

June 24, 2019

Theresa Eagleson  
Director  
Illinois Department of Healthcare and Family Services  
Prescott Bloom Building  
201 South Grand Avenue  
East Springfield, Illinois 62763  
[HFS.Rules@illinois.gov](mailto:HFS.Rules@illinois.gov)

**Re: Public Comment on Proposed Regulations Addressing Illinois Medicaid Coverage for Surgical Treatment of Gender Dysphoria**

Dear Director Eagleson,

On behalf of the AIDS Foundation of Chicago, we commend Governor Pritzker and his administration's commitment to supporting the LGBTQ community. AFC's mission is to mobilize communities to create equity and justice for people living with and vulnerable to HIV or chronic conditions. A key component to achieving our mission is ensuring equitable access to gender-affirming medical care for the treatment of gender dysphoria. We applaud the Illinois Department of Healthcare and Family Services' ("IDHFS") decision to remove the discriminatory prohibition on Medicaid coverage for surgical treatment of gender dysphoria.<sup>1</sup> We also recognize that Illinois has an opportunity to become a model for the rest of the country and to demonstrate its commitment to ensuring equitable access to medical care for all Illinoisans.

Nevertheless, we are concerned that the proposed regulations contradict current medical standards for treatment of gender dysphoria and would result in many transgender individuals<sup>2</sup> being prevented from accessing lifesaving medical care. We wish to thank you for taking time on June 13, 2019 to hear our concerns about the proposed regulations. Additionally, we appreciate your consideration of our previous correspondence on this matter, including most recently on December 21, 2018 and February 4, 2019. We write now to provide a more detailed account of our concerns, as well as to offer recommendations to ensure Illinois Medicaid meets the healthcare needs of transgender people.

**Illinois Lags Behind**

If Illinois wishes to cement its legacy as the most affirming state in the country for LGBTQ individuals, the proposed regulations must be revised to provide adequate coverage for treatment of gender dysphoria. To date, 17 other state Medicaid programs and the District of Columbia have affirmative coverage policies for treatment of gender dysphoria, acknowledging the critical importance of

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<sup>1</sup> Illinois Administrative Code Title 89, § 140.412(e), which prohibits Medicaid coverage for "transsexual surgery."

<sup>2</sup> References to transgender individuals are inclusive of individuals who are non-binary, gender non-conforming, agender, or genderqueer.

providing this care. States such as Colorado, Minnesota, Montana, New Jersey, Nevada, Montana, and Pennsylvania have voluntarily removed exclusions for the treatment of gender dysphoria and adopted affirmative coverage protocols. Other states have faced successful legal challenges to their Medicaid exclusions, with courts in Iowa, Wisconsin, New York, and Minnesota finding blanket or procedure-specific exclusions to violate state and federal law.<sup>3</sup>

### **Surgical Treatment of Gender Dysphoria Promotes Public Health and is Cost Effective**

Medicaid coverage for surgical treatment of gender dysphoria promotes public health and has been shown to be cost effective. As an initial matter, the number of individuals seeking surgical treatment for gender dysphoria in Illinois is extremely low. Approximately 0.51% of Illinoisans identify as transgender.<sup>4</sup> Of that limited pool of individuals, only a small portion are both Medicaid-eligible and require surgery to treat a diagnosis of gender dysphoria.

The medical and scientific communities concur that access to medically necessary transition-related care improves the health and wellbeing of transgender individuals.<sup>5</sup> In turn, this leads to significant reductions in negative health outcomes associated with untreated gender dysphoria such as depression, anxiety, suicidality, substance abuse, and unsupervised self-administration of hormone injections.<sup>7</sup> Transgender people living with HIV are also more likely to adhere to HIV treatment regimens

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<sup>3</sup> See, e.g., *Good v. Iowa Dept. of Human Servs.*, 924 N.W.2d 853 (Iowa 2019) (finding that the regulation excluding Medicaid coverage of surgical treatment for gender dysphoria violated state laws); *Flack v. Wis. Dept. of Health Servs.*, 328 F.Supp.3d 931 (W.D. Wisc. 2018) (granting a preliminary injunction enjoining the state from excluding Medicaid coverage of surgical treatment for gender dysphoria); *Outfront Minn. v. Johnson Piper*, No. 62-CV-15-7501 (Minn. Dist. Ct. 2nd Dist. Nov. 14, 2016) (order permanently enjoining the Minnesota Department of Human Services from excluding transition-related care from Medicaid coverage).

<sup>4</sup> FLORES ET AL., THE WILLIAMS INSTITUTE, HOW MANY ADULTS IDENTIFY AS TRANSGENDER IN THE UNITED STATES 3 (June 2016), available at <https://williamsinstitute.law.ucla.edu/wp-content/uploads/How-Many-Adults-Identify-as-Transgender-in-the-United-States.pdf>.

<sup>5</sup> See, e.g., American Medical Association (2008) Resolution 122 (A-08); Endocrine Treatment of Transsexual Persons: An Endocrine Society Clinical Practice Guideline (2009); American Psychological Association Policy Statement on Transgender, Gender Identity and Gender Expression Nondiscrimination (2009).

<sup>6</sup> See, e.g., AM. MED. ASS'N, HEALTH INSURANCE COVERAGE FOR GENDER-AFFIRMING CARE OF TRANSGENDER PATIENTS 3-4 (2019); Cornell Univ., Public Policy Research Portal, *What does the scholarly research say about the effect of gender transition on transgender well-being?*, available at <https://whatwewknow.inequality.cornell.edu/topics/lgbt-equality/what-does-the-scholarly-research-say-about-the-well-being-of-transgender-people/>.

<sup>7</sup> See, e.g., William Byne et al., *Report of the American Psychiatric Association Task Force on Treatment of Gender Identity Disorder*, 41 ARCHIVES OF SEXUAL BEHAVIOR 759 (2012); Marco Colizzi, Rosalia Costa & Orlando Todarello, *Transsexual Patients' Psychiatric Comorbidity and Positive Effect of Cross-Sex Hormonal Treatment on Mental Health: Results from a Longitudinal Study*, 39 PSYCHONEUROENDOCRINOLOGY 65 (2014); Audrey Gorin-Lazard et al., *Hormonal Therapy is Associated with Better Self-Esteem, Mood, and Quality of Life in Transsexuals*, 201 J. Nervous & Mental Disorders 996 (2013); M. Hussan Murad et al., *Hormonal Therapy and Sex Reassignment: A Systematic Review and Meta-Analysis of Quality of Life and Psychosocial Outcomes*, 72 CLINICAL ENDOCRINOLOGY, 214 (2010); Griet De Cuypere et al., *Sexual and Physical Health After Sex Reassignment Surgery*, 34 ARCHIVES OF SEXUAL BEHAVIOR 679 (2005); Giulio Garaffa, Nim A. Christopher & David J. Ralph, *Total Phallic Reconstruction in Female-to-Male Transsexuals*, 57 EUROPEAN UROLOGY 715 (2010); Caroline Klein & Boris B. Gorzalka, *Sexual Functioning in Transsexuals Following Hormone Therapy and Genital Surgery: A Review*, 6 J. OF SEXUAL MEDICINE 2922 (2009).

when they are receiving appropriate transition-related care.<sup>8</sup> Reducing access to surgical treatment of gender dysphoria by excluding certain procedures from coverage often results in collateral conditions that come with additional long-term costs and burdens on the Medicaid program.

It is therefore unsurprising that studies of public and private health plans have found that providing coverage for transition-related care does not impose significant costs, and can lead to *cost savings* in the long term. For example, the California Department of Insurance’s Economic Impact Assessment of its 2012 rule prohibiting insurance discrimination against transgender people concluded that “any such costs are immaterial and insignificant,” and that eliminating transgender exclusions could create cost savings, including “lower costs associated with the high cost of suicide and attempts at suicide, overall improvements in mental health and lower rates of substance abuse.”<sup>9</sup> The removal of transgender exclusions from the Massachusetts Group Insurance Commission was found to be highly cost-effective, with a budget impact of \$0.016 per member per month that was offset by a reduction in negative health outcomes, such as HIV infection, depression, and suicidality.<sup>10</sup> Other public and private employers similarly reported zero or very low costs in providing this medically necessary care.<sup>11</sup>

### **Surgical Treatment of Gender Dysphoria is Medically Necessary Healthcare**

Gender identity is a well-established medical concept, referring to an individual’s internal sense of oneself as belonging to a particular gender. At birth, infants are typically classified as either male or female, based on an examination of the infant’s external physical characteristics. Often, individuals assigned male at birth later identify as boys or men and individuals assigned female at birth later identify as girls or women. However, transgender individuals identify differently than the gender they were assigned at birth. This incongruence can result in gender dysphoria, which is a serious medical condition characterized by a clinically significant and persistent feeling of stress or discomfort with one’s assigned

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<sup>8</sup> See K. Clements-Nolle, R. Marx, R. Guzman, M. Katz, *HIV Prevalence, Risk Behaviors, Health Care Use, and Mental Health Status of Transgender Persons: Implications for Public Health Intervention*, 91 AM. J. PUB. HEALTH 915 (2001).

<sup>9</sup> Cal. Dep’t of Ins., *Economic Impact Assessment: Gender Nondiscrimination in Health Insurance* (2012), available at <http://transgenderlawcenter.org/wp-content/uploads/2013/04/Economic-Impact-Assessment-Gender-Nondiscrimination-In-Health-Insurance.pdf>.

<sup>10</sup> William V. Padula et al., “Societal Implications of Health Insurance Coverage for Medically Necessary Services in the U.S. Transgender Population: A Cost-Effectiveness Analysis,” 31 J. GEN. INTERNAL MED. 394 (2015).

<sup>11</sup> For example, the Human Rights Campaign’s Corporate Equality Index reports that for the 750 employers who did so, eliminating exclusions “comes at an overall negligible cost to the employers’ overall health insurance plans. This holds true across industries.” Human Rights Campaign, *Corporate Equality Index 2018: Rating Workplaces on Lesbian, Gay, Bisexual, Transgender, and Queer Equality* 28 (2018); Similarly, the Wisconsin Department of Employee Trust Funds estimated costs of removing a similar exclusion to be between 0.007% and 0.018% of the \$1.3 billion in state health plan premiums. State of Wisconsin, Department of Employee Trust Funds, *Correspondence Memorandum* (August 14, 2018), <http://etf.wi.gov/boards/agenda-items-2018/gib0822/item6a1.pdf>; State of Wisconsin, Department of Employee Trust Funds, *Correspondence Memorandum* (January 30, 2017), <http://etf.wi.gov/boards/agenda-items-2017/gib0208/item4.pdf>. See also Jody L. Herman, *Costs and Benefits of Providing Transition-Related Health Care Coverage in Employee Health Benefit Plans: Findings from a Survey of Employers*, (2013), available at: <http://williamsinstitute.law.ucla.edu/wp-content/uploads/Herman-Cost-Benefit-of-Trans-Health-Benefits-Sept-2013.pdf>; San Francisco Human Rights Comm’n, *San Francisco City and County Transgender Health Benefit* (Aug. 2007), available at [http://www.hrc.org/files/assets/resources/San\\_Francisco\\_City\\_and\\_County\\_Transgender\\_Health\\_Benefit\\_-\\_2007-08-10.pdf](http://www.hrc.org/files/assets/resources/San_Francisco_City_and_County_Transgender_Health_Benefit_-_2007-08-10.pdf).

gender.<sup>12</sup> Gender dysphoria can be alleviated through medical treatment, including surgical procedures to bring an individual's physical body into alignment with the person's gender identity.

Medical and scientific consensus is clear that transition-related treatments, including surgical procedures, are medically necessary, effective, and safe when clinically indicated to alleviate gender dysphoria. Indeed, major medical associations in the United States support public and private insurance coverage for medically necessary transition-related care, and oppose exclusions of gender dysphoria treatment.<sup>13</sup> According to the American Medical Association, untreated gender dysphoria "can result in clinically significant psychological distress, dysfunction, debilitating depression and, for some people without access to appropriate medical care and treatment, suicidality and death."<sup>14</sup> Numerous studies and meta-analyses, including a recent comprehensive literature review on the issue,<sup>15</sup> have similarly demonstrated the significant benefits of transition-related care in the treatment of gender dysphoria.<sup>16</sup> As such, treatments for this condition cannot be considered "cosmetic" or "experimental."

Recognizing this, the Medicare program rescinded its 30-year exclusion of transition-related surgical care in 2014 after concluding that gender confirmation surgery "is safe and effective and not experimental," "has gained broad acceptance in the medical community," and "is an effective treatment option."<sup>17</sup> Following the removal of the exclusion, the Medicare Appeals Council issued a decision in favor of covering transition-related surgery when medically necessary.<sup>18</sup> Similarly, the U.S. Office of Personnel

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<sup>12</sup> AM. PSYCHIATRIC ASS'N, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS 452 (5th ed., 2013).

<sup>13</sup> See, e.g., Am. Academy of Fam. Physicians, Resolution No. 1004 (2012); Am. Medical Assn., Resolution 122 (A-08), Removing Financial Barriers to Care for Transgender Patients (2008); Am. Psychiatric Assn., Position Statement: Access to Care for Transgender and Gender Variant Individuals (2012); Am. Psychological Assn., Policy on Transgender, Gender Identity & Gender Expression Non-Discrimination (2008); Am. College of Physicians, Lesbian, Gay, Bisexual, and Transgender Health Disparities: A Policy Position Paper, 163 ANN INTERN MED. 135-137 (2015); Am. Coll. of Obstetricians & Gynecologists, Committee Op. 512, 118 OBSTETRICS & GYNECOLOGY 1454 (2011); National Assn. of Social Workers, Transgender and Gender Identity Issues Policy Statement (2008).

<sup>14</sup> Am. Med. Ass'n House of Delegates, *Removing Financial Barriers to Care for Transgender Patients* (2008).

<sup>15</sup> Cornell University, Public Policy Research Portal, *What does the scholarly research say about the effect of gender transition on transgender well-being?*, <https://whatwewknow.inequality.cornell.edu/topics/lgbt-equality/what-does-the-scholarly-research-say-about-the-well-being-of-transgender-people/>

<sup>16</sup> William Byne et al., *Report of the American Psychiatric Association Task Force on Treatment of Gender Identity Disorder*, 41 ARCHIVES OF SEXUAL BEHAVIOR 759 (2012); Marco Colizzi, Rosalia Costa & Orlando Todarello, *Transsexual Patients' Psychiatric Comorbidity and Positive Effect of Cross-Sex Hormonal Treatment on Mental Health: Results from a Longitudinal Study*, 39 PSYCHONEUROENDOCRINOLOGY 65 (2014); Audrey Gorin-Lazard et al., *Hormonal Therapy is Associated with Better Self-Esteem, Mood, and Quality of Life in Transsexuals*, 201 J. Nervous & Mental Disorders 996 (2013); M. Hussan Murad et al., *Hormonal Therapy and Sex Reassignment: A Systematic Review and Meta-Analysis of Quality of Life and Psychosocial Outcomes*, 72 CLINICAL ENDOCRINOLOGY, 214 (2010); Griet De Cuypere et al., *Sexual and Physical Health After Sex Reassignment Surgery*, 34 ARCHIVES OF SEXUAL BEHAVIOR 679 (2005); Giulio Garaffa, Nim A. Christopher & David J. Ralph, *Total Phallic Reconstruction in Female-to-Male Transsexuals*, 57 EUROPEAN UROLOGY 715 (2010); Caroline Klein & Boris B. Gorzalka, *Sexual Functioning in Transsexuals Following Hormone Therapy and Genital Surgery: A Review*, 6 J. OF SEXUAL MEDICINE 2922 (2009).

<sup>17</sup> Departmental Appeals Board, *NCD 140.3, Transsexual Surgery*, Decision No. 2576 (2014), available at: <http://www.hhs.gov/dab/decisions/dabdecisions/dab2576.pdf>.

<sup>18</sup> Dep't of Health and Human Services, *NCD 140.3, Transsexual Surgery*, 12 (2014); HHS Department Appeals Board, *Decision of Medicare Appeals Council, Docket Number M-15-1069, United Healthcare/AARP* (January 21, 2016)

Management-directed Federal Employee Health Benefit eliminated its blanket exclusions for transition-related care in 2015.<sup>19</sup>

State and federal regulatory action and legal developments, coupled with advocacy from the medical community have led other private and public health insurance plans to eliminate discriminatory transgender exclusions. A study by Out2Enroll of over 600 plans being sold in the individual marketplace in 2019 in 36 states found that 94% of Marketplace plans did not have an exclusion on transition-related care. Nearly half of all plans (41%) had affirmative coverage protocols for treatment of gender dysphoria, up from 18.5% in 2017.<sup>20</sup> To date, 19 states and the District of Columbia have taken action to clarify nondiscrimination protections in private insurance for transgender consumers,<sup>21</sup> and 18 states and the District of Columbia have adopted affirmative coverage standards for transition-related care to help ensure that their Medicaid programs do not discriminate against transgender beneficiaries.<sup>22</sup>

### **Proposed Sections 140.413(a)(16)(A) – (E) Contradict the WPATH Standards of Care**

The World Professional Association of Transgender Health Standards of Care for the Health of Transsexual, Transgender and Gender-Nonconforming People (“Standards of Care”) is internationally recognized as the authoritative guide for treatment of individuals with gender dysphoria. The Standards of Care are authored by the World Professional Association for Transgender Health (“WPATH”), a global association of 2,000 medical and mental health professionals worldwide specializing in the treatment of gender diverse people.<sup>23</sup> The American Medical Association, the Endocrine Society, the American Psychological Association, the American Psychiatric Association, the World Health Organization, the American Academy of Family Physicians, the American Public Health Association, the National Association of Social Workers, the American College of Obstetrics and Gynecology and the American Society of Plastic Surgeons all endorse protocols in accordance with the WPATH Standards of Care.<sup>24</sup>

In 2016, WPATH issued a statement that transition-related care is medically necessary and should be covered by both public and private health insurance plans. In particular, WPATH stated that gender affirming surgeries, including non-genital surgeries such as facial feminization surgery, are not in any way

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<sup>19</sup> FEHB Program Carrier Letter No. 2015-12, Covered Benefits for Gender Transition Services, (June 24, 2015).

<sup>20</sup> Out2Enroll, *Summary of Findings: 2019 Marketplace Plan Compliance with Section 1557* (2017), <https://out2enroll.org/out2enroll/wp-content/uploads/2018/11/Report-on-Trans-Exclusions-in-2019-Marketplace-Plans.pdf>

<sup>21</sup> These states include California, Colorado, Connecticut, Delaware, the District of Columbia, Hawaii, Illinois, Maryland, Massachusetts, Minnesota, Montana, Nevada, New Jersey, New Mexico, New York, Oregon, Pennsylvania, Rhode Island, Vermont, and Washington.

<sup>22</sup> These states include California, Colorado, Connecticut, the District of Columbia, Hawaii, Maryland, Massachusetts, Minnesota, Michigan, Montana, Nevada, New Hampshire, New Jersey, New Mexico, New York, Oregon, Pennsylvania, Rhode Island, Vermont, and Washington.

<sup>23</sup> World Prof. Ass’n for Transgender Health, *Standards of Care for the Health of Transsexual, Transgender, and Gender Nonconforming People* 16 (7th ed. 2011), <https://www.wpath.org/publications/soc>.

<sup>24</sup> See, e.g.: World Prof. Ass’n for Transgender Health, *Position Statement on Medical Necessity of Treatment, Sex Reassignment, and Insurance Coverage in the U.S.A.* (21 December 2016), <https://www.wpath.org/media/cms/Documents/Web%20Transfer/Policies/WPATH-Position-on-Medical-Necessity-12-21-2016.pdf>.

“cosmetic”, “elective” or “for the mere convenience of the patient.” According to WPATH, these types of reconstructive procedures “are not optional in any meaningful sense, but are understood to be medically necessary for the treatment of the diagnosed condition.”<sup>25</sup>

Several provisions of the proposed regulations contradict WPATH’s statement and the Standards of Care, and will likely be even further outdated when the newest edition of the Standards of Care is released next year. We strongly urge IDHFS to review the Standards of Care and ensure that the finalized regulations consider the medical authority of WPATH. We outline the most important diversions from the WPATH Standards of Care below.

### Required Letters of Support

Section 140.413(a)(16)(A)(i) requires two letters of support from qualified medical providers before prior approval for transition-related surgery will be granted. This provision should be amended to conform with the WPATH Standards of Care, which recommends two such letters for genital surgery, but only one such letter for breast or chest surgery. We are in support of the proposed regulations’ requirements regarding the content of the referral letters, with a two exceptions that are detailed below.

First, the proposed requirement that an individual seeking prior approval for any genital surgery must complete “12 consecutive months with a consistent gender identity,” contradicts the Standards of Care. WPATH recommends that individuals have lived in a gender role congruent with their gender identity for 12 continuous months prior to *metoidioplasty*, *phalloplasty*, or *vaginoplasty*. This requirement is *not required* for any other procedures such as hysterectomy, salpingo-oophorectomy, or orchiectomy.

Second, the proposed requirement that an individual have “no other significant medical or mental health conditions that would be a contraindication to the gender-affirming surgery, service or procedure, or if so, that those are reasonably well-controlled” also contradicts the Standards of Care to the extent it would bar individuals with co-existing mental health conditions from receiving necessary medical care. The Standards of Care only require that surgery not be performed when a patient is actively psychotic (or otherwise unable to provide informed consent). Depression and anxiety are commonly associated with untreated gender dysphoria and should never serve as a barrier to gender-affirming surgeries. The current language regarding “contraindications” or, indeed, “reasonably well-controlled” is vague and could create confusion and unnecessary barriers to healthcare.

### Procedures Excluded as “Purely Cosmetic”

Section 140.413(a)(16)(B) states that gender-affirming surgeries, services, and procedures that are not “purely cosmetic” shall be covered by Illinois Medicaid. The provision proceeds to list about one dozen “cosmetic” procedures and excludes them from coverage. Excluding these listed procedures from

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<sup>25</sup> World Prof. Ass’n for Transgender Health, *Position Statement on Medical Necessity of Treatment, Sex Reassignment, and Insurance Coverage in the U.S.A.* (21 December 2016), <https://www.wpath.org/media/cms/Documents/Web%20Transfer/Policies/WPATH-Position-on-Medical-Necessity-12-21-2016.pdf>.

coverage contradicts current medical practices, the WPATH Standards of Care, as well as state and federal law.

As written, the proposed regulations would prevent medical providers from being able to exercise their professional discretion when treating patients, and would deprive patients of access to necessary medical care. Determinations of medical necessity should be made by a medical professional with professional expertise in treating gender dysphoria who has *actually examined* the individual seeking treatment. Rather than creating a list of surgeries, services, and procedures excluded from coverage, the regulations should state that “the Department will cover all gender-affirming surgeries, services, and procedures that are necessary medical care. Gender-affirming surgeries, services and procedures shall include, but are not limited to, breast/chest reconstruction, genital surgeries, and other medically necessary reconstructive surgeries.”

Ultimately, a provision expressly excluding “purely cosmetic” surgeries from Medicaid coverage is not necessary to ensure that individuals do not receive coverage for medically unnecessary procedures. If an individual were to seek Medicare coverage for a cosmetic procedure that was wholly unrelated to gender dysphoria or another medical diagnosis, they would simply be unable to meet the stringent requirements set forth in section 140.413(a)(16)(A).

From a medical standpoint, no procedure is inherently cosmetic or reconstructive – that distinction depends on the purpose for which the procedure is conducted. For example a breast augmentation may be an elective cosmetic procedure for one individual, but that same procedure would be medically necessary reconstructive surgery for another individual – for example, someone who underwent a mastectomy to prevent or treat breast cancer or, indeed, a transgender individual for whom hormone therapy or other treatment is insufficient to treat their gender dysphoria. Additionally, many of the non-covered surgeries deemed to be cosmetic are in fact extremely common treatment for gender dysphoria, with “tracheal shave” (reduction thyroid chondroplasty), electrolysis or laser hair removal of facial hair or in preparation for vaginoplasty or phalloplasty, and other facial feminization surgeries being especially typical.

The WPATH Standards of Care are clear that gender-affirming surgeries such as breast augmentation or facial feminization surgeries should not be considered “cosmetic” when medically necessary to treat gender dysphoria. According to the Standards of Care, medically necessary reconstructive procedures include procedures such as “nipple resizing or placement of breast prostheses, facial hair removal, certain facial plastic reconstruction, and voice therapy and/or surgery”, as deemed medically necessary to treat gender dysphoria in each individual patient. Indeed, surgical intervention such as facial feminization surgery “are often of greater practical significance in the patient’s daily life than reconstruction of the genitals.”<sup>26</sup>

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<sup>26</sup> World Prof. Ass’n for Transgender Health, *Position Statement on Medical Necessity of Treatment, Sex Reassignment, and Insurance Coverage in the U.S.A.* (21 December 2016), <https://www.wpath.org/media/cms/Documents/Web%20Transfer/Policies/WPATH-Position-on-Medical-Necessity-12-21-2016.pdf>.

A blanket exclusion of coverage for specific procedures in the regulation—without taking into account individual medical necessity—would also violate federal law. Federal courts have found that under the Medicaid Act and Affordable Care Act state Medicaid programs must ensure access to medically necessary care for gender dysphoria treatment. For example, a federal court last year held that Wisconsin Medicaid’s exclusion of coverage for transition-related care violated Section 1557 of the Affordable Care Act.<sup>27</sup>

Similarly, New York was required to amend its Medicaid regulations<sup>28</sup> to remove its list of non-covered excluded gender affirming services after a federal court found that having blanket exclusions of *specific procedures* for gender dysphoria treatment violated the Medicaid Act’s availability and comparability provisions.<sup>29</sup> Oregon<sup>30</sup> and Connecticut<sup>31</sup> similarly removed their lists of non-covered services after revisions to their Medicaid program coverage guidelines. More recently, the state of Wisconsin had to pay \$780,500 in damages for two transgender state employees for denying coverage of medically necessary care, including facial feminization surgery. Only around \$80,000 of the total award was related to out-of-pocket costs of the procedures, with the rest constituting compensation for mental and emotional suffering.<sup>32</sup>

We urge IDHFS to remove the provision excluding certain procedures from coverage, and instead make clear that Illinois Medicaid will cover medically necessary procedures. We recommend that IDHFS consider the following language from the New York Medicaid regulations:

“For individuals meeting the requirements of [medical necessity as outlined in this rule for], surgeries, services, and procedures in connection with gender [affirming care] not specified [in this rule], or to be performed in situations other than those described [in this rule], including those done to change the patient’s physical appearance to more closely conform secondary sex characteristics to those of the patient’s identified gender, shall be covered if it is demonstrated that such surgery, service, or procedure is medically necessary to treat a particular patient’s gender dysphoria, and prior approval is received. Coverage is not available for surgeries, services, or procedures that are purely cosmetic, i.e., that enhance a patient’s appearance but are not medically necessary to treat the patient’s underlying gender dysphoria.”

#### Coverage Excluded for Individuals Under 21 Years of Age

Section 140.413(a)(16)(A) states that “[g]ender-affirming surgeries, services and procedures are covered only with prior approval by the Department for individuals who are 21 years of age or older.” The

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<sup>27</sup> *Flack v. Wis. Dept. of Health Servs.*, 328 F.Supp.3d 931 (W.D. Wisc. 2018).

<sup>28</sup> New York Codes, Rules and Regulations. Volume C (Title 18), SubChapter E, Article 3, Section 505.2.

<sup>29</sup> *Cruz v. Zucker*, 195 F.Supp.3d 554 (S.D.N.Y. 2016)

<sup>30</sup> Oregon Medicaid. Prioritized List of Health Services. Guideline Note 127 (October 1, 2019).

<sup>31</sup> Husky Health Connecticut. Provider Policies & Procedures. Gender Affirmation Surgery (updated February 2019).

<sup>32</sup> *Boyden v. Conlin* 341 F. Supp. 3d 979 (W.D. Wis. 2018); Think Progress. *Transgender women celebrate monumental court win* (October 30, 2018), <https://thinkprogress.org/wisconsin-transgender-women-health-care-court-victory-e5ca758264b4/>



regulations should clearly state that individuals under the age of 21 are entitled to coverage for hormonal, mental health and surgical treatment of gender dysphoria under the Early and Periodic Screening, Diagnostic, and Treatment (“EPSDT”) benefit. We urge the Department to include language in the regulation explicitly stating that medically necessary gender affirming services will be covered under EPSDT. For example, the Department could use language similar to the State of Washington’s Medicaid program,<sup>33</sup> which states: “If gender dysphoria treatment is requested or prescribed for clients age 20 and younger under the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program, the agency evaluates it as a covered service under the EPSDT program’s requirement that the service is medically necessary, safe, effective, and not experimental.”

To the extent this provision is intended to limit access to only individuals over the age of 21, it would be plainly in contradiction of current medical practice and the WPATH Standards of Care. The WPATH Standards of Care recognize the importance of allowing practitioners to exercise professional discretion and consider individual circumstances, including the age, maturity, and condition of each patient. Surgical procedures, particularly mastectomies, are routinely considered medically necessary for teenagers. For many young adults, it is essential to be able to move on to college, the workforce, or the next phase of their life in a body that conforms to their gender identity. For this reason, the Standards of Care do not impose a firm age minimum and instead allow for medical professionals to make decisions based on their own medical expertise and clinical evaluation of the patient.

#### *Minimum Requirements for Medical Professionals*

Section 140.413(a)(16)(C) requires that genital surgeries “be performed by a urologist, gynecologist, or plastic or general surgeon who is board-certified in the practitioner’s area of expertise and has demonstrated specialized competence in gender-based genital reconstruction as indicated by documented supervised training or post-graduate training in the field of gender-based genital reconstruction.” We commend IDHFS’s effort to ensure that individuals receive treatment from competent and qualified medical professionals. We support the inclusion of this provision to the extent the criteria for determining competence is reasonable and the process for making such a determination does not cause burdensome delays or barriers to healthcare.

#### *Additional Requirements for Surgeries Resulting in Sterilization*

Section 140.413(a)(16)(D) provides that all surgeries resulting in sterilization must meet the requirements of section 140.413(a)(2), which distinguishes between “therapeutic sterilization” and “nontherapeutic sterilization.” We do not oppose the inclusion of this provision, but only on the condition that gender-affirming genital surgeries resulting in sterilization are considered to be “therapeutic sterilization.” This classification is appropriate because these procedures are necessary medical care for many individuals and thus “a necessary part of the treatment of an existing illness” (i.e. gender dysphoria).

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<sup>33</sup> Washington Apple Health. *Physician-Related Services/Health Care Professional Services Billing Guide* (April 15, 2018). <https://www.hca.wa.gov/assets/billers-and-providers/physician-related-serv-bi-20180415.pdf>

It is not appropriate to classify gender-affirming genital surgeries as “nontherapeutic sterilization,” and the additional requirements described in this provision would cause the proposed regulations to contradict the Standards of Care. Requiring patients with gender dysphoria for whom genital surgery or surgeries are medically necessary to wait until age 21 is not recommended practice under the WPATH standards and would not correspond with current medical practice. As discussed above, a minimum age requirement of 21 years would cause severe and irreparable harm to many individuals.

### Coverage for “Reversal” Surgeries

Section 140.413(a)(16)(E), which states that IDHFS will not cover “the reversal of gender-affirming surgeries, services, and procedures,” should be removed. This provision gives credence to the harmful myth that transgender people are merely “deluded” or are “unable to make up their minds” about their own identity. In reality, it is extremely rare for an individual to seek reversal of gender-affirming surgeries. The safeguards outlined in the Standards of Care – including requiring a formal diagnosis of gender dysphoria, the recommendation of a qualified medical professional – as well as the extraordinary physical burden are sufficient to minimize later regret. In the exceptional and extreme circumstances where individuals might require a reversal, failure to provide coverage would be likely to cause severe harm to the individual.

Furthermore, this provision could be misinterpreted to bar coverage for procedures related to revisions, complications, non-healing, or suboptimal outcomes from a previous gender-affirming surgery. Failure to provide coverage in these scenarios would be unethical and likely to cause severe physical and emotional harm.

### Conclusion

While we applaud Governor Pritzker and his administration’s vocal support for the LGBTQ community and commitment to eliminating the current exclusion of gender-affirming surgeries from Illinois Medicaid coverage, we share serious concerns about the proposed regulations in their current form. We strongly urge IDHFS to reconsider the provisions that conflict with current medical practice and the WPATH Standards of Care as described above. Please advise us if any additional information or documentation would be helpful for IDHFS to consider.

Sincerely,

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