Submission to the Statutory Review of the Public Health Act 2010

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2016 Statutory Review of Public Health Act 2010

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About SWOP NSW

Sex Workers Outreach Project is Australia's largest and longest established community based peer education sex worker organisation focused on HIV, STI and Hepatitis C prevention, education and health promotion for sex workers in NSW.

Last year SWOP interacted with over 5,000 NSW sex workers, visited over 440 sex services premises throughout NSW including 44 visits to regional and rural areas and distributed more than 270,000 pieces of safe sex equipment. We distributed over 20,000 printed pieces of information and developed 19 new resources; trained 52 non-sex work organisations and held 15 small group workshops for sex workers.

SWOP was established in 1990 after it's predecessor the Australia Prostitutes Collective which had been established in 1983 ceased operation. Since 1990 SWOP has been funded by the NSW Ministry of Health (NSW Health) to provide sexual health information and support to sex workers in NSW, specifically in relation to HIV and other sexually transmissible infections..

General Comments

SWOP's Aims in Responding to this Review

SWOP's aim in responding to the discussion paper on the review of the Public Health Act is threefold;

- First, how best the legislation can be used to support the attainment of the goals in both the NSW HIV Strategy 2016-2020 and the NSW STI Strategy 2016-2020 with particular attention to the goals of
    - the virtual elimination of HIV transmissions by 2020 including the continued virtual elimination of HIV in sex workers and
    - sustaining the low rates of STI's among sex workers.
- Second, how best to support the health, well-being and human rights of persons living with HIV and in particular sex workers who live with HIV.
- Third, how best to maximise public health outcomes in general for people in NSW.

SWOP's Community

SWOP represents NSW sex workers, a section of the NSW population who are highly stigmatised due to their occupation and whose occupations are not well understood. NSW sex workers are subject to high levels of discrimination across nearly all aspects of their lives. This fact makes sex workers keenly attuned to the stigma faced by people with HIV, and understandably fearful of experiencing what is in effect double stigma, should they ever find themselves in the situation of testing positive for HIV.

SWOP's Community (cont)

For many NSW sex workers, their occupation also involves travelling interstate for work. This means they are well aware of differing Australian legislation surrounding both HIV and sex work. A NSW sex worker, whose income depends upon working in Victoria (where working as a sex worker whilst HIV positive is a criminal offenses), is unlikely to test for HIV in NSW if the Ministry decides to bring in named notifications, unless they can have a guarantee that their personal information will be kept completely confidential and not shared across agencies or between states..

Last financial year the sex workers in NSW that SWOP engaged with included 44.7% who identified as culturally and linguistically diverse. Many of these sex workers are recent immigrants, who can easily recall the State's interest in their HIV status as they entered Australia. Being asked by the State about your HIV status adds to fears about the future disclosure of your HIV status, and remains a significant barrier to NSW sex workers accepting the changes proposed by the Ministry. Fears about the State's view on HIV positive people is not unfounded – only last year did our community see media reports of a gay HIV positive man being denied "a tourist visa because he did "not satisfy" a section of the Migrant Regulations and his "disease or condition (HIV)… would be likely to require health care or community services"."[1]

SWOP works with migrant sex workers across all visa types, including those on student visas, who do not necessarily have permanent residency in Australia and the resulting access to our Medicare system. Some sex workers we see work in violation of their visa conditions. Working in violation of visa, combined with a perception that the State is against people with HIV is yet another reason migrant sex workers might choose to only participate in HIV testing anonymously. Should a migrant sex worker test positive, SWOP hears anecdotally that they often chose to return to their country of origin where HIV medications or treatment is easier to obtain.

Migrant sex workers in Australia also come from parts of the globe where there might be a significantly different attitude to sex work, HIV prevalence, social and State-directed attitudes and treatment of people with HIV. Cultural background will thus be another key determinant of how sex workers respond to these proposed changes by the Ministry. In the course of making this submission, SWOP's position was informed by our service users whom we contacted via a brief online survey, promoted on our social media accounts on Facebook and Twitter. The short timeframe of this submission meant we were unable to translate our survey into community languages to obtain feedback from culturally and linguistically diverse sex workers.

[1] Power, Shannon, *HIV-positive man mistakenly denied tourist visa to Australia*, Sydney Star Observer, accessed http://www.starobserver.com.au/news/national-news/hiv-positive-man-mistakenly-denied-tourist-visa-to-australia/145324 accessed 01/06/16.

Special Considerations as to Highly Marginalised and Stigmatised Communities

Sex workers are a highly marginalised and stigmatised community. We are often not given the same rights and considerations as non sex workers and suffer discrimination in many different forms. When individuals from our community intersect with other communities such as people living with HIV, people who use drugs, trans people, indigenous people, migrants and persons from minority races then sex workers can be subject to multiple stigmas.

Sex workers and SWOP know from experience that for people experiencing multiple stigmas rules, guidelines and often even laws are not complied with and sex workers are further marginalised and alienated from social systems including health and justice.

S79 of this Act came into being due to a political reaction to the intersection of sex work and HIV in one person; Sharleen Spiteri. Sharleen was originally detained using public health law for political reasons and that detention continued for 16 years until her death in 2005. For the sex working community the Sharleen case remains as source of deep mistrust of fair and equitably applied legislation.

Whilst most high profile cases of breaches of sex worker privacy have occurred in other jurisdictions NSW sex workers are highly aware of a number of cases. The most disturbing of these was a case of a South Australian sex worker living with HIV who moved to the Australian Capital Territory. The South Australian Health Department immediately notified the ACT Health Department and the New Zealand Government (as it was thought he had holidayed in New Zealand en route to the ACT). The ACT Health Department then took the extraordinary step of simultaneously notifying the media and police of this persons HIV status, name and address. These breaches of procedure, law and privacy were done in “the public interest” even though there was no evidence that there was any risk to public health and despite an extensive and well publicised police investigation no such evidence was ever found.

Our Consultations on this Review

SWOP’s response to this review has been informed by consultation with members of our community through a community survey, a community forum and submissions to SWOP from individual community members. As our community members are often members of other communities as well as the sex work community we analysed feedback from the ACON/Positive Life NSW Forum. We also consulted with other organisations in the HIV sector, drew on our knowledge of other jurisdictions both here in Australia and overseas with particular reference to sex workers and our 30 years of organisational experience working in the HIV sector.

SWOP's Responses to the Issues

The Objects of the Public Health Act

SWOP supports ACON in asking that a change be made to the Objects to note the ongoing importance of privacy in the application of the Act.

We also do not see the inclusion of an additional objective as being necessary , as we feel that the actions in the additional objective already exist in the current objectives.

Named notifications 3.5 (c) Section 56

This is the proposed change that will encounter the most resistance from NSW sex workers. SWOP's position is that while there are some modest benefits to both public health and to individuals, to be gained from notifying individuals diagnosed with HIV by name and address, these benefits are not significant enough benefits to risk impacting sex worker willingness to undergo HIV testing.

Most of the benefits that the Ministry outlines in the discussion paper only improve the lives of small subsets of individuals. For example, SWOP recognises that some individuals may be lost to care in the period immediately following diagnosis with HIV. We agree that named notifications would enable public health officers to make direct contact with individuals at risk of being lost to care and to offer alternate pathways to care to those individuals. We can see that this might be of some benefit to a small subsection of the people who are newly diagnosed with HIV, but question whether sex workers subsequently contacted by the State about their diagnosis would be likely to respond positively to that contact.

With respect to the more vulnerable sub-populations of sex workers, including culturally and linguistically diverse sex workers, and sex workers residing in rural or regional areas, stigma and discrimination in healthcare settings, and the fear of stigma and discrimination in healthcare settings are not to be underestimated. Sex work stigma is already a barrier to sex workers accessing mainstream health services. We believe sex workers, particularly those in sub-populations who are at higher risk of acquiring HIV, will feel less comfortable with named notifications than they do with coded notifications. We are concerned that moving to named notifications would potentially introduce an **unnecessary barrier to HIV testing.**

These concerns were a strong theme of the feedback SWOP received to our survey. Of the respondents (who all chose to answer this question) 89.29% gave a flat no to named notifications, 7.14% qualified their no answers with narrative about the importance of confidentiality, stating things including "*confidentiality is important for protecting vulnerable people. In environments where confidential testing and treatment is available, rates of HIV seroconversion and STIs are proven to go down.*" Only 3.57% of respondents were in favour of named notifications responding that HIV should be brought in line with other notifiable diseases because the current codification "*doesn't reflect the current environment or outcomes for a new HIV infection*". As we mentioned in the introduction, these figures do not include feedback from sex workers from culturally and linguistically diverse backgrounds, particularly recent migrant sex workers, and sex workers on student visas.

SWOP asked NSW sex workers whether named notifications would impact upon their willingness to test. Of the (96.43%) of respondents who chose to answer this question, only 3.70% indicated it would not impact their willingness to take a HIV test because they were comfortable with the level of security the Ministry takes with their data. Not having their information able to be subpoenaed would convince a further 11.11% of respondents, with one respondent adding:

"*I would be comfortable with more information being provided if I was confident in the security of the data*." The ongoing guarantee of anonymous testing is clearly important to sex workers, as 27.04% of respondents indicated they would continue to test if they could do so anonymously, however nearly half (44.44%) of the respondents said they would not test at all if named notifications were brought in.

SWOP's main concern is that sex workers, including Aboriginal and Torres Strait Islander people who trade sex for favours, will find this change to named notifications lowers their trust in medical professionals, which can already be tenuous due to their stigmatised profession. We have made considerable gains in this area, while sex workers still experience stigma and discrimination in a variety of settings not limited to healthcare, the battle here is by no means won.

SWOP asked our service users who they would like to be able to call them about HIV treatment options. Of the (96.43%) of respondents who chose to answer this question, more than half (62.96%) felt it should only be their treating doctor, with some respondents adding impassioned comments including:

> *I have chosen my doctor, therefore I trust and have a relationship with them. If the ministry of health calls me I would already think 'great, they've already breached my trust and are passing around my details. I can't trust them.' also I would think 'who are you? I don't know you, you don't know me, you don't understand me. Don't call me telling me what I should be doing. fuck off!'*

Other respondents cited concerns about the mental health impact of being called by the Ministry:

> *I would feel intensely exposed if a government official were to contact me regarding a recent test. It is unreasonable for any contact to be made by anyone outside the therapeutic relationship for the continued mental health of the patient.*

Of the remaining respondents, 29.63% felt that if the Ministry of Health wants to contact them, they must do so through their doctor, which we understand is reflected in the current system. Another 3.70% of respondents felt comfortable with contact by their doctor and the Ministry of Health, while the remaining 3.70% of respondents were unhappy with being called at all. One respondent explained: "*Nobody should call anyone - it should be discussed in person when the diagnosis is made, and follow up appointments discussed if necessary.*" SWOP agrees that it would be possible to achieve the same outcomes by improving the capability of diagnosing doctors to educate patients, offer referrals and retain those individuals in care. We support strengthening the doctor-patient relationship rather than introducing an additional party (namely a public health officer) into that relationship.

SWOP is most concerned that named notifications will impact sex workers' willingness to test, and when they do test, it will reduce the information they choose to provide about their sexual history, about any additional contributing factors like drug use, and about their occupation. SWOP feels sex workers receive the most nuanced healthcare when they provide occupational information at the time of testing. Sex workers who do not disclose their occupation are not always being offered the full suite of relevant STI tests. Undiagnosed STIs increase the likelihood of sex workers acquiring HIV. From SWOP's point of view, sex worker health and public health is thus better protected by keeping coded notifications because to do otherwise would impact sex workers trust in medical professionals.

De-identified HIV diagnostic test requests

SWOP is moderately supportive of the proposal to remove the prohibition on including a person's identifying details in a pathology request form for HIV once the individual has consented to be tested for HIV. Arriving in a discussion paper that also suggests named notifications however has coloured this component of the Ministry's proposed changes negatively for sex workers, who seemed to view it as being asked something that is tantamount to the same thing. If this was explained more fully, we believe there the Ministry is likely to find more support and less negative impacts from this proposal, given that the majority of people with HIV don't object to their name being on a viral load test.

Sharing clinical information

While SWOP agrees that there is a health benefit to the individual patient afforded by the sharing of clinical information amongst those participating in their medical care, we're also keenly aware that this positive must be balanced against the negative effects of stigma and discrimination that underlie the reasons that people in marginalised groups silo their health information. For example, sharing your occupation as a sex worker may derail your psychiatric care for anxiety, if the psychiatrist perceives your sex work as the problem.

Even within the broad category of sex worker, there are many different groups of SWOP service users who report siloing health information on a need-to-know basis:

- *Rural and regional sex workers* face higher levels of stigma, discrimination and social exclusion than urban sex workers. Many of them see a family doctor for most general health problems, but silo off sexual health to anonymous sexual health clinics, sometimes located in the next town.
- *Aboriginal and Torres Strait Islander people who do sex for favours* report similar issues when using their local Aboriginal Medical Service (AMS), which are often staffed by people from within their communities. These service users report to SWOP that they often do not disclose paid sexual encounters to the AMS in the course of obtaining other medical care, either not disclosing this information to any service other than SWOP, or siloing off sexual health testing to non-community based services when they visit urban centres.
- *Culturally and linguistically diverse sex workers*, anecdotally report travelling to suburbs far away from where they live in order to avoid the stigma and shame of being outed as a sex worker. These workers report visiting sexual health centres near locations where they work, far from their home suburbs, because even being seen near a sexual health centre might out them to their community.
- Urban male sex workers report siloing off information about their paid sex work, flying under the radar by HIV testing as men who have sex with men (MSM). Regionally based male sex workers from satellite locations like Wollongong report travelling to Sydney to work, and wouldn't disclose being a sex worker to local health services where they live.

NSW sex workers are already wary of sharing their health and occupational information due to ongoing stigma and discrimination they have experienced within the medical profession, SWOP believes the idea of sharing clinical information about HIV even more widely will likely distress sex workers, and remove the perception of their healthcare being patient-centred. Accordingly, SWOP believes this proposed change has the potential to impact upon sex workers' willingness to test for HIV.

We asked our service users what they thought, and of the (96.43%) of respondents who chose to answer this question, a resounding 96.30% were against anyone other than their treating doctor having access to their HIV diagnosis, unless they decided to give that information out. One respondent explained:

> *Electronic records could be disastrous for many marginalised groups. You all don't want to acknowledge it but doctors DO discriminate. It's fact. I need to know my most sensitive information is only viewable by my trusted doctor and that if I have to be treated elsewhere then my privacy is safe. This is imperative.*

Other respondents took the opportunity to point out that a patient centred approach is important, saying "*it should always be the choice of the person to disclose their status to other professionals. It could easily be done by their treating doctor, with discussion and consent.*" SWOP agrees that this idea undermines the rights of people with HIV to reveal their HIV status to medical and health care workers at a time of their choosing. Given that the majority of people with HIV have directly experienced HIV-related stigma in healthcare settings, exercising control over the release of this information is very highly regarded.

Should the Ministry proceed with this change, SWOP recommends clear delineation of what types of medical professionals will have access to this data being outlined and explained to the general public. SWOP would also advocate for a patient-centred approach that offers back control to the person diagnosed with HIV to opt out of clinical sharing of their HIV status should it be distressing to them. SWOP and our service users would also be reassured by seeing a concurrent commitment to anonymous sexual health testing remaining an option in NSW, including anonymous HIV testing, available without the requirement of producing a Medicare card.

Guaranteed, anonymous testing without the provision of a Medicare card is particularly important to NSW sex workers. We note that in the last year, even seeing a Medicare sign appear on the front counter of one of the highest volume Sexual Health Clinics frequented by sex workers was a disincentive to testing. Multiple sex workers reported to SWOP Outreach staff that they saw the sign, assumed it meant they would have to produce a Medicare card in their real name, and turned around without testing. This issue was discussed at length at meetings of the Sexual Health Outreach Workers Network (SHOWnet), and even though the clinic in question still allowed testing without a Medicare card, it demonstrates how even small procedural changes can have an impact upon sex worker willingness to test.

Disclosure of HIV Status

We have a strong commitment to the removal of s79 from the Public Health Act and whilst we welcome the inclusion of the exculpatory defence in the last review of the Act we believe that the complete removal of this section would have significant benefits.

S79 works against the fundamental principal of mutual responsibility and universal precautions that has underpinned our community's response to HIV so effectively in the last 30 years. The public law as to disclosure (s79 of the Act) and the criminal sanctions on HIV transmission are poorly understood by the public and are often conflated. This leads to a reliance being place on persons living with HIV to disclose and unfortunately leads persons to believe that unprotected sex is safe with persons who have not disclosed HIV infection.

There are many factors that may lead persons who are living with HIV not to disclose their status to partners in sexual encounters; including a very real fear of physical violence. It is also well documented that a substantial number of HIV transmissions occur where one partner has an undiagnosed HIV infection.

This section also creates vulnerability for persons living with HIV and especially for sex workers living with HIV. SWOP is aware of cases of attempted blackmail of HIV positive sex workers where it has been alleged by a client that there was no disclosure. As negotiations with regard to sex work are private one on one worker to client arrangements and not witnessed and sex workers are highly stigmatised sex workers living with HIV are highly vulnerable to this type of activity.

This section also forces sex workers living with HIV to disclose their private health information every time that they work (if they offer sexual intercourse as defined in the Act). Not only is this disclosure unnecessary, there being no documented cases of HIV transmission in the Australian sex industry ever but it puts the HIV status of sex workers living with HIV in the public domain which can then impact on their health and safety.

SWOP asked our service users what they thought about removing Section 79 from the Act. Of the (96.43%) of respondents who chose to answer this question, 88.89% agreed it should be removed, citing reasons like:

> *Yes! Safe sex is EVERYONE'S responsibility. You should protect yourself every time anyway! It's like a doctor doesn't say to her patient 'do you have anything infectious? No? Oh, ok then I won't wear gloves today'*

Of the remaining respondents, 3.70% were unsure, and 7.40% were in favour of retaining Section 79, stating things like: "*I think s79 has the potential to discourage testing, but it is established in precedent that taking 'reasonable steps' to prevent transmission is a defence against failing to disclose. I think this should be kept.*"

Public Health Orders

SWOP believes that it is of critical importance that responses to cases where people may be putting other people at risk or where there is alleged transmission of HIV should be dealt with where possible through a health framework and not by the criminal justice system.

SWOP does however have concerns about public and community perceptions of public health orders and strongly supports proposals to increase transparency requirements in the Act.

SWOP's Recommendations

Working with so many different sex worker communities means that while SWOP in principle agrees with the Positive Life NSW position "*that the proposed changes will have more benefit to people with HIV than harm*"[2] we find it hard to reconcile that with properly representing the combined interests of the diverse communities of sex workers that we represent. As an organisation, SWOP cannot support these changes until such a time when our various communities are brought along with us.

Extensive Public Education

SWOP believes to achieve these changes without impact to our 2020 target of ending HIV, the Ministry will need to run an extensive public health campaign that clearly conveys the rationale and benefit to the individual of the proposed changes, as well as detailing how an individual will be protected from stigma and discrimination. This campaign will need to be translated into community languages.

Clear Definitions

SWOP recommends clear delineation of what types of medical professionals will have access to HIV information being outlined, and explained to the general public. We would also advocate that keeping the pool of clinical data confined to doctors would be most acceptable to sex workers.

Opt Out Provisions

SWOP advocates for a patient-centred healthcare approach that offers back control to the person diagnosed with HIV by allowing them to opt out of clinical sharing of their HIV status, should the idea of this be distressing to them.

Commitment to Ongoing Anonymous Testing

SWOP service users would be most likely to accept these changes if they came with a concurrent commitment to anonymous sexual health testing, including anonymous HIV testing, remaining an option in NSW. This testing must be widely available without the requirement of producing a Medicare card.

[2] Feeney, Lance, *Changes to the NSW Public Health Act 2010 – What will it mean for you?*, Positive Life NSW, http://www.positivelife.org.au/blog-advocacy-and-policy/nsw-public-health-act-2010.html accessed 16 May 2016.

Concurrent Legislative Changes

SWOP's support for the proposed changes to the NSW Public Health Act 2010 is contingent upon a number of concurrent legislative changes. The most significant and non-negotiable change is that identifying information provided to the Ministry needs to be protected from being subpoenaed.

SWOP also recommends the following concurrent legislative changes will likely improve sex worker acceptance of the proposed changes to the Public Health Act 2010:

- Sex workers would be more likely to accept named notifications if occupational discrimination legislation was created, affording them the same protections against vilification. SWOP notes that it is the anti-vilification and anti-discrimination legislation is largely responsible for the reduction of stigma and discrimination against gay and lesbian people, and people with HIV, which has prompted the Ministry to suggest historically coded notifications are no longer necessary in the first place.
- Interstate laws preventing sex workers from working with HIV need to be changed to assuage sex worker fears about being unable to work interstate after testing positive for HIV in NSW.
- Immigration laws preventing entry of HIV positive people to Australia, or making it harder for people with HIV to obtain permanent residency because of the cost of HIV treatment on the public health system, need to be rescinded.