

**Experiences of Access to Transition-Related Health Care for Transgender Youth
and Adults in New York State**

Focus Group Research (2009-2010)

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*Most of them are getting the hormones on the street, especially the female to male...you see they really go through a lot of trouble to get their hormones from Medicaid...and for undocumented...they can't get it at all...so you have to make them understand that when they won't do our paperwork, when they come up with barriers to getting Medicaid, those rules, they are denying us medications and what is that?....you know that it has a lot to do with discrimination that exists. It's not a lot of benefits that they give us... even if we do get hormones on Medicaid...it's the basics. You see they think we take these medications just to take them... but these are not recreational things that we just do on the side just to feel pretty...**this is our lives.***

(Participant: Focus Group 2)

Society alone is harsh. You want to keep your appearance, you want to be able to walk on the streets and blend in. You want to be able to go anywhere and not have someone say, "Oh my god, that's a man", you know. It's hard enough to go through that. On top of that, you having issues with getting hormones and then perhaps you get hormones and then OK, you feel fabulous, you feel lovely but then come next month, you ran out of hormones, they give you a hard time and now you started to feel like a man again. Now you're getting depressed. Now you're not feeling real. Now you don't want to come out your house. They want to crush your energy, they want to crush your confidence and so they'll do it because you're not a real woman. Now we can't change everyone's perspectives but I think that this law for us to have access to our hormones, I think it should be fixed, it shouldn't be... 'cos we're taking chances because of it.

(Participant: Focus Group 1)

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The following report provides an overview of the key themes emergent across participant responses at three focus groups held between December 2009 and September 2010.

Recruitment and Data Collection:

Study participants were recruited via community-based agencies in New York City providing legal and/or health and social services to transgender youth and adults, and asked to speak on their experiences of access to transition-related health care:

Focus Group Questions:

- What are your experiences of access to transition-related health care?
- What barriers, if any, have you faced accessing transition-related health care?
- If you have encountered barriers to accessing transition-related health care, how have you negotiated these barriers?
- What are the consequences of no-access/limited access/or inconsistent access to transition-related health care?

Study participation was voluntary, and all respondents provided written and/or verbal informed consent prior to each focus group. For the focus group with Spanish speaking participants (see *Appendix B*), an agency-identified interpreter was present throughout the group, and informed consent documents were available in Spanish and English. With participant permission, each focus group was audio taped to facilitate accurate post-group transcription by the researchers. All participants received a \$25 gift card, and a return-fare MetroCard, as compensation for their time and contribution to the study.

Data Analysis:

Key themes emergent from participant responses were identified for each focus group (see *Appendix A*; *Appendix B*, and *Appendix C*). On completion of this final report, all audio files and informed consent documents have been erased, to maintain participant confidentiality.

Key Themes:**1. Experiences of Access to Transition-Related Health Care**

Across focus groups, participants explained how experiences of policy change, institutional bureaucracy, and discrimination on the basis of their gender identity were significant barriers to accessing transition-related health care.

(i) Experiences of Policy Change

A number of adult transgender participants had experienced the impact of policy change in relation to access to transition-related health care. Prior to the change in Medicaid eligibility, participants explained how they had been receiving consistent medical treatment and monitoring toward transition at a local clinic. However, one day, “...*this just stopped without warning*”. For adult transgender women in this study, the impact of a change in Medicaid eligibility regulations was significant (i.e.) they were immediately faced with an **interruption in medical care and treatment** as they attempted to negotiate the new system:

Actually there was no warning. One day I'm in the clinic and I'm getting hormone therapy and then all of a sudden it was that the government won't accept that - you have to change your name - and so I went through changing my name and I went through all the legal process and then the next minute, you know, the government's not accepting that and you have to have an F - now it's not sufficient to have a female name but you have to have the letter F - if you don't have the letter F on it, you still can't get hormones. But now, even when we get an F, they sometimes still try and find ways so we can't get it.

(Participant: Focus Group 1)

(ii) Experiences of Institutional Bureaucracy

Participants spoke of how accessing hormones via Medicaid was “*a fight*” or “*a battle*”. Even when participants had followed formal procedures (i.e., seeing a psychiatrist, receiving counseling etc), they faced the challenge of negotiating inconsistently applied rules and impenetrable bureaucracy, and were often required to make multiple return visits to Medicaid offices. Negotiating the system was time consuming, with participants having to wait months (in one case over a year) to have their case reviewed. During this time, participants had **no access to required medical treatment toward transition**:

We have to call what the problem is, and its Medicaid. Medicaid is a problem because a lot of the times they do not want to give transgenders anything...even with the designation of female...even though they present as female...they refuse to give hormone access to a lot of the girls and what ends up happening is that I was knocking on many doors trying to get people to assist me, trying to come with different archives...documents...seeing doctors

and counselors...trying to get people to assist me and they still would not help me.

(Participant: Focus Group 2)

It can take a year or half a year to organize, to go through this process to get medical care...and so to be cut off like that from your hormones during all that means that our bodies start changing and we don't even feel comfortable going out and even doing the process and dealing with people.

(Participant: Focus Group 2)

(iii) Experiences of Gender-Identity Discrimination

In addition to having to negotiate multiple levels of bureaucracy, participants also spoke of how they routinely faced discrimination on the basis of their gender-identity. Transgender adults and youth spoke of how they were “*not taken seriously*” by staff at Medicaid offices. Even when they produced all the required documentation, it was not unusual for staff to openly ask them personal questions regarding their gender and gender-identity in the public space of the office:

It's the people that work for them - they don't take you serious - for me it was OK they did it eventually - I was blessed that didn't happen to me - but I did have to go back a few times because the first times they were terrible. It goes back into who is working there, they say "Did you get the sex change yet?" - it's really mortifying.

(Participant: Focus Group 3)

So even after a situation where you have to go to doctors knock on doors etc...and fight for your rights, it's not over because when it comes down to going into the Medicaid office to get it changed, somebody who is not a doctor who doesn't know anything still thinks that they can judge based on their preconceived ideas.

(Participant: Focus Group 1)

People say I don't want to go on Medicaid - see some people are afraid to go for Medicaid - see it's not like that when you go for Medicaid it's like LGBT friendly - it's most likely especially in some areas, it's most likely that there's heterosexuals there in the office and everyone's judging you because of who you are...and you just got to be really strong about it but it's bad for us.

(Participant: Focus Group 3)

2. Narratives of Risk: Consequences of Interrupted/Delayed/Limited or No-Access to Transition-Related Health Care

(i) Physical and Mental Health Risks: Interrupted Treatment

For transgender patients receiving transition-related health care, there are **significant physical and psychological consequences** to interruption in required medical treatment and monitoring:

Well, physically it does damage to the body, you know...you're shrinking...because the medicine (i.e., hormones) you had before was creating and shaping you to be the person you feel like you really were going to be and then when they just cut you off, you start to shrink, you start to get more masculine, you start to grow hair...it comes back quicker...the process is reversed. And psychologically - it's like a chemical imbalance...like, if you don't have it, it's like a mood swing...it's a depression state.

(Participant: Focus Group 1)

Many of us have had to sacrifice families who will no longer speak to us because of the decisions that we have made going on to transition to live our lives as a woman and you need to understand the withdrawals that a lot of the trans women face upon having their hormones cut off like that by Medicaid - just like that - there are emotional repercussions and mental repercussions that this can have on trans people who require these medications - when the body and mind gets accustomed to this type of medication...so to get them just abruptly cut off is very dangerous and reckless on behalf of whomever is making that decision at Medicaid.

(Participant: Focus Group 2)

(ii) Physical and Mental Health Risks: Negotiating the Barriers to Treatment

Faced with institutional bureaucracy, extended waiting times (with no access to transition-related health care), and experiences of discrimination on the basis of their gender-identity, participants discussed their 'forced' reliance on 'alternative' means of accessing transition-related health care.

Finding doctors willing to "work around the rules"

On occasion, participants reported having been able to find doctors and/or pharmacies willing to (at a cost) circumvent Medicaid exclusions. Whereas this allowed access to otherwise precluded treatment, participants were aware that without the necessary monitoring and follow-up (e.g., monitoring of potassium levels and liver functioning), this did not represent transgender specific health care, and moreover incurred considerable (and possibly fatal) physical and mental health risks:

Not all doctors who prescribe hormones necessarily know about trans women and hormones, you know, so that's also a problem, you know, you get the doctors who will prescribe you...no problem, here's a high dosage but they're really not monitoring.

(Participant: Focus Group 1)

Purchasing transition-related hormones over the Internet

It was not unusual for participants to attempt to purchase hormones toward transition over the Internet. The risks inherent in taking hormones with no medical monitoring were further exacerbated by the possibility that these medications could be contaminated:

A lot of the girls go online and order them...to go through all of that – they order them from Germany. But it's very endangering to go online and order something from overseas and think its Premarin and it's labeled Premarin, but it's really not Premarin when you test it...it's a risk factor right there.

(Bi-racial female, age 22 years)

Purchasing transition-related hormones on the street

In addition, participants had experience of purchasing hormones on the street. In addition to the risk of contamination, this route of access to transition-related health care placed participants at significant risk for HIV infection through needle sharing:

The risks? The risks? Death. Death. You don't know what you're taking if it's not prescribed by the medical doctor. That's why we need to change the policy...that's why we need to change Medicaid...I had a friend who through taking street hormones that way, well, she had to have her gall bladder removed. You see, when they're selling you hormones, they don't just sell you pills...we're not just talking about pills...you also have the estrogen that they sell in the bottle and the syringe needles...and a lot of the time, you don't know what you're getting...they could be selling you dirty unpackaged syringe needles along with the hormone to insert into your body. You expose yourself to the risk of getting Hepatitis, HIV...all sorts of other types of illnesses...this is our lives on the line and that's very important for people to know that.

(Participant: Focus Group 2)

Yes there is risks but girls do it because of the process...because it takes time...because we feel like we don't have time...we have to get ID's changed and wait and wait and there's the whole process. We feel like we don't have time.

(Participant: Focus Group 3)

Involvement in sex work

Participants discussed how discrimination on the basis of their gender-identity was pervasive across all areas of their lives, and was not limited to their experiences of

discrimination while attempting to gain access to required medical treatment. However, lack of access to treatment was perceived as a barrier to ‘passing’ – often an unstated requirement to accessing employment.

So Medicaid cuts off so...no option to get hormones okay....so what next? It means that without hormones...how are you passing? If you can't pass – how can you get a job, even if it one was available...so by not giving us access to hormones, the health care system makes it even harder for us to find a job...so how are we supposed to get the money to pay for the hormones that they won't pay for? Do we have no choice than to get involved in illegal activities to survive?

(Participant: Focus Group 2)

Limited or no access to formal employment resulted in limited available options to obtain finances to pay for private health insurance and/or purchase treatment legally. Consequently, when treatment was interrupted or unavailable via public health insurance, involvement in sex work was viewed as one of the “*last resort*” but “*unavoidable*” options available:

For transsexuals, it's hard for us to get a basic job – imagine us being able to find a job that pays health insurance...you see that's why they categorize us as prostitutes all the time...because we don't have the facility of being able to gain employment. So people judge us if we are sex workers and they say that we're trying to gain money fast and we are in danger – that we're exposing ourselves to diseases, to anyone who could take your life...but why are we doing this in the first place?

(Participant: Focus Group 2)

...and I know a lot of girls that prefer working the streets to go buy their hormones instead of having to go through this process...instead of going through this discriminatory nightmare...they'd rather just go sell themselves or place an ad on Craigslist and just buy them off the black market.

(Participant: Focus Group 1)