

Women, Drugs, HIV – *a discussion paper*

In addressing some of the issues arising in the context of women, drug use and HIV this article draws on the personal perceptions of the author, the staff of the Ana Liffey Drug Project and on the perceptions of women and men who are directly affected by drug use or HIV as they have been related in conversation, in counselling or in research. In some ways, then, this presentation may at points appear to be very subjective but we would argue that personal perceptions and people's direct experience cannot be undervalued

INTRODUCTION

In the 1990 Ana Liffey Drug Project Annual Report, we asserted that it is not possible to respond to the issue of problem drug use in isolation from social factors.

Problem drug use is fundamentally a “social problem”. In the Irish experience it has been principally a “community problem”. Its causes and effects are most apparently social in those small geographic areas where opiate use and a variety of activities associated with it have been most prevalent. The first escalation of opiate use in the late 1970s – and its continuation since – was and is clearly confined to a small number of flat complex communities in the inner city of Dublin and a number of local authority housing estates in its suburbs. These areas are characterised by high unemployment and generalised deprivation. This social problem is indicative of a breakdown in community and of a limiting of social, recreational, educational and employment choices. We cannot respond to the drug problem in isolation from these factors.

In a similar vein then the argument presented here is that we cannot respond to the issue of women's drug use or indeed women's experience of HIV in isolation from the broader picture for women.

Estimates have been offered by various agencies as to the numbers of people involved in illicit drug use. But it is only recently that the importance of a gender breakdown has been recognised. In terms of HIV to date, the majority of women have been categorised as having contracted the virus through the sharing of needles and/or syringes, while others have acquired the virus through sexual contact. Of the 619 drug users who have tested HIV positive up to December 1991, 461 are men and 150 are women. Of the 129 people categorised as heterosexual it is believed that over 75% are women. However, these women are generally perceived as DRUG USERS or PARTNERS OF MEMBER OF HIGH RISK GROUPS rather than as WOMEN, so that their issues and concerns and those of women drug users in general are seldom examined in a gender specific context.

GENDER SPECIFIC ISSUES

In 1989, Shane Butler, of the Addiction Studies Unit in Trinity College, and Marguerite Woods carried out a brief qualitative research project. This was commissioned by the Institute for the

Study of Drug Dependence in London in order to explore and examine the needs of women with HIV and those who are caring for them. A number of gender specific issues were identified, principally in relation to pregnancy, motherhood, child care and the cultural, institutional and constitutional restraints experienced by Irish women in general and women with HIV in particular. The advent of HIV has merely served to highlight the tendency of women to care for others – particularly their male partners and children- to the detriment of their own health and well-being. It is generally believed that women are slow to utilise existing services, some of which are deemed to be inaccessible to them or unaware of their needs. The advent of HIV has highlighted the inadequacies in our services for drug users. It has also highlighted the inadequacies of our services for women.

As a result of this research, a paper based on the findings has been published, (*c.f.* **Butler, S., Woods, M.** “Drugs, HIV and Ireland: responses to women in Dublin” in *AIDS, Women, Drugs and Social Care*, edited by N. Dom, *et. al.* London: ISDD. 1992) This article focuses on the perpetuation of powerlessness among women drug users and women with HIV. “Powerlessness” would appear to be the key word here and is crucial in the context of women’s experience in general and particularly in the context of the realities of the lives of women who use drugs with or without HIV and other women with HIV.

It is important to examine and assess services in the context of gender specific issues. There has been an absence of this kind of perspective and indeed these gender specific issues have, with some exceptions, been almost totally ignored. It is timely now that an interest in women’s issues has emerged. As Joy Roulston said in a paper to the 1st Scottish Women and HIV conference in 1988 – “Once again, as with so many societal issues, we are in danger of extrapolating from the male situation to the female, and this is neither possible nor indeed tenable.” It is necessary to examine attitudes towards women drug users, and attitudes to women who live with HIV whether their infection has occurred as a result of injecting drug use or through sexual contact. There are women who use drugs who have contracted the virus through sexual contact, there are women who have never used drugs who have contracted the virus through sexual contact with a drug using partner and there are women who have contracted the virus heterosexually who have no known contact with drug users. However in the Ana Liffey Drug Project we have had a number of contacts from women who are directly affected but who have never used drugs or had a drug use connection yet in the absence of services for women have actually requested counselling and support from this supposed drug specific agency. This really raises problematic questions about services for women.

The issue of women as carers, either professional, voluntary or most importantly family carers is also crucial. A focus on the lives of these women which takes account of women’s traditional care giving role in society is necessary so there can be an adequate and comprehensive service delivered to women in this position. This is extremely important because there is a very large number of women in Ireland as everywhere caring for and supporting people who use drugs and people with HIV.

WOMEN AND DRUGS

Let us just look briefly at the gender breakdowns in the world of drugs. The world of drug use on the street, as the expression goes, would appear to be a male dominated arena, particularly in terms of the numbers. The findings of the Health Research Board in 1990 would suggest that of those attending all the various Dublin drug services, 74% of attenders are men and 26% attending are women. So just in terms of numbers it would appear that there are considerably fewer illicit women drug users than their male counterparts.

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Similarly, in the drugs services in Dublin although there are a phenomenal number of women working in the field the most powerful positions traditionally have been and are currently held by men. In only one Dublin drugs project is there a women coordinator or director. The supposed upper echelons are pretty much male dominated.

In terms of drug use and women's issues women's organisations or women's health groups tend not just to marginalise the issue of women and illicit drug use but to ignore it. Women and dependency may arise as a topic but the discussion will generally focus on women and alcohol and there are certainly attitudinal problems here. However more often there is a focus on women's use of tranquillisers, anti depressants and the like. This tends to be regarded as substance or drug dependence rather than "abuse". Once illicit drug use comes into question there is a kind of clamming up about this issue. The perception of women who use illicit drugs as "abusers" appears to be that most prevalent and these women are less "worthy" or "deserving" of discussion, attention or advocacy. As a result women drug users have less of a voice, they are more marginalised than many other groups of women and there is a silence and invisibility about them which is not just self imposed. They are largely "hidden" from view. They are regarded as "deviant" women by society, by some of the drug treatment services and by many women's organisations. Deviance is the concept employed throughout because of the interesting sociological relevance of notions of deviance and labelling. It demonstrates that women's "deviance" is somehow less acceptable than men's deviance. A definite perception I have gleaned over time working in the ALDP is that there is increased labelling, more stigma and isolation associated with women's drug use.

It would appear that AIDS/Drugs organisations have not been overly concerned with women's issues while women's organisations were certainly not overly concerned with issues about drugs and HIV. So where do women with HIV and drug use issues fit in?

The public perception of a drug user is frequently that of a young man. But despite the almost constant invisibility of the issue of women's drug use, it is on the other hand sometimes presented as evidence against a woman. There are perceptions of women who use drugs as "unfeminine", "unfit to parent" or "irresponsible". This sort of "deviance" may be regarded negatively but if a woman has already been regarded as "deviant" – if she is an ex-prisoner, as many women who use drugs are, if she has worked in prostitution as some women have, or if she is a lesbian, which a considerable number of women drug users are – the knowledge that she is using or has used drugs may only exacerbate the already existing assumptions about her. These attitudes are often internalised by women themselves and frequently prevent women from being open about their use of drugs and may actively stop some women from seeking help or support if they need it. Fears about drug use in relation to pregnancy and child care issues, particularly child protection issues, may have the same censorious effect.

Research has shown that many drug users may be well into their drug using "careers" (on average four years) before they present at an agency for medical treatment or for counselling and support. Perhaps future research will support the belief of many drug workers that women tend to present later, if at all. As mentioned previously the male/female ratio is estimated at approximately 3:1. The reasons for this difference are attributed variously to women's position and role in society, socialisation processes, less freedom, harsher familial attitudes to "deviance" in girls and women.

Interestingly considering the male/female ratio, the Ana Liffey Drug Project has witnessed an increased attendance of women in the last three years so that approximately 35-45% of people using the service in any one month are women. The majority are women with a history of drug use.

Others are the women partners of male drug users, women partners of women drug users, and mothers of adult drug users. In April last, women's attendance at the Centre represented 47% of that month's attendance and that does not include women seen in the prison, in hospital and at home. In 1991 we had a total of 10,770 meaningful contacts with a total of 631 individuals in our counselling and drop in centre. 61% of attenders were men, 39% women. This is considerably higher than the usual attendance at drug services, statutory or non-statutory. Some services are reporting women's attendance to be as low as 15%.

WOMAN USER-FRIENDLINESS

In the Centre we have not aimed to nor do we intend to positively discriminate in favour of women but we attempt to provide a service which meets the needs and aspirations of both women and men. We have, by accident rather than intent, a large number of women staff, all of whom would espouse strong feminist ideals and indeed a number of us have worked for various periods in women's organisations prior to becoming involved in this area. We have a large core group of women attenders who are also woman centred, very aware of the various issues for women around drug use and HIV and becoming increasingly vocal. It raises the argument about the necessity of services looking at what being woman centred and pro woman actually means. The notion of a "user friendly" service is certainly tossed about a lot in the context of drug services especially since the advent of HIV and the need to embrace harm reduction or health promotion policies. But the use of this terms to describe a service without examination and constant review and evaluation should be questioned. It is also necessary to gauge the WOMAN user friendliness of agencies in all contexts, but in a Dublin context it would appear to be a priority as the research revealed that many services were inaccessible to women or unaware of women's needs. It does not necessarily have much to do with creches and women's shop front days, which ironically are sometimes regarded negatively by women as invasive and supervisory. It can have more to do with the attitudes of workers, female and male, in the agencies. The overwhelming importance of non-judgemental attitudes and a non-directive approach cannot be overstated.

In the public psyche in Ireland HIV is more often than not tied in with the notion of "deviance", either "deviance" with regard to the use of drugs as already discussed or sexual "deviance" because to be sexually active outside of very narrow parameters or to be open about one's sexual activity is problematic in a country where we, as women, are denned in reproductive, procreative and maternal rather than sexual or other terms in the Constitution and in cultural and social attitudes. Consequently many women have found it so difficult to be open and forthright about their HIV status because in revealing their status they are revealing a lot more information about themselves. We have met a number of women who have revealed that they have contracted the virus sexually but will claim in wider circles to have acquired it through drug use, even in the absence of a history of drug use. This then perpetuates the silence and stigma felt by women both directly and indirectly affected by HIV and drug use. It has also led to the perpetuation of silence and invisibility of the women carers, family carers who are very often targeted and blamed for their offsprings' supposed "fall from grace" and hence the "bad mother", dysfunctional family approach often comes to the fore. There seem to be a number of dichotomies working here underlying the various perceptions – innocent/guilty; virgin/whore; victim/threat to society, good mother/bad mother oppositions.

It is also interesting to examine some of the ideas which have emerged as a result of research on women's crime. It has been suggested that sometimes women are treated in a more chivalrous

manner by the judicial system. For example when women come up in front of a judge they tend to be treated more leniently because of their role in society as women or mothers. However on the other hand contradictory research findings have indicated that young girls coming in front of the courts are treated more harshly so that deviance in women particularly at an early age is not as tolerated as male deviance and is punished more severely. Similarly it has been suggested that women are very often regarded as “sick” in some way if they commit crime, use drugs or “deviate” from the “norm” in any way. Interestingly in terms of drug treatment we see similar notions arising. Long before methadone maintenance was reluctantly accepted as one of a number of harm reduction approaches in the Dublin drug treatment scene women did have access to methadone maintenance programmes when they were pregnant. Some of these women were continued on maintenance following the birth of their children. The interesting thing today is that women appear to find it easier to access medical drug treatment than men in many cases. It could be argued that this is largely because women are viewed as being easier to deal with in a doctor-patient type relationship, easier to control, perhaps they are more compliant than men, perhaps there is more fear for women and risks as a result of non compliance, fears associated with the issues of pregnancy, childbirth, motherhood and being regarded as “fit to parent” which is an expression used by women a lot. On the other hand we have the scenario where women have never attended a drug treatment centre or general practitioner for drug treatment. They spend a fortune buying themselves street methadone and self administer their treatment so they can stay away from the services which they regard as controlling and oppressive. They are reluctant to be officially regarded or labelled as drug users.

It becomes clearer that one of the strongest determining factors in women drug user’s lives is the whole issue of motherhood, reproduction and sexuality.

WOMEN DRUG USERS AND HIV

Many people who use drugs perceive services in general as having been neglectful of their needs and interests in the past. Since the advent of HIV there have been certain definite improvements. There is a belief that these have been implemented as HIV prevention strategies more out of a concern for the general populace than for the needs of drug users themselves.

One woman interviewed in the aforementioned research (Butler and Woods, 1992, pp63-4) argued that

The only reason they are concerned about us now is because they think that if they keep us from using then we won’t spread the virus. In the detox if you don’t test for it you don’t get methadone.

Similarly many women believe that they are targeted for medical drug treatment because of issues in relation to HIV and pregnancy. They believe that family planning programmes and infection control, particularly prevention of pregnancy in women with HIV are the motives. They perceive the concern is not for themselves and they regard agencies sometimes as operating as agents of infection control. These perceptions are very dangerous and may alienate many from services which they need. They also reinforce the notion of people who use drugs as “vectors” or “transmitters” of HIV and again we witness the victim/threat to society dichotomy in operation. Whether these attitudes or practices are a reality in fact or not matters less than the fact that these are the service users’ perceptions.

Women have been expected to take a great deal of responsibility for the prevention of HIV both in relation to sexual and perinatal (mother-foetus) transmission. The difficulties of introducing safer sex into relationships cannot be underestimated. Women may feel ambivalent about sexuality, lack self esteem, have difficulty asserting their needs regarding safer sex, or feel a lack of control. It is these issues that need to be addressed in information and counselling with women.

Up to date and accurate information about safer sex, contraception, pregnancy, healthy living, etc. is of paramount importance for women with HIV to enable them to make informed decisions and choices. Women should be fully informed about research on pregnancy and HIV transmission as many women feel that they are not being adequately informed at present.

In terms of counselling in our experience at the Ana Liffey Drug Project the issues which are constantly brought up by women have little to do with drugs. Women's major concerns appear to be around issues of caring, around their partners, their children, their families.

Again as a psychologist interviewed in the research stated

Women take the total responsibility for the running of the house, the care of the children, for the finances, any problem becomes their problem and then if they have a partner who is HIV positive and sick they'll probably be looking after them. But nobody's looking after the women if they're sick. They're expected to be looking after the partner. If he's sick they're running up to the hospital or looking after him at home. If he's in prison they're expected up twice a week with the children looking clean and turned out, to make sure he's alright. But there is absolutely nobody to look after them.

We find that counselling tends to focus on issues such as these and on others such as relationships, child care, HIV, safer sex, pregnancy, sexuality and significantly rape and sexual abuse.

There are also important issues for women with regard to self-help groups. The London based organisations, Positively Women and the women's core group of Body Positive, are providing and prioritising facilities, care, support, advocacy and self-help opportunities for women with HIV. Here in Ireland, the self-help arena has been largely male dominated thereby alienating women and preventing participation. This has changed remarkably in the recent past and the Body Positive group now has 24 full members, 13 men and 11 women. However it would still appear that the fear, stigma and isolation experienced by those who are HIV+ would appear to be greater for women.

Contact with women with HIV, and particularly women drug users makes one aware of the extent to which they are experiencing oppression and powerlessness. In order to improve our delivery of services we must acknowledge the extent to which we, as workers, are a part of that oppression and the perpetuation of a whole range of dependencies.

CONCLUSION

In conclusion, dealing with the issue of drugs and HIV/AIDS, many of us have had to review our practice as social workers, counsellors, volunteers, etc. we have to be aware of the increased sensitivities of those who were in contact with various services prior to the advent of HIV, and the concerns of those newly in contact with the services. It is indeed the latter group who will probably be in a position to challenge us, our attitudes and our practice the most. We do talk about concepts such as empowerment, independence, autonomy, choice, being non-directive, and non-

judgemental. But how much do we actually apply them in our day to day work? In order to empower others those who have power must learn to disempower themselves and to equip the powerless with a greater understanding of power and its uses. This is as crucial in practice as in theoretical terms. This, issue in my opinion, is central to the position of women in receipt of counselling, care, support and services.

Marguerite Woods

Team Leader

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