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# TESTIMONY from the SYLVIA RIVERA LAW PROJECT

Public Hearing on Healthcare in New York correctional facilities

Monday, October 30, 2017 11:00 A.M.

# Respectfully Submitted by:

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# Basis for Comments and Recommendations from the Sylvia Rivera Law Project

The Sylvia Rivera Law Project (SRLP) works with transgender, gender non-conforming, and intersex (TGNCI) people who are of color or low-income. We offer services to people in the New York City area, including those held by the New York City Department of Correction, and people incarcerated by New York State in the Department of Corrections and Community Supervision (DOCCS). We provide TGNCI people with direct legal services on a variety of civil issues including assistance in obtaining correct and consistent healthcare.

We are delighted to be joined by so many individuals and organizations who we know are providing excellent services across the state. As there is so much knowledge in this room, we will be sticking to the issues of healthcare as they specifically concern transgender and gender non-conforming (TGNC) people in the NYS DOCCS context. We want to acknowledge that the experience of accessing healthcare within DOCCS is universally horrific. It affects TGNC people in particularly ways, but there is no one who benefits from the current system. People who are incarcerated suffer, and those of us who love people on the inside and try to assist them in their return home, suffer as well.

### **TGNC Healthcare in the DOCCS System**

Before we discuss healthcare specific to TGNC people, it is important to note that this is a complex area. It is difficult to contain a subject that people have written books, made films, held international conferences on, into a ten minute speech. Historically, our identities have been tied to a diagnosis found in the DSM – the Diagnostic and Statistical Manual of Mental Disorders – a handbook that provides mental health professionals with guidelines for diagnosis. For people both in prison and the free world, a diagnosis of "gender dysphoria" (GD) is key to accessing all medical needs. ¹ This is an incredibly charged process. Research from mental health professionals shows that TGNC individuals who aren't able to access the competent care they need suffer greatly.² We have higher risks of suicide, self-harm, depression, anxiety, and drug and alcohol use than our peers.³ Yet, the diagnosis also medicalizes our identities and places our fate – whether we are able to live

<sup>3</sup> See generally Grant, J., et al. *Injustice at every turn: a report of the transgender discrimination survey.*Washington, DC: National Center for Transgender Equality and National Gay and Lesbian Task Force, 2011

<sup>&</sup>lt;sup>1</sup> The American Psychiatric Association has an excellent explanatory webpage on the history of these diagnoses. *What is Gender Dysphoria?* Reviewed by Ranna Parekh, M.D., M.P.H., February 2016 https://www.psychiatry.org/patients-families/gender-dysphoria/what-is-gender-dysphoria

<sup>&</sup>lt;sup>2</sup> There is extensive research on this issue. Some excellent introductory writings include: Grant, J., et al. *Injustice at every turn: a report of the transgender discrimination survey.* Washington, DC: National Center for Transgender Equality and National Gay and Lesbian Task Force, 2011; Kenagy, G. P. "Transgender health: Findings from two needs assessment studies in Philadelphia." *Health & Social work* 30.1 (2005); and Nuttbrock, L., Hwahng, S., Bockting, W., Rosenblum, A., Mason, M., Macri, M., & Becker, J. Psychiatric impact of gender-related abuse across the life course of male-to-female transgender persons." *Journal of Sex Research* 47.1 (2010). Many position statements from health care organizations affirm this research as well. *See generally* Endocrine Society, Position Statement on Transgender Health, September 2017 <a href="https://www.endocrine.org/-/media/endosociety/files/advocacy-and-outreach/position-statements/2017/position\_statement\_transgender\_health.pdf?la=en.">https://www.endocrine.org/-/media/endosociety/files/advocacy-and-outreach/position-statements/2017/position\_statement\_transgender\_health.pdf?la=en.</a>

as our true selves – in the hands of medical authorities instead of our own. We want to hold this difficult balance as we go forward with our testimony.

For TGNC people in the NYS prison system, there is a health services policy memo – HSPM 1.31 – which governs how individuals access a GD diagnosis and the rights that come with it.<sup>4</sup> In reality, this governance is never adhered to. The majority of the advocacy SRLP does for TGNC healthcare is enforcing this directive across the 54 prisons. On a daily basis, we hear from individuals whose identity and subsequent healthcare needs are not taken seriously.

To illustrate this point, for the past five years, NYS DOCCS has contracted with only one doctor to supply the necessary GD diagnosis. This doctor is based in Buffalo and insists on face-to-face interviews. For our clients in the Hudson valley or Canadian-border region, this means a two-day trip one-way. The average wait to see this doctor is six months and the primary reason given is the difficulty in scheduling appointments. This is easily solvable by contracting with other local doctors. Most major areas have mental health practitioners able to make a GD diagnosis; there is no excuse as to why DOCCS contracts with only one doctor.

In addition, this doctor takes three months after the appointment to write his report. In the free world, most people wait one to two months for an appointment and get their diagnosis that same day. SRLP has received copies of some of his reports and it is clear that he is using highly outdated methods for diagnosis. Even if he diagnoses a person with gender dysphoria, he will continue to use the wrong pronouns and name throughout the report. For one client of ours, this doctor insisted on contacting her abusive former spouse to find out if the spouse agreed with her gender identity. Their conversation is now immortalized in her report, which follows her everywhere. The doctor greeted another client, a transgender man, with "oh I've never met one of you before" and later in the conversation asked our client "why can't you stay a lesbian?" This lack of knowledge around transgender lives has made it very difficult for our gender non-conforming clients to receive an accurate diagnosis. DOCCS continues to contract with this doctor despite his obvious deviation from contemporary norms for GD diagnosis. It is an ongoing humiliation for our clients to visit him.

Due to the long waiting time, our clients often do not get their first hormone shot until well over a year after they try to initiate the process. This kind of delay causes horrific strain. Delayed access to medically necessary care is cruel and unusual treatment. Yet, this delay is standard for any TGNC person in the NYS system.

<sup>&</sup>lt;sup>4</sup> A copy of HSPM 1.31 is attached to this testimony. Transgender health care information is not available anywhere on the DOCCS website.

<sup>&</sup>lt;sup>5</sup> In 2015, SRLP submitted a Freedom Of Information Law (FOIL) request to DOCCS for information on all of the doctors they contract with or employ relating to transgender health. The FOIL response came back with only this doctor's information.

<sup>&</sup>lt;sup>6</sup> Courts across the United States have continuously found that untreated GD results in increased risks for mental health affects including depression, anxiety, and increased suicidality. In a few particular cases courts needed to issue injunctions for treatment after the individual attempted self-mutilation when her requests were repeatedly

Once an individual has access to hormones, other concerns inevitably arise. One such concern is that many facilities have a standard "no injection" rule and only provide oral medications. The Endocrine Society, the world's oldest organization devoted to hormonal health, has published guidelines indicating that compound hormones are not as effective as naturally occurring hormones, which are more likely to be prescribed as injections. <sup>7</sup> The common substitute, Premarin, has also been linked to heart attacks for cisgender (non-transgender) women. <sup>8</sup> These methods are still common place in most facilities.

We often hear that upon transfer to a new facility, hormone levels are dropped or the specific administration of hormones (injection method versus pills) is altered. Only after advocacy from SRLP are these issues corrected. Sometimes our clients go months on incorrect dosages simply because of a transfer.

In one instance, a client of ours was on a temporary transfer. During that period, he missed three weeks of his medication. The other facility was not prepared for him to be there and did not have his medication on hand. He was informed that his medication was "non-standard" and they did not carry it. No effort was made to get the medication to the facility. This lack of care around his serious medical need is standard for TGNC people in the DOCCS system.

## **Issues in Cultural Competency of Medical Staff**

One of the requests we get most often from TGNC individuals is for more information on healthcare. We always send the most up-to-date and accurate resources we can, in addition to HSPM 1.31, DOCCS' own governing memo. One hundred percent of the time, our clients write back that they were never told that HSPM 1.31 even existed. Some individuals have even been told that there is no guideline at all for transgender healthcare.

Others have been told information so incorrect that it is inconceivable that medical professionals said these words. One transgender woman we worked with was told she could not receive hormones while she was receiving treatment for a different medical concern. She was informed that she had to wait until all other medical concerns were cleared up before beginning hormones. This is simply not true. It is more than possible – it is, in fact, normal – to hold multiple medical diagnoses. A transgender man was told that if he began using testosterone, he would certainly develop cancer. Luckily, he wrote to SRLP and we were able to provide him with accurate healthcare information and advocate that he be transferred to a different, competent doctor. Neither of these experiences is unique.

denied. Gammett v. Idaho State Bd. Of Corr., No. CV05-257-S-MHW, 2007 (D. Idaho July 27, 2007); De'Lonta v. Angelone, 330 F.3d 630, 635 (4th Cir. 2003).

<sup>&</sup>lt;sup>7</sup> Macht, Hilary, Endocrine Society Warns Against Use of Custom Compounded Bioidentical Hormones. EndocrineWeb, April 8, 2016 https://www.endocrineweb.com/news/other-endocrine-disorders/20696-endocrine-society-warns-against-use-custom-compounded-bioidenti

<sup>&</sup>lt;sup>8</sup> Smith, Nicholas L. et. al., Lower Risk of Cardiovascular Events in Postmenopausal Women Taking Oral Estradiol Compared With Oral Conjugated Equine Estrogens. JAMA Internal Medicine, January 2014.

# Recommendations from the Sylvia Rivera Law Project

Based upon all of the above, SRLP recommends that the following specific steps be taken to provide better quality healthcare to TGNC people in the New York State Prison system:

- DOCCS should immediately seek additional mental health professionals able to provide competent GD diagnosis for each local prison hub;
- Individuals seeking a GD diagnosis should be treated with the same level of medical need that they would encounter in the free world:
- A universal policy towards HRT usage throughout DOCCS' facilities be developed, including a protocol that allows for people to maintain access to their medical care, regardless of their security classification or length of stay in a facility. This protocol should include access to the least-risky and most-effective HRT. TGNC-specific organizations should be called upon to review and strengthen this policy;
- All medical staff must be trained on TGNC competency and this training must be accompanied by refresher courses. Failure to pass the training should lead staff to being placed on probation. This training must be available to transgender-specific healthcare organizations to review, strengthen, and provide;
- DOCCS should immediately review and revise HSPM 1.31 with input from TGNCI individuals and organizations and take steps to ensure that it is being properly implemented.

In closing, we wish to thank Assembly Members David I. Weprin and Richard N. Gottfried for the invitation and opportunity to testify today. SRLP looks forward to being able to provide a copy of the speech via email to the Assembly members offices later this week.

Respectfully Submitted,

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New York State Department of Corrections and Community Supervision Division of Health Services	Title: Gender Dysphoria		Number
POLICY	Section: Health Care Services		1.31
Supersedes: HSPM 1.31 dated 5/20/13	Page: 1 of 4	Date: 5	/12/14
References: Diagnostic and Statistical Manua	al of Mental Disorders, Fifth Edition (DSM-V	)	
Approved by: Carl Man	ugun mo		

#### I. POLICY:

It is the policy of the New York State Department of Corrections and Community Supervision to recognize Gender Dysphoria (GD) (previously known as Gender Identity Disorder) as a mental health diagnosis defined in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) and that the Department will address inmate health care needs consistent with this diagnosis and in a manner that protects privacy and confidentiality. A GD diagnosis can be established prior to admission to the Department or, subsequent to admission, upon referral to a Mental Health Professional with specific expertise in this condition.

#### II. **DEFINITION:**

Per DSM-V, Gender Dysphoria is a new diagnostic class that reflects a change in conceptualization of the disorder's defining features by emphasizing the phenomenon of "gender incongruence" rather than cross-gender identification.

For an individual to be diagnosed with Gender Dysphoria, there must be a marked difference between the individual's expressed/experienced gender and the gender others would assign him or her. The diagnosis must include evidence of clinically significant distress or impairment in social, occupational, or other important areas of functioning.

Gender Dysphoria is manifested in a variety of ways, including strong desires to be treated as the other gender or to be rid of one's sex characteristics, or a strong conviction that one has feelings and reactions typical of the other gender.

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#### III. PROCEDURE:

#### A. Verifying or Establishing the Diagnosis:

- 1. Inmates may present upon entry to DOCCS claiming a previously established diagnosis of GD or Gender Identity Disorder. Medical staff will attempt to verify the diagnosis by contacting prior health care providers. This will be initiated at reception and continued at the permanent facility if not completed. If the diagnosis cannot be verified, the Regional Medical Director (RMD) GD Coordinator will be contacted. The RMD GD Coordinator will review the case and decide if the diagnosis is established or if the inmate requires a diagnostic evaluation. Once the diagnosis is verified, the inmate's FHS1 Problem List must be updated using code 3028.
- 2. Inmates presenting during incarceration with complaints or symptoms consistent with GD will be referred to the RMD GD Coordinator for consideration of a GD diagnostic evaluation. The RMD GD Coordinator will conduct an independent review of all pertinent information and determine if a diagnostic evaluation for GD is medically appropriate. If recommended by the RMD GD Coordinator and approved by the Deputy Commissioner/Chief Medical Officer, the inmate will be referred for consultation to a Mental Health Professional with specific expertise in this condition to establish a diagnosis and make treatment recommendations. Once the diagnosis is established, the inmate's FHS1 Problem List must be updated using code 3028.

#### B. GD Hormone Therapy:

1. Inmates entering DOCCS claiming a previously established diagnosis of GD or Gender Identity Disorder and on hormone therapy will have the therapy temporarily continued while the diagnosis is verified. If there is concern about the diagnosis, the RMD GD Coordinator will be contacted and the RMD GD Coordinator will consult with the Deputy Commissioner/Chief Medical Officer regarding continuation of therapy. When the diagnosis is verified, treatment will be continued and appropriate laboratory testing for monitoring will be obtained as necessary. If, during the course of therapy, hormone dosage adjustments are required, a consultation with an Endocrine Specialist will be obtained.

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- 2. If an inmate has a diagnostic evaluation and a diagnosis of GD is established and hormone therapy is recommended, the inmate will be referred to an Endocrine Specialist for purposes of initiating appropriate hormone and other medications.
- 3. Prior to the initiation of hormone therapy or the continuation of hormone therapy for inmates entering DOCCS on hormone therapy, consent of the inmate must be obtained and documented on the appropriate Hormone Treatment Consent Form (i.e. <u>female to male</u> or <u>male to female</u>). The information contained in the consent form must be explained to the inmate by the primary care provider.

#### C. State-Issue Undergarments:

GD diagnosed inmates (male to female and female to male) can make a request to the facility Health Unit to obtain, possess and wear DOCCS state-issued undergarments appropriate to their desired gender. Ordering and procurement will follow the below listed procedures:

1. GD diagnosed inmates (male to female) requesting bras will be called to the facility Health Unit to measure themselves by following the instructions in the *Bra Measuring Instructions and Sizing Chart*. This will be done in the presence of a health care professional who will observe the measurements and determine the bra size based on the information in the measuring chart. Once the size is determined, a health care professional will notify the Deputy Superintendent for Administration (DSA) at their facility by completing the "Bra Request" portion of Section 1 of the "*Undergarment Request*" Outlook eform.

For GD diagnosed inmates (male to female) requesting female underwear or (female to male) requesting male undershorts, a health care professional will notify the DSA at their facility by completing the "Underwear Request" portion of Section 1 of the "<u>Undergarment Request</u>" Outlook eform.

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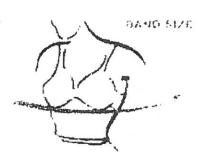
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- 2. The DSA will complete Section 2 of the applicable eform and forward the eform to the appropriate Facility Steward (as identified on the eform).
- 3. Upon receipt of an eform from a DSA, the Facility Steward will complete Section 3 of the eform and send it back to the requesting facility. The Steward will procure the requested undergarments and forward them to the requesting facility Health Unit along with a hard copy of the applicable eform.
- 4. Upon receipt of the undergarments at the requesting facility, the inmate will be called out to the facility Health Unit and be issued the undergarments along with a medical permit to possess and wear them.
- 5. Documentation of all steps in the undergarment request process, along with a copy of the completed eform and medical permit, will be placed in the Consults Section of the inmate's Ambulatory Health Care Record.

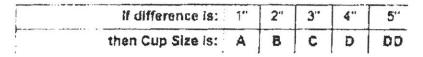
**NOTE:** GD inmates <u>cannot</u> receive undergarments appropriate to their desired gender through the package room or through personal purchase.

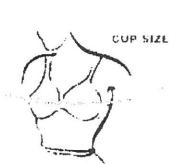
# Bra Measuring Instructions and Sizing

Use the provided tape measure



- 1) Band Measurement:
  - Take a snug measurement around your rib cage, under your bust and shoulder blades (see Band Size figure).
  - Add 2 inches to the measurement to account for the extra tissue that most women have at the sides of their breasts that men don't have.
- 2) Determine even band size:
  - o If you get an even number in Step 1), this is your band size.
  - o If you get an odd number in Step 1 (like 35), round up one to get your Band Size.
- 3) Bust Measurement:
  - o With shirt off and T-shirt on, take a loose measurement around the fullest part of your bust (see Cup Size figure).
- 4) Determine Cup Size:
  - o Subtract Band Measurement (From Step 1 Above) from Bust Measurement (From Step 3 Above)
    - " Use the chart below to determine your cup size.





# Bra Request Gender Identity Disorder (GID) Confidential HIPAA Protected Information

Section 1: to be filled out by He	ealth Care Professional	Γ
Offender Name:	Date :	
DIN:	Facility:	
Health Care Professional Name:		
Offender Bra Size:		
Please choose one of the following 2 choices: (Mark With an	×)	200
Offender opts to receive & bras.		=
Offender opts to receive 4 bras and 2 sports bras.		2
Health Care Professional Comments:		1
Instructions for Health Services: Email this form to your DSA. Ilici then the "Prepare Email" button at the bottom of the ba Address the folk to your D.	ge to create in email with this attachment.	
Section 2: to be filled  DSA Name:  DSA Comments:  instructions for Facility D. A: Email this form to ather Albion CF Stev  closest. Click the blank form field at the nottom of the page and th  page to sceate an email with this at achment. Address the form	Date:  ward or Bedford Hills CF Steward, whichever facility is nen the "Prepare Email" button at the bottom of the	Section 2
Section 3: to be filled out by Stewa	rd (Albion/Bedford Hills)	
A	equest Received:	
iteward Comments:		Sectio
xpected Date of Delivery to Requesting Facility		on 3
Instructions for Steward; Email this form to Request The Bras are to be sent to the request Click the blank form field at the bottom of the page and then the "f create an email with this at Address the form to the Facility Physician In addition, physically mail form along wit	ing facility health unit.  Prepare Email" button at the bottom of the page to ttachment.  I and DSA and click send.	

Click this form field before clicking Prepare Email Button ->