. Thus, Tanner stages do not match with chronological age, but rather maturity stages. Tanner

These recommendations are echoed in clinical practice research.[10] The use of puberty-suppressing therapy may give adolescents more time to explore their gender non-conformity and may facilitate eventual gender transition by delaying the development of certain sex characteristics. [11]

It is important to understand that puberty-suppressing therapy is also known as Gonadotropin-releasing hormone analogue (GnRH analogue), which is different from adult hormone therapy and is completely reversible.[12] Physicians attest to the need for coverage of puberty suppressing therapy for some gender non-conforming young people, due to the high incidence of depression, substance abuse and even suicide among these individuals.[13] A tragic recent example of the plight of such young people was the suicide of Leelah Alcorn, a 17-year-old who wrote that since age 4, she had felt like "a girl trapped in a boy's body."[14]

HCFANY also seconds comments on puberty-suppressing therapy submitted separately by the Legal Aid Society. Those comments suggest that since puberty-suppressing therapy has been provided for decades to one group of young people – those experiencing precocious puberty – denying that same therapy to another group of young people (those uncomfortable with the gender assigned them at birth) might violate federal law.

505.2(l)(3) ***Requirements for gender reassignment surgery***

Age requirement

HCFANY recommends changes to several aspects of this section:

First, we do not support the proposed age requirements in the proposed regulation. Although federal law places age restrictions on funding for procedures that would result

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stage 2 is a better indication for primary care providers to determine if someone is ready for puberty suppression therapy rather than an age limit.
Neinstein, L. S. (Ed.). (2008). *Adolescent health care: a practical guide* (Vol. 414). Lippincott Williams & Wilkins.

[9] Hembree, Wylie C., et al. "Endocrine treatment of transsexual persons: an Endocrine Society clinical practice guideline." The Journal of Clinical Endocrinology & Metabolism 94.9 (2009): 3132-3154.

[10] Hembree, W. C., Cohen-Kettenis, P., Delemarre-van de Waal, H. A., Gooren, L. J., Meyer III, W. J., Spack, N. P., ... & Montori, V. M. (2009). Endocrine treatment of transsexual persons: an Endocrine Society clinical practice guideline. *The Journal of Clinical Endocrinology & Metabolism*, *94*(9), 3132-3154.

[11] WPATH SOC. V. 7

[12] *Primary Care Protocol for Transgender Patient Care,* Center for Excellence in Transgender Health, University of California, San Francisco, Department of Family and Community Medicine, April 2011, accessed at http://transhealth.ucsf.edu/trans?page=protocol-youth

[13] For example, see the comments being submitted separately by Dr. Carolyn Wolf-Gould.

[14] http://www.sanfranciscosentinel.com/?p=173697

in sterilization, the CMS State Medicaid Manual § 4435 acknowledges that there are circumstances where funding is available for sterilization surgeries that are medically indicated. Surgical treatments for cancers and congenital abnormalities can result in sterilization and still be covered by Medicaid because they are deemed to be a medical necessity. As such, transgender people should also have medically necessary surgeries covered by Medicaid that result in sterilization. While the experience of gender dysphoria is diverse, many transgender people experience the worst gender dysphoria around having genitals incongruent with their gender identities. Patients can work with providers to determine the appropriateness of surgeries resulting in sterilization. The proposed rule already provides significant safeguards -- far beyond nearly all other policies under New York's Medicaid program -- to ensure client protection, informed consent by families and minors and, ultimately, that the best interest of the patient is taken into account.

We propose two possible alternatives to the current age limitation language:

1) Simply refer to medical standards of care and existing statutes, thus allowing for evolution of this rule as standards change and laws follow those changes; or
2) Allow an exception to the age limitation in cases based on a clinician's assessment that without gender affirming surgery, the patient would suffer serious emotional distress including suicidal ideation.

Required documentation

Second, HCFANY recommends changes in the proposed requirements for documentation (i.e. two letters from specified types of clinicians who have independently assessed the individual) in order to receive Medicaid payment for gender affirming surgery. This requirement could be nearly impossible to meet in areas of the state where there is a scarcity of qualified professionals who are competent to treat gender non-conforming individuals and also take Medicaid coverage. As noted previously, transgender individuals are often living below the poverty line and are unlikely to be able to afford to pay out of pocket for consultations with qualified professionals who do not take Medicaid, or to travel to places where there are more available and qualified clinicians. A survey conducted in 2011 shows that 50% of transgender individuals reported having to teach their medical providers about transgender care and 19% reported being refused care altogether, with even higher numbers among people of color in the survey.[15]

Once again, HCFANY recommends DOH refer to nationally recognized standards of care to design more appropriate requirements, in order to ensure timely access to medically

[15] Grant, J. M., Mottet, L., Tanis, J. E., Harrison, J., Herman, J., & Keisling, M. (2011). Injustice at every turn: A report of the National Transgender Discrimination Survey. National Center for Transgender Equality.

necessary care. The Endocrine Society, for example, recommends that the provider overseeing hormone treatment is able to write one of the two referral letters for surgery.[16] In addition, we urge that the list of qualified mental health practitioners be expanded to include licensed clinicians such as licensed clinical social workers or mental health counselors, who may be more available in some areas of the state. The training and experience of these clinicians qualifies them to provide one of the two referral letters. Oregon is an example of a state that has adopted such language in policies for its Medicaid program.[17] Therefore, we urge DOH to replace the proposed regulatory language concerning referral letters with the following:

> *The two referral letters may be from a patient's established primary care provider and a mental health provider who deems the patient capable of providing informed consent for surgery. This mental health practitioner may hold licensed psychiatrist, psychologist, physician, licensed clinical social worker accreditations (LCSW / LMSW under clinical supervision), or licensed mental health counselor (LMHC) accreditations.*

Additionally, the parameters of the required therapeutic relationship with the mental health provider should be clarified. Some mental health providers writing these letters only require one visit to show that the patient is competent to give informed consent, while others require over a year of psychotherapy to verify gender dysphoria. We recommend that mental health practitioners providing surgical clearance be asked to assess only two criteria in order to recommend surgery: 1) Ability of the patient to give informed consent for the desired procedures; and 2) Established prior diagnosis of gender dysphoria.

Many transgender patients require multiple surgeries to align their outward appearance with their gender identities. Clarification should be provided as to whether referral letters are valid for a specific period of time, similar to a prescription, and if different letters are required for each specific surgery. Ideally, one set of letters should serve to qualify a patient for multiple surgeries, regardless of the specific surgical procedures or the provider administering gender affirming surgery.

505.2(l)(3)(i) *Requirement for "persistent" and "well-documented" case of gender dysphoria*

The regulation requires referral letters to document a "persistent" and "well-documented" case of gender dysphoria, but does not explicitly define these terms. This lack of clarity could potentially make it unnecessarily difficult for transgender patients to obtain *medical necessity* clearance. HCFANY recommends the removal of these

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[16] The Endocrine Society: Clinical Guidelines. *Endocrine Treatment of Transsexual Persons: An Endocrine Society Clinical Practice Guideline*. Updated 2009. P. 27:

[17] http://www.basicrights.org/wp-content/uploads/2015/01/OHP-FAQ-for-Individuals_01_05_15.pdf

qualifiers and the substitution of the simple requirement for "a medical diagnosis of gender dysphoria," as documented in the required two letters from licensed health professionals.

505.2(l)(3)(ii) ***Hormone therapy requirement***

HCFANY recommends that this section be taken out entirely. Hormone therapy is not always medically necessary or appropriate to achievement of an individual's gender goals and as such, should not be made a requirement preceding any surgery. For many individuals, preparation for gender affirming surgery may involve the use of hormone therapy, but it is not the universally appropriate.

505.2(l)(3)(iii) ***Requirement for living 12 months in a gender role congruent with the individual's gender identity and receiving mental health counseling***

We recommend that the requirement be that an individual "has lived for 12 months in a gender expression congruent with the individual's personal, preferred gender identity, if deemed appropriate by the individual's primary care provider, and has received gender identity care assessment or mental health counseling, if deemed medically necessary, during that time."

This suggested rewording allows for some discretion on the part of the provider working with the patient because some patients have physical characteristics (such as an individual with large breasts who identifies as male) that leave them unable to live in a gender presentation that is congruent with their gender identity. Please note that our suggested wording changes the phrase "gender role" to "gender expression," following the lead of the Center for Excellence on Transgender Health.[18] People may present or express gender in a variety of ways that may or may not correspond with their gender identity. As with any clinical situation, the need for and desirability of these procedures should be made on an "individual" basis by qualified medical practitioners and their patients.

We note that Medicaid coverage must be provided for such gender identity case assessment or mental health counseling, if it is to be a prerequisite for approval of coverage for surgery.

505.2(l)(4) ***Exclusions***

The proposed regulations related to exclusions are needlessly broad and include services that are medically necessary in some cases. Consequently, HCFANY

[18] Primary Care Protocol for Transgender Patient Care , Center of Excellence for Transgender Health, University of California, San Francisco, Department of Family and Community Medicine, April 2011

recommends the addition of the words "unless medically necessary" to the first sentence of this subsection, so that it reads as follows*:*

Unless medically necessary, payment will not be made for the following services and procedures:

(i) cryopreservation, storage, and thawing of reproductive tissue, and all related services and charges;

(ii) reversal of genital and/or breast surgery;

(iii) reversal of surgery to revise secondary sex characteristics;

(iv) reversal of any procedure resulting in sterilization; and

(v) cosmetic surgery, services, and procedures

505.2(l)(v) ***Exclusion of cosmetic surgery, services, and procedures***

HCFANY further recommends removing the list of specific procedures under the subsection (v) cosmetic surgery, services and procedures. Whether a service is "cosmetic," or a medically-necessary "reconstructive procedure," should be determined based on standards of care and the licensed health professional's assessment of the patient. Currently, the WPATH Standards of Care differentiate between "aesthetic" or cosmetic surgery and "reconstructive" surgery -- where the former is NOT medically necessary and the latter is medically necessary. HCFANY cautions that the inclusion in the rule of such a specific list of excluded services would make it difficult for this regulation to evolve along with ever-changing standards of care and medical technology.

HCFANY is aware that the proposed exclusion of "cosmetic services" may be motivated, in part, by cost concerns. First, it's important to note that coverage of medically necessary services for transgender patients would be used by a tiny portion of the population. In 2010, it was estimated that the cost of covering gender affirming care through Medicaid would only represent 0.003 percent of the total Medicaid budget.[19] Moreover, economic assessments show that use of these services has been found to decrease costs for other services associated with transgender patient. When transgender people have access to transition-related care, there is a decline in negative health outcomes, such as depression, anxiety, suicide, substance use, and self-administered hormone and silicone injections.[20] This is because transition-related care services improve people's health and overall well-being, which leads to other positive factors such as gaining employment, utilizing more primary care services and less emergency care services. This means that Medicaid would be able to save on costs for mental health care, treatment for suicide attempts and costs due to substance use.

[19] Sylvia Rivera Law Project, Eliminating the Medicaid Exclusion for Transition-Related Care in NYS (2011), available at http://srlp.org/files/Health%20Costs%20Final%20Memo.pdf.

[20] California Department of Insurance, "Economic Impact Assessment" (2012), available at http://transgenderlawcenter.org/wp-content/uploads/2013/04/Economic-Impact-Assessment-Gender-Nondiscrimination-In-Health-Insurance.pdf

Non-Transition Related Health Care

We recommend that the DOH additionally reflect the need for insurance coding that is not gender specific. When a person corrects their gender marker on insurance and legal documents, it often interferes with their insurance coverage. For example, if a person who was assigned male at birth corrects their gender marker to reflect their female identity, their insurance may not cover prostate exams, even though the patient still needs this care. The lack of coverage is related to gender-specific coding discrepancies that cause problems with insurance billing. Some other examples of health care that may not be covered when there are discrepancies between the individual's gender marker and the gender-specific coding for procedures include: Pap smears, mammograms, prenatal and maternity care and abortion services.

Thank you for working to remove discriminatory Medicaid coverage provisions that have prevented transgender New Yorkers from receiving medically-necessary care. HCFANY appreciates the opportunity to submit these comments on behalf of the LGBT Task Force of Health Care for All NY. Should you have any questions about our comments, please contact Lois Uttley, Co-Chair of the HCFANY LGBT Task Force, at 212.870.2010 or lois@mergerwatch.org.

Sincerely,

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