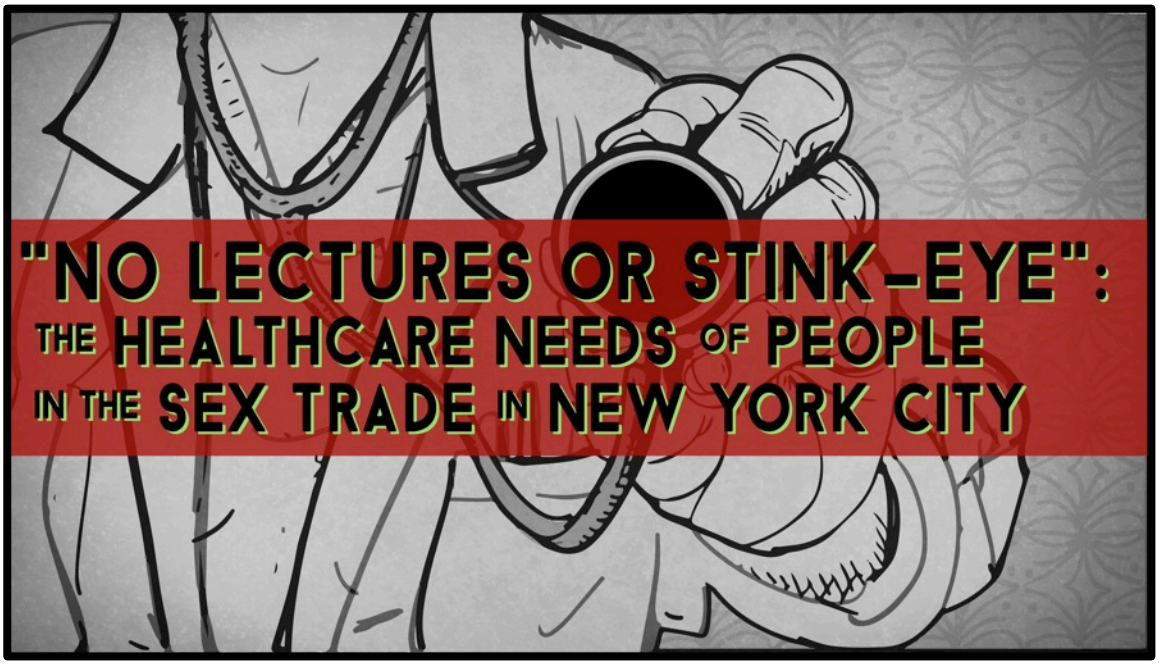

Persist Health Project
April 2014
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Introduction

Persist Health Project

Persist (Providing Education and health Resources in Support of Individuals in the Sex Trade) Health Project (Persist) is a New York City-based (NYC) organization, made up of nurse practitioners, health educators, community organizers, and social workers, who are/have been in the sex trade (or are committed allies). We believe that people in the sex trade, regardless of our experiences, are entitled to health care spaces that are supportive and affirming of the realities of our lives. We work to build our own spaces to serve other community members; we also work with health care professionals to better serve us and others in communities involved with or impacted by the sex trade.

Persist was founded in January of 2012 after a meeting of activists in Brooklyn, New York, which included founding staff members Laura G. Duncan, Lindsey Hennawi, Chance Krempasky, Claire Paradis McCullough, Sarah Elspeth Patterson, and Lola Pellegrino. We were soon joined by community organizer Kate D'Adamo and nurse practitioner Zil Garner Goldstein (now the Clinical Director of Persist). We came together from sex worker activism, the harm reduction community, and reproductive justice organizing. We identify as transgender, cisgender,[1] Mixed Race, White, female, male, current sex workers, former sex workers, trafficking survivors, survivors of sexual violence, current drug users, former drug users, and allies. We saw a need for peer-led health resources for people in the sex trade, regardless of their experiences in the sex trade.

From our own experiences and the experiences of our friends and community members, we know that people in the sex trade face a lot of judgment and discrimination in health care settings, which impacts the way we feel about our health and how we care for ourselves. We believe that when people in the sex trade take control of our health and wellness, it is an act of empowerment and a tool for positive social change. We work to assist those from our own communities, as well as others involved in the sex trade, to make

[1] Cisgender is defined as non-transgender, or people who identify with the gender they are assigned at birth.

their own health decisions and take care of themselves as they see fit.

Prior to Persist, there were no explicitly peer-led health care services in NYC for people in the sex trade. For those of us in Persist who been in the sex trade and are currently health care professionals, we saw a need to fill in the gaps in health care with peer support. We want others in the sex trade in NYC to know that there were people with shared experiences working in health care services across the city. To that end, we connect other community members with a Persist health care provider, or navigate them through NYC's complex health care system. We also conduct workshops for people in the sex trade on health topics, as well as best practices trainings for health care providers. Our ultimate goal with Persist is to have clinic space of our own, so that we can provide comprehensive and community-centric health services in a fully equipped space.

2013 Persist Health Project (from left to right) staff, interns and volunteers: Karen Gardiner, Hannah Mogul-Adlin, Sarah Elspeth Patterson, Zil Garner Goldstein, Kate D'Adamo, Claire Paradis McCullough, Chance Krempasky. Not pictured are Lola Pellegrino, Lindsey Hennawi, and Laura G. Duncan.

Barriers to Care

In public health, people in the sex trade (those who trade sexual services for money, food, drugs, housing or other resources)[2] are talked about as having disproportionately high rates of violence, significant exposure to HIV/AIDS and other sexually transmitted infections, as well as psychological stress related to working conditions.[3][4] Yet despite these ways in which people in the sex trade are defined as "at risk" or vulnerable by researchers and health professionals, the health needs of people in the sex trade are still largely unaddressed or unknown in many conventional health care settings. In New York City (NYC), where trading sex is illegal, people in the sex trade have limited ability to safely and voluntarily receive health and social services. Obstacles include the illegal and stigmatized nature of trading sex, as well as discrimination in health care settings.[5] Internationally, where people in the sex trade have greater legal protections, there is greater access to health and social services and people in the sex trade are less likely to be victims of violence or coercion.[6]

In NYC, the possession of condoms has been used for decades as a means to intimidate, arrest and detain New Yorkers on prostitution charges, undermining the health and safety of people trading sex, particularly street-based sex workers, LGBTQ youth, transgender women and gender non-conforming people.[7] 37.2 million free, NYC-branded condoms are distributed by the Department of Health every year, which are then use as grounds to detain and arrest New Yorkers who carry them.[8] A 2012 report conducted by the PROS (Providers and Resources Offering Services for sex workers) Network found that about half of overall respondents reported that police had confiscated, damaged, or

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[2] Persist's definition of people in the sex trade is intended to encompass the multitude of experiences people have in the sex trade have. This definition may include those who identify as sex workers, trafficking survivors, as well as those who do not see their involvement in the sex trade as an identity or use this language.
[3] C. Angel Torres and Naima Paz, "Bad Encounters List: A Participatory Action Project," Young Women's Empowerment Project, 2012, http://ywepchicago.files.wordpress.com/2012/09/bad-encounter-line-report-2012.pdf
[4] Lisa Lazarus, Kathleen N. Deering, Rose Nabess, Kate Gibson, Mark W. Tyndell, & Kate Shannon, "Occupational Stigma as a Primary Barrier to Health Care for Street-Based Sex Workers in Canada. *Culture, Health & Sexuality*, 2012, http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3359131/
[5] ASHM & NCHSR, "Stigma and Discrimination around HIV and HCV in Healthcare Settings: Research Report: Commercial Sex Workers," 2012, http://www.ashm.org.au/Publications/Stigma_and_Discrimination.pdf
[6] B. Donovan, C. Harcourt, S. Egger, L. Smith, K. Schneider, H. Wand, J. Kaldor, M. Chen, Fairley and S. Tabrizi, "The Sex Industry in New South Wales: A Report to the New South Wales Ministry of Health," The Kirby Institute, 2012, http://www.med.unsw.edu.au/nchecrweb.nsf/resources/SHPReport/$file/NSWSexIndustryReportV4.pdf
[7] Recent efforts to end this discriminatory practice have resulted in a "No Condoms as Evidence" bill being passed in the State Assembly; efforts are still being made to pass this bill in the Senate by the Access to Condoms Campaign.
[8] Audacia Ray & Sarah Elspeth Patterson, "No Condoms As Evidence: A Sex Worker Campaign in New York," *Research for Sex Work 13*, 2013, http://www.nswp.org/sites/nswp.org/files/R4SW%2013%20-%20No%20Condoms%20as%20Evidence.pdf

destroyed their condoms; 67% reported that police destroyed condoms they were carrying solely as a means of harassment, without making an arrest.[9] This endangerment of public health occurs in spite of the high rates of HIV/AIDS in NYC, where more than 110,000 people live with HIV and the AIDS case rate is three times the national average.[10]

Post-arrest, people in the sex trade face laws and social conditions that undermine their health and wellness. In 24 states, those arrested on prostitution charges face mandatory HIV testing upon arrest and enhanced penalties for those facing prostitution charges while being HIV positive.[11] In New York State, if a victim of sexual assault has been arrested for prostitution in past three years, it can be admitted into evidence at the trial as evidence against the complainant, limiting one's ability to a fair trial.[12] This admittance is in spite of the Rape Shield Law, which otherwise protects the rights of other victims of rape and sexual assault. In addition to these discriminatory practices post-arrest, people arrested for prostitution also face the social and psychological impact of having their mugshots published or being outed within their communities, which can result in lose of residence, lose of other work, child custody issues and/or being socially isolated. The social stigma and fear of being outed or discriminated against is also a barrier to health care, limiting how much people seeks health and social services as well as how much they tell their health care provider.[13]

Many health care providers have limited training on working with populations in the sex trade or do not know how to deal with sex-related issues in general. Many providers either know little about those who trade sex – because no one has ever disclosed to them – or are afraid to ask for fear of appearing ill informed.[14] Medical students may also feel especially unprepared to work with these communities or speak comfortably about sexual topics with their patients. A study published in 2010 surveyed over 2,200 medical students

[8] Leigh Tomppert, the Sex Workers Project and PROS Network, "Public Health Crisis: The Impact of Using Condoms as Evidence of Prostitution in New York City," 2012, http://sexworkersproject.org/publications/reports/public-health-crisis/
[10] Megan McLemore, "Sex Workers at Risk: Condoms as Evidence of Prostitution in Four US Cities," Human Rights Watch, 2012, http://www.hrw.org/reports/2012/07/19/sex-workers-risk-0
[11] Ahmed, Sienna Baskin and Shkordoff, Poster #MOPE333, International AIDS Conference, 2012.
[12] Sarah Elspeth Patterson, "Rough Summer in the City: Recent Rape Cases and the NYC Rape Shield Law," RH Reality Check, 2011, http://rhrealitycheck.org/article/2011/08/25/rough-summer-city-recent-rape-cases-rape-shield/
[13] Lisa Lazarus, Kathleen N. Deering, Rose Nabess, Kate Gibson, Mark W. Tyndell, & Kate Shannon, "Occupational Stigma as a Primary Barrier to Health Care for Street-Based Sex Workers in Canada. *Culture, Health & Sexuality*, 2012, http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3359131/
[14] Tracy M. Clements, "Prostitution and the American Healthcare System: Denying Access to a Group of Women in Need," *Berkeley Journal of Gender, Law & Justice*, 2013, http://scholarship.law.berkeley.edu/cgi/viewcontent.cgi?article=1111&context=bglj

and found that over 53% felt they had not received enough training in medical school to address their patients' sexual concerns.[15] These students were also more likely to report not being comfortable talking to patients about sexual health, suggesting a correlation between being educated and feeling comfortable talking about sexual issues. Lack of formal training coupled with limited comfort leaves health care professionals to base their care upon preconceived notions about people in the sex trade, often the result of sensationalized media coverage or harmful stereotypes. Since people who trade sex are already unlikely to disclose or are afraid of being judged, these preconceptions can create an unproductive, and in some cases unsafe, spaces for health care to occur.

Saint James Infirmary, the occupational health clinic for sex workers in San Francisco, reported that 70% of those they served had not previously disclosed to a provider, either due to negative past experiences, fear of disapproval, embarrassment or not seeing the work as relevant to their care.[16] Community-based interviews conducted by a research team in Ontario, Canada, found that interview participants limited their disclosure in health care setting in order to avoid shaming or disapproval.[17] Participants noted that health care providers were more likely to engage in stigmatizing behavior if they knew a patient was a sex worker, going so far as to assume a HIV+ status was due to reckless sexual activity while trading sex. Participants also reported that health workers would question them about their work in a sexualizing or degrading manner. Some feared deportation due to their status in the sex trade, or worried that they would be isolated from their communities. Sex workers in Miami also described concealing their status in order to obtain supportive services, noting that it was very rare to find providers that were both knowledge about their health needs and willing to assist sex workers.[18] In conditions in which contact with health care professionals is common and regular for someone trading sex, non-disclosure may contribute to poor health outcomes, suggesting a link between effective care and

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[15] A. W. Shindel, K. A. Ando, C. J. Nelson, B. N. Breyer, T. F. Lue, and J. F. Smith, "Medical Student Sexuality: How Sexual Experience and Sexuality Training Impact U.S. and Canadian Medical Students' Comfort Dealing with Patients' Sexuality in Clinical Practice," *Academic Medicine,* 2010, http://www.ncbi.nlm.nih.gov/pubmed/20671459

[16] D. L. Cohen, Alex Lutnick, P. Davidson, Charles Cloniger, A. Herlyn, Johanna Breyer, C. Cobaugh, D. Wilson and J. Klausner, "Sex Worker Health: San Francisco Style, *STI Online,* 2006*,* http://stjamesinfirmary.org/Uploads/Sex%20Work%20SF%20Style.pdf

[17] C. L. Logie, C. James, W. Tharao, and M. R. Loutfy, "HIV, Gender, Race, Sexual Orientation, and Sex Work: A Qualitative Study of Intersectional Stigma Experienced by HIV-Positive Women in Ontario, Canada," *PLoS Med,* 2010.

[18] Kurtz, S.P., H.L. Surratt, M.C. Kiley, and J.A. Inciardi, "Barriers to Health and Social Services for Street-Based Sex Workers," *Journal of Health Care for the Poorand Underserved,* 2005, http://www.ncbi.nlm.nih.gov/pubmed/15937397

disclosure.[19]

Due to these barriers, many people in the sex trade in NYC avoid entering care altogether or do so under costly emergency conditions due to lack of affirming services within reach. A 2005 report on 53 indoor sex workers in NYC found that 63% were without healthcare and in need of affordable care.[20] This report, as well as a 2003 report on NYC outdoor sex workers, noted that health services should be comprehensive, focusing not solely on disease transmission, but also including general health, sexual health, sexuality education, and mental health counseling.[21] Simply not enough is known about the health needs of people in the sex trade in NYC. Research on health interventions globally, however, provides strong evidence that health interventions with people in the sex trades work best when those most affected are involved, using community-driven methods such as peer education and group empowerment models.[22] This international research suggests that a peer-led project like Persist Health Project can be an effective way to bridge the gaps, by helping communities involved with and impacted by the sex trade get health care that fits their lives.

Focus Groups

Design

The design for these focus groups was inspired by participatory action research (PAR), also called action research or community-based research, which is both a research design as well as means for social change. PAR is used in order to understand community structures and ensure community participation in research about individuals' lives.[23] PAR complicates the relationship between the "researcher" and the "researched" by involving those being

[19] N. Jean & C. Salisbury. "A Health Needs Assessment of Street-Based Prostitutes: Cross-Sectional Survey," *Journal of Public Health*, 2004, http://www.ncbi.nlm.nih.gov/pubmed/15284317
[20] Juhu Thukral, Melissa Ditmore and Alexandra Murphy, "Behind Closed Doors: An Analysis of Indoor Sex Work in New York City," 2005, http://sexworkersproject.org/downloads/BehindClosedDoors.pdf
[21] Juhu Thukral, Melissa Ditmore and Berny Horowitz, "Revolving Door: An Analysis of Street-Based Prostitution in New York City," 2003, http://sexworkersproject.org/downloads/RevolvingDoor.pdf
[22] Sarah Elspeth Patterson, "Turning the Tide: Sex Workers in the US," *Achieve Quarterly*, 2013, http://www.thebody.com/content/72647/turning-the-tide-sex-workers-in-the-us.html
[23] L. van Niekerk, & D. van Niekerk, "Participatory Action Research: Addressing Social Vulnerability of Rural Women through Income-Generating Activities," *JAMBA: Journal of Disaster Risk Studies*, 2009.

researched in the research process as either co-researchers or research partners.[24] This approach is gaining popularity amongst researchers conducting research about and with people in the sex trade.[25] PAR can challenge the idea of people in the sex trade as victims or outsiders, by centering their voices in the research.

To best shape our vision for a clinic space and assess the current health access of people in the sex trade in New York City, Persist conducted a series of focus groups in the spring of 2013. Persist collected input on a range of topics including desired services, positive or negative experiences with health services, conceptions of ideal health care or health providers, as well as aspects of sex work/trading sex that were not addressed by current services. With the PAR research design in mind, Persist staff members with experience in the sex trade, as well as those with shared identities with the focus group participants, facilitated the groups whenever possible. Though focus group participants were not involved in the process of analyzing or compiling the data, a community advisory meeting was held in early 2014 to gain feedback and discuss the findings.

Methodology

Focus groups have been used in research as a means to explore the experiences of different social groups; they can also provide collective power for disenfranchised or marginalized groups.[26] In preparation for the focus group, Persist staff members received a full day training on focus group facilitation from Megan Reed of Strength in Numbers Consulting. Participants were recruited through community organizing groups for people in the sex trade, a sex worker support group, an LGBTQ support group at a day treatment center, harm reduction organizations, peer networks, flyering at public venues frequented by people in the sex trade, and social media sites such as Tumblr, Facebook and Twitter (Appendix B). Snowball sampling was utilized to maximize recruitment numbers.

[24] M. McNeill. "Cultural Criminology and Sex Work: Resisting Regulation through Radical Democracy and Participatory Action Research," *Journal of Law and Society*, 2010, http://dro.dur.ac.uk/6547/
[25] Penelope Saunders & Jennifer Kirby. "Move Along: Community-Based Research into the Policing of Sex Work in Washington, D.C," 2011, http://www.questia.com/library/journal/1G1-258131655/move-along-community-based-research-into-the-policing
[26] Pranee Laimputtong, "Focus Group Methodology: Principle and Practice," 2011, http://www.sagepub.com/upm-data/39360_978_1_84787_909_7.pdf

The five focus groups (21 participants in total) were conducted as follows:

1. Sex Worker Support Group: n = 3
2. Transmasculine Group: n = 2
3. HIV+ Group: n = 8
4. Youth Group (18-24 years old): n = 4
5. Male-Identified Group: n = 2
6. General Call Group: n = 2

Consultant Megan Reed conducting the focus group training.

The focus groups ranged from 60 to 120 minutes. They were each facilitated by Persist staff members, recorded and transcribed. A notetaker was present for all groups in case of recording failure. At the beginning of each focus group, the facilitator explained the purpose of the focus group and assured confidentiality. Participants filled out a brief optional form with questions about demographics and experience in the sex trade (Appendix A). Participants were informed that the group would be recorded; the group at the day treatment center declined to be recorded due to confidentiality concerns. Participants were free to leave the focus group at any time or ask that they not be recorded. The group at the day treatment center was held during a pre-existing group meeting time. All other focus groups were held in Downtown Manhattan at a private location in the mid-evening to

accommodate participants' schedules. All participants were provided with a meal, as well as Metrocards as needed.

Data Analysis

Using grounded theory, the analysis was not seeking to confirm a pre-existing hypothesis.[27] Persist staff members allowed themes to arise from the data. As a team, staff hand-coded the raw transcripts for major themes along the research and protocol questions developed in the focus group training; the themes that emerged were Provider Relationships and Attributes, Experiences with Disclosure, Experiences with Stigma and Discrimination, Community Support, Clinic Environment, and Specific Services.

Research and Protocol Questions

The following research questions were developed during the focus group training. They were used to guide the research, but were not directly asked within the focus group setting.

1. What experiences have people in the sex trade had with health services?
2. What aspects of being in the sex trade do not get addressed in your current services?
1. What qualities could this clinic space have that would make it desirable to people in the sex trade?

To learn about participants' experiences and interactions with the health care system, as well as how Persist might provide the best community-based services to serve sex workers' needs, we asked the following protocol questions. These questions were used to generate discussion, which was then led by conversations generated by the focus group participants.

1. Think about the best health provider you've ever had. If you haven't had this health care provider, think about an ideal health provider. What were they like/what would they be like?
2. What sorts of things make you comfortable with a health care provider?
3. What do you think makes somebody a good provider for people in the sex trade?

[27] B. Glaser & A. Strauss, *The Discovery of Grounded Theory*, Aldine Publishing Company, 1967.

4. Tell me about how you decide whether or not to tell a provider about being in the sex trade.
5. Tell me about a time when you disclosed your experiences in the sex trade to a provider.
6. For those of you who have disclosed, what was the best thing about that experience? The worst?
7. How does being in the sex trade/having been in the sex trade impact your health? Which of these things should a provider know? What do you wish your provider wouldn't focus on?
8. What would make you come into a clinic that was for people in the sex trade?
9. What else should we know?

Findings

Demographics from Questionnaire

Prior to each focus group, facilitators distributed questionnaires to all participants (Appendix A). These questionnaires included demographic information, as well as short-answer responses on respondents' experience in the sex trade; barriers to care; and most desired services. All questions were optional. A summary of the demographics can be found in the tables below.

Table 1. Demographics*

	Overall	Percentage
Gender [17]**		
Male	7	41%
Female	6	35%
Trans MTF	2	12%
Non-binary	2	12%
Age [18]		
18-24	6	33%
24-39	6	33%
40-64	6	33%***

Race/Ethnicity [16]		
Asian	1	7%
Black	3	20%
Hispanic	1	7%
More than one race	**5**	**33%**
White	**5**	**33%**
Sexual Orientation [16]		
Bisexual	3	19%
Gay	4	25%
Queer	4	25%
Straight	**5**	**31%**
Annual Income [15]		
<$10,000	**3**	**20%**
10,000-20,000	**7**	**47%**
20,000-30,000	1	7%
30,000-40,000	3	20%
40,000-50,000	0	0%
>50,000	1	7%

***Aside from annual income and age, all demographic questions were open-answer, so that findings would be self-identified and participant-driven.**
**Not all participants chose to respond to every question. The total number of respondents for each demographic variable is noted on the lefthand side.
***Percentages are an approximation, without the use of decimal points.

47% of survey respondents were female-identified, with 35% identifying as female and 12% identifying as trans MTF.[19] 41% of respondents were male-identified and 12% identified as non-binary.[20] Ages were evenly divided between the ranges of 18-24 years old, 24-39 years old, and 40-64 years old, with 6 respondents in each (33% each). The majority of survey respondents identified as either White or more than one race (33% each, totaling 66%), with others self-reporting as Black (20%), Hispanic (7%), and Asian (7%). Sexual orientation was divided between straight (31%), gay (25%), queer (25%), and bisexual (19%). 67% of respondents who reported income said they made less than $20,000 a year.

Table 2. Access to Care		
	Overall*	Percentage
Where do you Receive Care? [17]		
Private	4	24%
Hospital	3	18%
Community Health Center	6	35%

Other	2	12%
Don't Routinely Access Care	2	12%
Do you Have Insurance? [17]		
Yes: Private	6	35%
Yes: Public	7	41%
No	4	24%

Table 3. Involvement in the Sex Trade		
	Overall*	Percentage
Currently in the Sex Trade? [16]		
Yes	9	56%
No	7	44%
How long are/were you in the sex trade? [13]		
Traded a few times	1	8%
1 Year	3	23%
2 Years	5	38%
3 Years	2	15%
7+ Years	2	15%

Themes

I. Ideal Provider Relationships and Attributes

When imagining their ideal health care provider, participants emphasized the importance of respectful communication, open-mindedness, as well as a nonjudgmental attitude towards sex work, sexuality, and drug use.

> *"Having that kind of longitudinal relationship [would be] nice, someone you could actually talk openly about, not just sex work, but drug use or multiple partner involvement or just being queer in general. Basically…to have someone respect what I said that I needed, obviously listen to my symptoms and they have the expertise in some way, but to then know that because of my resources, like they had to meet me halfway."*

Participants emphasized alternative understandings of expertise, knowledge, and the importance of shared decision-making. They spoke of wanting providers who could bring their training to the table, but also respect their patients' understanding on their own bodies.

> *"I've always respected providers who are open to different opinions. For too often, you get a provider that, what they say is law or the final word, and they're not open to alternative treatments or alternative ways to of dealing with a problem. So I really like someone who's open to ideas in their practice."*

> *"It's really your body and your instrument, and whether or not you're using it for sex work or not, it doesn't matter...I think just being really open to whatever your patient is bringing you and hopefully being able to answer questions, and if you don't have answers, kind of pushing you in a direction that might. So I guess having the well-rounded wellness."*

Several participants were excited about the idea of having providers who had been in the sex trade. This peer care would lessen concerns about judgment or discrimination and minimize the need to explain oneself.

> *"I do think also that having people who have worked in the sex work industry will hopefully have that sensitivity, they will hopefully have that skill set too, because they know what it's like on our side. I hope that that translates. I have a good feeling that it probably will. It's going to be very exciting to see."*

> *"Oh, I do think that maybe that will help bridge the gap, I'm assuming the way a lot of sex workers feel when using industry–specific language, let's call it. Because a lot of the time, it's like you're speaking a totally different dialect of English. So to have someone who understands that would be useful."*

II. Experiences with Disclosure

For many participants, the choice to disclose or not disclose was an internal one, with decisions being made based on perceptions about the provider/clinic, personal circumstance, their level of comfort or their immediate need. One participant noted how care might change, based on the providers' level of knowledge about the sex trade:

"It's an important piece of information. It shapes, it gives them some context to what you're coming in with, and to not be able to say that…you know, not that it's going to negatively affect your care – you're still going to get the testing, but there's a little pieces that's missing. You know, when they ask, 'Why do you have anxiety? Why do you have depression?' Well, I'm in the sex trade, and not a lot of people get that, and I don't know where to go to explain this."

Of participants currently accessing care, few had disclosed their experience in the sex trade to their current providers. The choice to disclose or not disclose was a careful one. Participants recognized how care was changed both, based on a providers' knowledge of people's diverse experiences in the sex trade. For some, the decision to disclose was compounded with other factors: participants who were more marginalized from services were simultaneously more concerned about further discrimination.

"I'm so hyperconscious of legal ramifications that I have never disclosed to a provider and I don't see myself doing that. And then also talking about a gender variance, because I don't go to [an LGBTQ-friendly health care provider] and I go to just like wherever I can get whatever services I need. So I walk in there thinking they're going to make their assumptions and I try not to let that affect me, so it feels like its not worth disclosing because then you are going to become this joke immediately."

The decision not to disclose was also motivated by prior experience with discrimination after disclosure (in the health system or other environments), reports from friends or community members, or knowledge about potential legal problems. Just one poor experience with disclosure could change an individual's decision to disclose.

"I used to be very open about it until going to see a male OBGYN who literally said to me, 'Oh that's fucking stupid.' *And that's when I made the decision to just not talk about it [the sex trade] anymore. Not to ignore my own health. You know, I would still get whatever treatment that was necessary, but I felt if it wasn't absolutely necessary to mention it, I just wouldn't because of that one experience. And clearly I think it's a pretty touchy topic for many sex workers. And it's kind of like walking on eggshells. And it's tough to tell what their reaction will be, how that might affect your appointment, any follow up care you might need. So I think this idea of vetting specific physicians, or providers let's say, is a really great idea, so that people feel safe talking about what they do, without fearing judgment or criticism."*

> *"I think for security reasons I don't usually disclose.* Mainly because I don't trust doctors…I sort of treat them slightly like law enforcement. *And I have had friends who have disclosed, and it's turned out kind like a gnarly situation, where they just walk away feeling totally hurt, not even sure, confused, angry, all sorts of things. But I think, for what this [Persist] is trying to be in general, I think that will bypass that for a lot of people, wanting to disclose, because it will, you will be able to talk more freely with language that we use."*

Conversely, trusting a provider and wanting to maintain a positive bond with them was also a reason to not disclose. After all, having to disclose about sensitive topics, such as sexual behavior or involvement in the sex trade, might impact the care being given.

> *"Even now, having a private doctor, I haven't mentioned sex work or multiple partner involvement. He's a gay doctor, but I haven't gone there yet with him and I've seen him a few times. And once for a physical, and we talked and we did the STD screening, and he did say, you know, 'how many partners have you had?' And I gave a skewed number, and it was awkward, and I went into it thinking that I could, oh, it's a gay doctor, he's going to be kind of open. But I didn't, I'm like, I got there, ah, I don't know if I can…He seems great enough, but I don't know if I can just put it out there. Not quite sure."*

For those avoided care due to prior bad experiences or lack of affordable options, the landscape for accessing affirming care seemed bleak:

> *"I feel like in my entire life, I really haven't had that much interaction with health care providers, because I've never had health insurance. I think probably the most has probably been the ER, where, like, I absolutely have to go the ER because I'm dying. Yeah, and I don't know if I can say I've ever had a good experience and I don't know what that would be. I've had a lot of negative experiences...I cannot share my work with any of my doctors."*

III. Experiences with Stigma and Discrimination

Experiences with stigma and discrimination were defined in two ways: by the behaviors of the health care providers and by the statements of the health care providers.

While some providers make rude remarks or attempt to encourage the person to change their behavior or exit the sex trade, others discriminated through behavior:

> *"I came out once as a sex worker in those [intake] questions…I checked the box, I wanted to see what would happen, like I traded sex for money or drugs or whatever, and then afterwards I was pulled into, while you're waiting for your test results, they pull you into a side room with a counselor of some sort. I had this women who was just, just so concerned…it finally got to a point where it was clear that I didn't want to have this conversation with her…so then I was taken down to another room in the basement and I was waiting for someone to come to that room. And this white woman comes in, and it's a professional counselor. And she has nothing to do with healthcare connecting people to services. And she's like, she starts asking me questions, so what are you doing? So let's set up some times for you to come in for counseling.* And then I left. But that was, that was the last time I went into a clinic in New York.*"*

The avoidance of stigma influenced how participants felt about disclosure and when they chose to disclose. Some participants cited statements of judgment their providers made, such as suggesting they exit the sex trade:

> *"I would say what I was doing, and they wouldn't be OK. You know, they would say, 'You have so many opportunities, you can do this, you can do that.' I just felt uncomfortable, it took a while of going around [to different providers], this is what I have, this is my history, this is what happened, unprotected sex, bad shit happened, I was doing drugs, this drugs and this drugs and this drugs. And it took me a while to find someone who was like, ok cool. And after that, treated me like a person."*

Stigma also manifested itself in judgments about sexual behavior, particularly those with multiple sexual partners.

> *"I do it [get tested] every three months also, so it's like, I know these questions are coming, but when they're in front of me I'm never prepared for them. I'm like, what do you mean how many partners have I had? It sounds bad the higher the number goes. I think to myself, like god, this person's gonna look at me like, really? So that part is definitely nerve-wracking…*they have no clue who you are, no clue about your background, you can't read them or know that they're not going to try to lecture you or give you a stinkeye."

Other participants shared concerns about providers pathologizing them or drawing on societal myths about sex workers' mental health and stability.

> *"I think also the social stigmas, people assume you're a slut, or they assume you have daddy issues, or whatever it is they assume."*

IV. Community Support

When imagining a health care space for people in the sex trade, participants suggested that the clinic space be not only a center for health care, but also a space for community support, peer counseling, and community organizing.

> *"I think the word community is really key. I don't think most people, when going to the doctor, think about the types of people they might meet. But to know that there's that common thread, that general common thread of experience, I think could be powerful."*

> *"I would prefer a place that would assume that I very much could be involved in the sex trade, and that regardless, that that should be among the top priorities."*

Participants suggested peer counseling, support groups, and peer escorts as specific services:

> *"I think peer counseling is really important, maybe as social service more than a clinical service. Because I think it provides that same sort of emotional support…"*

> *"If Persist could have, say, an escort. An escort for an escort. To bring you to a clinic, who knows the provider at a certain ER that, will go to that's been through a certain training about it."*

V. Clinic Environment

Many participants spoke of feeling alienated by clinical spaces and clinical atmospheres; they envisioned Persist as a space that felt community-oriented, with resources that accommodate their lives and schedules.

"Definitely I would agree [it shouldn't be just clinical]…I think that an organizing space would be awesome just to see that there's more going on there than just sitting in a waiting room. Something that indicates that the vision is about more than you know, walk in the door, walk out. Something to definitely feel more like a sex worker clinic than a clinic clinic."

Many participants recommended having educational pamphlets and posters in the room specific to the needs of people in the sex trade. They reflected that many pamphlets in clinics currently accessed utilize "scare-tactics," encouraging abstinence from sex or drug use. Participants suggested educational materials that give examples of how to minimize risk of STI transmission, violence, or overdose, rather than blaming the individual when such events occur.

"I mean, a lot of the posters that you see now are like: do you use drugs? 13-21, then you're positive. I mean, they're just scary images. They're threatening. And it's in no way inviting. And it makes you feel like you have everything and you're going to come out positive for every STD. And the whole set up is threatening and scary, you know. We're going to scare you into being healthy and protection."

VI. Specific Services

In the focus group, participants discussed their needs for health care in four types of health care settings: primary care, mental health, sexually transmitted infections (STI) free clinics and alternative care (acupuncture). The discussion focused predominately on primary care, with some discussion of mental health as well as STI clinics. Of those who shared about STI testing, participants shared neutral or negative experiences with city STI clinics. Some of these experiences included staff judgment about participants getting screened "too often." Participants were also uncertain what happened to their reported information on the screening questionnaires. Additionally, they "shopped around" at different locations, and most said they would simply be relieved to have a central, reliably "no-questions asked" health center that understood their needs for regular screening. As one participant shared:

"I think in general it's potentially going to be great to just be able to get tested whenever. And by

whenever, I mean, more consistently. Because that's one of the biggest problems I run into. They're like 'weren't you just here?" Just relief that I can go somewhere and hopefully more, hopefully more consistently, where I'm not getting the third degree as to why I'm getting the same test again."

One participant shared an experience during acupuncture that was negative, suggesting the need for competency from health professionals beyond the scope of general care and STI testing. Another participant described how disclosing to her primary care provider created a bond with that provider, allowing her continue seeing the provider while transitioning out of sex work:

"I have one care provider and she knows about when I was doing sex work 3 years ago. Before, it was, 'You gotta do this, you gotta do that. I'm gonna give you condoms for this, you gotta be careful, and whatever you need, if you suspect anything, you've gotta come back to me.' She knew, and that was between me and her. That was just confidential, that bond between me and her."

Some participants suggested that Persist offer legal references and support post-crime, and emphasized free/sliding scale services.

"Taking Medicaid will be important for a lot of people. So having sliding scale serving available… That I think, you know, for the people that have health insurance, they can find good services somewhere. So I really hope Persist has a means-based focus."

"If I ever get hurt by a client or a police person or whatever, then, or by an intimate partner, then I have a safe place to go that isn't going to be about my sex work. Then it's going to be about documenting what needs to be documented and treating me...I think Persist should be knowledgeable as a result."

Summary of Results

Disclosure and Access

- Participants avoided seeing health care providers due to prior experience with stigma and judgment.

- Only one participant described a positive experience with disclosure about sex work, noting the bond it created with the provider. Others shared neutral or negative experiences.

- Participants chose not to disclose based on past bad experiences with disclosure, negative accounts from other sex workers, concerns that the nature or quality of care would change, and/or the belief that involvement in sex work is not pertinent to care.

- Participants were limited by lack of access to free or affordable care; knowledge of how to navigate the health system; and time constraints.

- Participants accessed city clinics for STI screening more than any other type of health care setting. At the same time, participants reported the most dissatisfaction with the kind of care they received at these clinics. Participants described barriers to care, including stigmatizing questions about multiple partners and frequent screening.

- Participants felt unsure what would happen with their information once they disclosed (e.g. on a screening questionnaire).

- Participants' disclosure about their sexual orientation or sexual behaviors informed if and how they chose to disclose about sex work. LGBTQ participants experienced discrimination based on their identity or involvement with multiple sex partners.

Ideal Providers and Models of Care

- Participants spoke of an ideal provider as one who is open-minded, respectful, and a good listener.

- Participants emphasized the importance of having a provider who is affirming and nonjudgmental about both sexual behavior and sex work.

- Participants noted that any questions that a provider asks should be directly relevant to the care they provide, rather than "prying" into one's personal and private matters.

Holistic Health and Wellness

- Participants noted experiences health care providers as developing a "tunnel vision" for sexual risk factors. In describing current, past, or imagined ideal providers, participants repeatedly described a model of wellness and harm reduction: the ideal provider would focus on their stated priorities, which often (but not always) centered on mental health, stress/anxiety, and harm reduction for occupational hazards, rather than just STI transmission.

Participant Recommendations for Clinic Space

- Common recommended services included: mental health; peer counseling; legal support and references; Medicaid enrollment; affordable or sliding scale care; general wellness services (e.g. nutrition); STI screening "no questions asked"; a space for community-building and organizing; and a network of screened sex work-positive providers for referral.

- Participants noted a desire for peer support and counseling, if not for themselves, but for the general community. They emphasized the need for emotional support within the clinic space, as well as the desire to have opportunities for community organizing.

- Participants almost unanimously suggested that the clinic space resemble more community health centers, rather than hospitals, which were seen as too cold and uninviting. The environment should reflect Persist's mission as both a center of care and community.

Limitations

Recruitment for these focus groups was largely conducted via convenient sampling of Persist's outreach and peer networks, as well as sites known to be frequented by people in the sex trade. Continued efforts to assess the health and wellness needs of those who trade sexual services in NYC would need to involve both a larger survey as well as specific focus groups, including but not limited to: trafficking survivors, those who trade sex for drugs, transfeminine and gender non-conforming individuals, street-based workers, and non-English-speaking people in the sex trade.

Organizations working specifically with trafficking survivors were contacted in our outreach efforts, though none of the participants in the focus groups disclosed that they

identified as trafficking survivors[28]. Additionally, though there were transfeminine and gender non-conforming participants, as well as street-based workers and IV drug users, in the focus groups, there were not specific groups for these populations. Similarly, it would be ideal for people in the sex trade who do not speak English as their first language to be included in a larger survey of people in the sex trade in NYC.

Due to the limited funding of Persist Health Project, compensation for the focus group participants was limited to providing one meal per focus group and metrocards upon request. This limitation was noted by other organizations as a barrier to people's involvement in the focus groups. Location and time of the focus groups also limited individuals' ability to attend the focus groups. With the exception of the morning focus group at the day treatment center, all focus groups were conducted in the evenings in Manhattan, which was less accessible for those who worked at night or lived in the outer boroughs.

Discussion

These focus groups were conducted to gain a greater understanding of the health service needs of sex workers in New York City, in order to build more sustainable and effective entries to care. Based on these data, Persist will pursue finding and establishing a clinic space that offers affordable care, holistic health and wellness services, as well as community support. Because participants reported numerous and considerable barriers to care - ranging from financial concerns to embedded societal discriminations based on sexual orientation or their status in the sex trade - Persist will maintain a strong commitment to and develop further strategies for reducing such barriers.

Accessibility to care is a complex challenge that can be approached from many fronts: addressing stigma and discrimination, affordability, and other access barriers. For many focus group participants, the suggestion of stigma was as debilitating as the act of

[28] Though both Persist staff members and focus group participants identify as survivors of violence or coercion, none of the participants disclosed as identifying as a trafficking survivor in these focus groups.

stigmatization (as demonstrated in providers' behavior or statements). As the focus group participants illuminate, while many have has negative experiences with providers in the past, the internalization of stigma about being in the sex trade manifests itself in the avoidance, or management, of disclosure. Many participants discussed how they avoid disclosure, for fear of it being at the expense of their care.

Since over half of questionnaire respondents earned less than $20,000 a year, the need for free and sliding scale services emerged as a clear need, which was echoed by participants' responses in the focus groups. Participants would also be more likely to seek services as a clinic space that offers benefits counseling, referrals to a network of screened nonjudgmental and affirming providers, and hours/locations that best fit their needs. Accessibility also speaks to the notion of an accessible culture. Walking into a care center that is perceived as "cold and uninviting," or where health providers and staff pass judgment on clients, significantly decreases the likelihood an individual will return for a second visit.

This need for approachability and friendliness extends to all levels of the clinic staff, including administrative and front desk staff. Fostering an environment where patients/clients feel safe to disclose any aspect of their life and health if they so choose, free of judgment and discrimination, is central to quality and dignified care people in the sex trade in NYC. Efforts should also be made to build the capacity of our peer counseling and care coordination services, as well as consider how meaningful input from the community can continuously be heard and acknowledged within our programming.

Based on the input of the focus group participants, Persist will:

- Expand our care coordination program, in order to ensure that people in the sex trade are linked to affirming, nonjudgmental health care at every opportunity
- Continue to provide accurate and up to date information to people in the sex trade in NYC about sexual health and general health, via peer health educators and health professionals
- Pursue a clinic space with a community-focused atmosphere, where care moves beyond general and sexual health needs, such as regular testing services, to emphasize peer support and holistic health care

- Provide health services at low to no cost whenever possible

- Emphasize the need for affirming and nonjudgmental care for people in the sex trade in trainings for other health professionals

- Train volunteer students and medical personnel involved in Persist on the needs of people in the sex trade in NYC

- Maintain involvement of people in the sex trade at all levels of the organization; recruit staff with a range of experiences and identities.

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Acknowledgements

This report was written by Claire Paradis McCullough and Sarah Elspeth Patterson.

Coding was conducted as a team, by Claire Paradis McCullough, Sarah Elspeth Patterson, Zil Goldstein, Lola Pellegrino, Kate D'Adamo, and Lindsey Hennawi. Claire Paradis McCullough brought our scraps of paper and poster board onto the typed page.

The focus groups were facilitated by Laura G. Duncan, Claire Paradis McCullough, Chance Krempasky and Sarah Elspeth Patterson. Notes were taken by Claire and Laura, in the event that there was another facilitator.

The cover photo design is by Deviant Beauty Creations; the image was adapted from Opensourceway, which is licensed for distribution and adaptation via Creative Commons.

Additional thanks to Megan Reed for training the team for the focus groups and Beth Israel for providing space for the training.

Our deepest thanks to our fellow community members to took the time to share their stories with us and helping us to demand more space for the health and wellness of people in the sex trade in New York City.

Appendix A

PERSIST: Providing Educational Resources in Support of Individuals in the Sex Trade

The Persist Health Project is a New York City-based health partnership, made up on nurse practitioners, health educators, social workers, advocates and caring volunteers, all of whom have current or former experience in the sex trade or are committed allies.

We are aiming to set up a drop-in clinic specifically for people in the sex trade. To shape the face of this clinic, we are asking you to provide input on a range of topics, such as: what specific service should the Persist Health Project aim to provide; what positive and negative experiences have you had with health services; and what aspects of being someone in the sex trade don't get addressed by your current services? All names and identifying information will be kept anonymous. You may decline to answer any portion of the survey below.

Where do you receive medical care?

- ❒ Private Doctor
- ❒ Hospital (name):

  _____
- ❒ Community Health Center (name): _____
- ❒ Other (please specify/name): _____
- ❒ I don't routinely access medical care

Please describe any challenges or barriers you face to accessing health care.

_____
_____
_____
_____
_____
_____

Please specify what services (clinical or social) you would be most interested in receiving at the Persist health clinic.

_____
_____
_____
_____
_____

Are you currently involved in the sex trade? (Yes/No)
How long have you been/were you involved in the sex trade?
_____

Describe your experience in the sex trade:
_____
_____
_____
_____
_____

Demographics:

Region/Borough of Residence: _____	**Region/Borough of Work:** _____
Age ❒ 17 or younger ❒ 18-24 ❒ 25-39 ❒ 40-64 ❒ 65 or older	**Race/Ethnicity:** _____
Gender: _____	**How many people live in your household, including yourself?** _____
Sexual Orientation: _____	**Pre-tax annual income** ❒ Under 10,000 ❒ 10,000 to <20,000 ❒ 20,000 to 30,000 ❒ 30,000 to <50,000 ❒ 50,000+
Do you have health insurance? (Yes / No) **If yes, what kind?** _____	

Other questions, concerns, or recommendations?
_____
_____
_____
_____
_____

Appendix B


Do You Trade Sex in NYC?
We Want to Hear From You!
Persist Health Project is conducting a focus group for folks who trade sexual services in NYC.
We are opening a drop-in clinic for people in the sex trade and want to hear from you what you want and need for your life.
persist
HEALTH
Monday, April 29, 7-8:30 PM
Food and MetroCards provided. Confidentiality ensured.
For more details and to RSVP, text "RSVP" to 646.334.0581
or email SARAH@PERSISTHEALTHPROJECT.ORG