IN THE EUROPEAN COURT OF HUMAN RIGHTS **Application no.23800/06**

BETWEEN:

John Shelley

Applicant

-and-

THE UNITED KINGDOM

Respondent Government

SUBMISSION OF THE INTERVENOR
THE NATIONAL AIDS TRUST

INTRODUCTION

1. The National AIDS Trust ("NAT") is the United Kingdom's leading independent policy and campaigning organisation on HIV and AIDS. All NAT's work is focused on achieving four strategic goals: effective HIV prevention in order to halt the spread of HIV; early HIV diagnosis through ethical, accessible and appropriate testing; equity of access to treatment, care and support for people living with HIV; and eradication of HIV-related stigma and discrimination.

2. NAT has considerable experience over many years in policy issues relating to HIV and other blood borne viruses in prisons. Most recently, in 2005, NAT published with the Prison Reform Trust a report entitled 'HIV and hepatitis in UK prisons: addressing prisoners' healthcare needs'. This report contained results of a survey of healthcare managers in UK prisons as well as related data and policy recommendations, and will be referred to in more detail later in this submission.

3. From 2006 NAT has been working with an expert group to identify practical and effective approaches to blood borne viruses (BBVs) in prisons across the UK. Members of the expert group include government officials from the prison health departments of England and Wales, Scotland and Northern Ireland, as well as clinical and public health experts, prison governors, and representatives of people living with HIV and with hepatitis C.

4. NAT is an HIV-specific organisation but in all its work aims to maximise partnership with related NGOs and other voluntary organisations and community groups which share NAT's strategic goals. Whilst the content of this submission is NAT's alone, in its prison work NAT has benefited greatly from partnership working with organisations such as the Prison Reform Trust, the highly respected UK penal reform NGO, and the Hepatitis C Trust, the only national UK charity devoted to hepatitis C.

5. NAT also works for the human rights of people living with HIV at the European level. NAT is the UK representative on the European Commission's Civil Society Forum on HIV and AIDS. NAT is also a member of the steering committee of AIDS Action Europe, a pan-European partnership of non-governmental organisations which aims to create a more effective response to the HIV and AIDS epidemics in Europe and its neighbours. On behalf of AAE, NAT

will be organising from 19 to 21 April 2007 a European expert seminar on Legislation, Judicial Systems and HIV.

PART 1 – EPIDEMIOLOGY OF HIV AND HEPATITIS C IN ENGLAND AMONGST INJECTING DRUG USERS, AND IN ENGLISH PRISONS

6. Particular mention will be made in this submission of the Health Protection Agency document 'Shooting Up'[1] [October 2006] which looks at 'Infections among injecting drug users in the United Kingdom'. The document reports the epidemic as at the end of 2005. The Health Protection Agency ["HPA"] is the United Kingdom's public health agency, established as a non-departmental public body by Act of Parliament (the Health Protection Agency Act 2004). The function of the HPA is 'to protect the community (or any part of the community) against infectious diseases and other dangers to health' [HPA Act 2004].

7. Both HIV and hepatitis C are blood borne viruses. HIV infection is currently incurable. Treatment now exists for HIV which successfully prolongs life, reduces viral load and decreases the likelihood of opportunistic infections. There are, however, often serious side-effects of the treatment which means that HIV infection remains a serious life-limiting diagnosis. To this must be added the stigma and discrimination which still, unfortunately, surround HIV positive status in the UK. Despite progress in HIV treatments, there are approximately 500 deaths a year amongst people living with HIV in the UK, many as a result of late diagnosis which compromises the efficacy of treatment.

8. Chronic hepatitis C infection can result in serious liver disease or liver cancer. Treatment is available but is difficult to tolerate. It succeeds in clearing the virus from the blood in about 40 per cent of cases. It is currently hard to predict who and how many will progress to serious liver disease. But in England deaths, transplants and hospital admissions for hepatitis C-related end stage liver disease continue to increase.[2]

Infections amongst injecting drug users

9. Compared with many European countries, HIV infection amongst IDUs continues at low rates, probably, according to the HPA, 'as a result of prompt community and public health responses', including needle exchange.[3] Overall HIV prevalence amongst IDUs in England and Wales in 2005 was 2.1 per cent, but this was 'the highest level ever seen amongst current IDUs in this survey'.[4] HIV prevalence amongst white heterosexuals in the general population in 2005 was 0.08 per cent. The HPA survey data suggests 'a recent increase in transmission' amongst IDUs.[5] Increase in infection has been greatest outside London, but London retains particularly high prevalence rates amongst IDUs, at 4.3 per cent. There are also high rates of undiagnosed infection amongst IDUs, estimated from the 2005 HPA survey as 53 per cent unaware of their infection (a much higher undiagnosed rate than amongst the other groups most affected).[6]

[1] Health Protection Agency 'Shooting Up: Infections among injecting drug users in the United Kingdom 2005 – An update: October 2006'
[2] 'Hepatitis C in England: The Health Protection Agency Annual Report 2006' p.38
[3] 'Shooting Up' p.6 para.6
[4] 'Shooting Up' p.7 para.12
[5] 'Shooting Up' p.8 para.16
[6] 'Shooting Up' p.8 para.15

10. Hepatitis C is the most significant infectious disease affecting IDUs in England – 90 per cent of those diagnosed with hepatitis C who provide risk factor information gave injecting drug use as the route of infection.[7] 31 per cent of hepatitis C infections are in current IDUs, 57 per cent in ex-IDUs and only 12 per cent in the non-IDU population.[8] Hepatitis C prevalence amongst IDUs in England is estimated to be 44 per cent.[9] Of those infected with hepatitis C in the HPA survey, 48 per cent were unaware of their infection.[10] There is also strong evidence that the rate of hepatitis C transmission has increased in the early part of this decade.[11]

11. Whilst the overall numbers of IDUs are difficult to determine, indicators of IDU prevalence suggest an increase over the long term, and a pilot back-calculation model suggests that in 2000 the numbers may have been between 100,000 and 150,000.[12] Levels of reported needle and syringe sharing increased in the late 1990s and remain elevated, with over a quarter of IDUs reporting sharing in the previous month. The sharing of other injecting equipment is more common.[13]

12. **In summary**, compared with general population prevalence rates there are elevated rates of HIV amongst IDUs. There are extremely high prevalence rates for hepatitis C amongst IDUs. Sharing of needles and injecting equipment is common. For both conditions roughly half of those infected are unaware of their infection, with obvious implications for willingness to share needles and for HIV/hepatitis C transmission.

Infection amongst prisoners

13. As in most other countries, rates of HIV and hepatitis C infection are higher amongst prisoners than amongst the population at large. The most robust evidence is now a decade old. This came from an anonymous serosurvey of HIV and hepatitis B and C in prisons in England and Wales. HIV prevalence was 0.3 per cent amongst adult male prisoners and 1.2 per cent amongst adult female prisoners. HIV prevalence in the general population in 1998 (the nearest year for which statistics are available) was 0.035 per cent, which gives some sense of the degree of elevated prevalence in prison settings when compared with the community.

14. Hepatitis C prevalence was 9 per cent amongst adult male prisoners and 11 per cent amongst adult female prisoners in the 1997 survey. It is hard to model overall hepatitis C prevalence in the general population, 'principally because the majority of infections (>80 per cent) seem to occur in injecting drug users (IDUs), a population that it is difficult to study'.[14] There are no readily available general population prevalence projections for 1997 but modelling for 2003 is a rate of 0.53 per cent.[15] In other words, as with HIV, hepatitis C prevalence in English prisons is substantially higher than that in the general population.

[7] 'Shooting Up' p.8 para.20
[8] 'Hepatitis C in England: The Health Protection Agency Annual Report 2006' p.8
[9] 'Shooting Up' p.9 para.23
[10] 'Shooting Up' p.9 para.25
[11] 'Shooting Up' p.10 para.26
[12] 'Shooting Up' p.6 para.2
[13] 'Shooting Up' Exec Summary p.4
[14] 'Hepatitis C in England: The Health Protection Agency Annual Report 2006' p.8
[15] 'Hepatitis C in England: The Health Protection Agency Annual Report 2006' p.10

15. It is clear that the main driver of these higher prevalence rates for both HIV and hepatitis C in prisons is the disproportionate number of IDUs in the prison system. In 2005 in the HPA survey 64 per cent of IDUs reported ever being in prison or a young offenders establishment, and of those 42 per cent had been to prison at least five times. 17 per cent of those who had been in prison reported injecting whilst in prison.[16]

16. Since the 1997 survey, the numbers in prison in England and Wales have increased from 60,131 to 80,000. In the same decade hepatitis C prevalence and incidence have also increased significantly amongst IDUs, and this has also been true, although to a lesser degree, for HIV. In other words, it is reasonable to assume that there are both greater numbers and a greater proportion of prisoners living with HIV and/or hepatitis C when compared with the 1997 data.

17. **In summary**, IDUs are disproportionately likely to be incarcerated in prison, often a number of times, and injecting drug use continues in prison at significant rates. Given the substantial proportion sharing needles and injecting equipment outside prison, it is reasonable to assume this continues in prison at even higher rates given the current absence of clean needles and injecting equipment.

PART 2 – THE PLACE OF NEEDLE EXCHANGE IN ENGLISH HEALTH PROVISION FOR IDUs

18. In 'Shooting Up', the Health Protection Agency states that 'NEX [needle exchange] services are key to preventing infections among IDUs' This is not only the settled opinion of the HPA but also that of the Government and National Health Service.

19. Current official health service policy in relation to IDUs is found in 'Models of care for the treatment of adult drug misusers: Update 2006'. This is published by the National Treatment Agency for Substance Misuse ["NTA"]. 'Models of Care' is the official framework for the commissioning of drug treatment services in England. It comprises the national standards against which the Healthcare Commission (the independent inspection body for healthcare in England) assesses health organisation performance.[17]

20. 'Models of Care' calls for 'a reinvigoration of harm reduction in all tiers of drug treatment'.[18] This is in explicit response to the epidemiological data found in 'Shooting Up', including high rates of needle and syringe sharing, increased prevalence and incidence of hepatitis C, recent increased prevalence of HIV, and increased deaths due to drugs misuse. In particular, 'Models of Care' makes clear that amongst the 'Tier 2 interventions which should be commissioned in each local area' are 'interventions to reduce harm and risk due to BBV [blood borne virus] and other infections for active drug users, including dedicated needle exchanges and the support and co-ordination of pharmacy based needle exchanges'.[19]

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[16] 'Shooting Up' p.18 para.69

[17] 'Models of Care: Update 2006 supports development "standard D2", described in Standards for Better Health (2004), which will be used as the basis of Healthcare Commission and NTA Improvement Reviews of drug treatment' Models of Care: Update 2006 p.6

[18] 'Models of care for the treatment of adult drug misusers: Update 2006' National Treatment Agency for Substance Misuse p.8

[19] 'Models of care for the treatment of adult drug misusers: Update 2006' National Treatment Agency for Substance Misuse p.21

21. The whole of England is divided into areas for Drug Action Teams ["DATs"]. The National Treatment Agency for Substance Misuse recently conducted a survey of needle exchange provision in England.[20] Whilst the detailed analysis found significant variation in how the needle exchange services were delivered, and identified issues for action and improvement, it also found that every DAT in England provided needle exchange services for IDUs. This demonstrates that needle exchange is a central and universal aspect of healthcare provision for IDUs in England. HPA evidence suggests that in 2005, 90 per cent of IDUs had accessed a needle exchange service. The equivalent figure for those who had first injected in the previous three years is 84 per cent.[21]

22. **In summary**, whilst injecting drug use remains illegal, the provision of needle exchange is a required and universal component of healthcare provision for IDUs in England. Recent epidemiological trends for blood borne viruses amongst IDUs have resulted in renewed emphasis on the importance of needle exchange provision and harm reduction generally.

PART 3 – FINDINGS OF THE NAT/PRT REPORT 'HIV AND HEPATITIS IN UK PRISONS'

23. In 2005 NAT and the Prison Reform Trust published a report 'HIV and hepatitis in UK prisons: addressing prisoners' healthcare needs'. The report coincided with the transfer of responsibility for prison healthcare from the Prison Service to National Health Service local bodies (known as Primary Care Trusts). A survey was sent to prison healthcare managers and sixty-three surveys were completed and returned from a total of 139 prisons in England and Wales.

24. In line with current Government policy, none of the prison establishments surveyed had needle exchange provision. Disinfectant tablets were available in only eight of the 61 prisons which responded to the relevant question, though it is now planned that disinfectant tablets will be rolled out across the whole of the prison system in 2007. A question was asked about harm minimisation interventions in prison – a quarter were able to identify some interventions with a harm reduction component, but 20 per cent were unable to cite an example and another 20 per cent responded solely in terms of reducing transmission risk to staff. It was clear, in other words, that understanding of the principles of harm reduction was very limited amongst healthcare staff in prisons. Inconsistent policy and practice in prison, particularly when compared with the community, can only undermine attempts to inculcate clear harm reduction principles in the prison environment.

25. **In summary**, the findings of the NAT/PRT report on 'HIV and hepatitis in UK prisons' confirmed the absence of needle exchange in the English prison system, and revealed considerable inconsistency and confusion over the application of harm reduction principles in prison settings.

PART 4 – THE HUMAN RIGHT TO HAVE ACCESS TO NEEDLE EXCHANGE IN ENGLISH PRISONS

[20] 'Findings of a survey of needle exchanges in England' National Treatment Agency for Substance Misuse May 2006
[21] 'Shooting Up' p.18 para.67

26. NAT has seen the submission sent to the Court by the Canadian HIV/AIDS Legal Network and the Irish Penal Reform Trust, which we formally adopt. Our submission has been drafted having reviewed their submission and with the aim of not duplicating their detailed evidence and arguments, all of which NAT supports.

27. This submission has demonstrated the high numbers of IDUs who enter the prison system in England, often repeatedly, and the evidence of continuing injecting drug use whilst in custody. Although evidence on HIV and hepatitis transmission whilst in prison is limited, it is reasonable to assume, given the numbers continuing to inject, that transmission is occurring, especially given the absence of what is agreed to be the key harm reduction intervention for IDUs – needle exchange. With the growing incidence of hepatitis C in recent years, which is significantly more infectious and more liable to transmission through shared injecting equipment and paraphernalia than other viruses, BBV transmission could well have increased in the prison environment.

28. There is a well established principle internationally obliging state bodies to provide equivalent healthcare in prisons to that available in the community. This is stated in such documents as the WHO Guidelines on HIV Infection in Prisons (1993) and in a number of UN General Assembly Resolutions.[22] This principle is also explicitly supported by the United Kingdom Government and the Prison Service, for example in one of the standards for 'Health Services for Prisoners' (May 2004) 'To provide prisoners with access to the same range and quality of services as the general public receives from the National Health Service (NHS)', or Prison Service Order 3200 'Health Promotion' (2003), 'The Prison Service in partnership with the NHS has a responsibility to ensure that prisoners have access to health services that are broadly equivalent to those the general public receives from the NHS. This means that prisons should already provide health education, patient education, prevention and other health promotion interventions within that general context'.

29. NAT respectfully submits that there is a link in certain circumstances, including the circumstances of this case, between this internationally recognised principle of equivalence and the Article 14 ECHR right prohibiting discrimination. Given the seriousness of HIV or hepatitis C infection and their impact on health and life expectancy, the connected convention rights are Articles 2, 3 and 8. Injecting drug users in prison settings are being denied an element of healthcare deemed in the community to be an essential component in reducing the risk of serious infection from that injecting drug use. Indeed you will have the same Primary Care Trust (the local health body responsible for local health services) providing significantly different standards of healthcare within in its locality based simply on whether or not the recipient is within or outside prison. This section of NAT's submission argues that this denial is not objectively justifiable, and is neither reasonable nor proportionate.

30. NAT believes it is discriminatory to deny IDUs in prison needle exchange when it is universally available in the community to protect from HIV and hepatitis C infection. Indeed in many instances incarceration will mean in effect the withdrawal of a health service provision which the IDU was previously

[22] For a comprehensive list of international commitments relation to the principle of equivalence, see footnote 11, page 10 of 'HIV/AIDS Prevention, Care, Treatment and Support in Prison Settings' United Nations Office on Drugs and Crime 2006

accessing. There is an additional burden of distress and mental anguish thus caused for those who know of the dangers of sharing needles but are no longer able to protect themselves. For those injecting drug users who enter prison repeatedly, often with chaotic lives, the repeated provision and then withdrawal of needle exchange can only undermine attempts to establish safer injecting practices in this vulnerable group.

31. In the absence of such needle exchange provision in prison, there is a significantly higher likelihood of infection with these viruses which almost certainly in the case of HIV and chronic hepatitis C infection result in increased and serious morbidity, and premature death. It should be added that denying prisoners needle exchange is to miss a crucial public health opportunity. One effective preventive intervention in prisons has been the hepatitis B vaccination programme. As a result of this programme, in 2005, 65 per cent of those IDUs who reported ever being in prison had taken up the offer of the hepatitis B vaccine (38 per cent in 2000), compared with 50 per cent of those IDUs who had never been to prison (31 per cent in 2000).[23] Prisons can be important public health opportunities. The prison environment might well be a good location, especially for those from more chaotic backgrounds, to introduce practices of safer injecting behaviour which can be sustained on release. The benefits of effective prison healthcare go wider than prisoners and ex-prisoners themselves but reach the wider community and public health generally.

32. It is the case that disinfectant tablets are to be rolled out across prisons in England in 2007. This is of course better than nothing but is in no sense a substitute for needle exchange, as is evidenced at length in the submission from the Canadian HIV/AIDS Legal Network and the Irish Penal Reform Trust.[24] NAT would stress the difficulties in following the correct disinfecting procedures, particularly in the prison environment, and the ineffectiveness of disinfectant tablets in acceptably reducing risk of hepatitis C infection. Most importantly, in both policy and practice the UK Government's Department of Health does not consider disinfectant tablets to be an adequate response to risks of HIV and hepatitis C transmission. That is why the Department states that the disinfectant tablet 'has only been shown to reduce the risk of HIV and may offer little or no protection against the more enduring and prevalent hepatitis C' and advises that 'it is best always to use sterile needles and syringes each time'.[25] That is also why, as previously discussed, the official framework for treatment of adult drug users requires accessible needle exchange programmes.

33. Of course were there strong countervailing reasons to deny needle exchange such as evidence of danger to staff and other inmates or that such programmes encourage increased injecting drug use, this might mean that the denial of this provision does not contravene the prisoner's human rights. However, there is now a significant body of evidence from around the world, where prison needle exchange has been introduced in a variety of contexts, that such countervailing effects do not in fact occur.[26] In extant and past needle exchange schemes in prisons there have not been instances of use of needle or syringe as a weapon. Nor does research suggest that any increase in drug use or the number of injectors will occur. Where such needle exchange programmes operate, drugs remain prohibited within the institution, including their use, possession and sale. Drugs

[23] 'Shooting Up' p.18 para.69
[24] see Submission of the Irish Penal Reform Trust and the Canadian HIV/AIDS Legal Network paras.11-13
[25] 'Drug Misuse and Dependence – Guidelines on Clinical Management' Department of Health 1999
[26] see 'Prison Needle Exchange: Lessons from a Comprehensive Review of International Evidence and Experience' Canadian HIV/AIDS Legal Network 2nd edition 2006

remain contraband and are confiscated if discovered, as are needles not part of the exchange programme. The one difference from jurisdictions which do not have needle exchange programmes is that the possession of needles that are part of the needle exchange programme is not illegal.[27]

34. Most importantly, there is substantial evidence that needle exchange in prison is an extremely effective health intervention. Evidence suggests strongly reduced syringe sharing, and either strongly reduced or no increase in prevalence of HIV and hepatitis C. Other health benefits include a dramatic decrease in overdoses and in abscesses and other injection-related infections.[28]

35. Given the strong evidence base that the harms predicted from such programmes do not occur and that many benefits do arise, there is no argument, in NAT's respectful opinion, to justify the discriminatory denial of this essential healthcare provision to prisoners who are injecting drug users.

36. Needle exchange in prisons is increasingly recommended in key international standards and guidelines, but has as yet only been introduced in a minority of countries, both internationally and amongst Council of Europe member states. NAT does not, however, believe that this is an issue that comes within a state's margin of appreciation. This evidence for the safety and effectiveness of such schemes has accrued relatively recently. It is not therefore surprising that prison needle exchange remains uncommon. To that must be added the fact that prisoners are a group who frequently experience human rights violations. It may well be, therefore, for the courts to require genuine, non-discriminatory equivalence of healthcare in those cases where its denial or withdrawal are discriminatory, and will result in serious and irreparable damage to health and life expectancy, as well as quite possibly significant mental distress.

37. The prohibition of drug consumption both in law and in prisons cannot be used to argue against needle exchange in prisons. As this submission has demonstrated, despite the unlawfulness of injecting drug use, there is official and explicitly stated support and funding for harm reduction interventions in the community, including needle exchange. Furthermore, the Prison Service will imminently issue a Prison Service Instruction reiterating and strengthening previous Instructions which call for the provision of disinfectant tablets in prison. The last Instruction, PSI 05/2005, explicitly recommended disinfectant tablets in the context of illicit drug use in prison and the need to reduce BBV transmission in this context. In other words, the principle of harm reduction is accepted and implemented both outside and within prison. This submission has also explained that needle exchange programmes do not make legal illicit activity. They simply allow for the possession of needles which are part of the exchange programmes.

38. It is sometimes argued that the absence of clean needles in prison is responsible for the reduction of injecting drug use in prisons when compared with the same cohort outside prison. It seems more likely that such a reduction in use relates to the fact that possession and use are illegal in prisons, and prisoners are closely supervised. As has been demonstrated, needle exchange does not affect the continuing illegality of drug possession and use in prisons. If the presence or absence of clean needles were a significant factor in decline in injecting drug use

[27] 'Prison Needle Exchange: Lessons from a Comprehensive Review of International Evidence and Experience' Canadian HIV/AIDS Legal Network 2nd edition 2006 p.47
[28] 'Prison Needle Exchange: Lessons from a Comprehensive Review of International Evidence and Experience' Canadian HIV/AIDS Legal Network 2nd edition 2006 pp.44-56

in prisons, we would expect to see empirical evidence of an increase in injecting drug use where such needle exchange schemes are introduced in prison. This has not happened. Although the extent of injecting drug use may decrease, significant numbers continue to inject, and at much greater risk. They retain a right to the healthcare necessary to preserve their lives and well-being.

39. NAT and the Prison Reform Trust recommended the introduction of needle exchange on a pilot basis throughout the United Kingdom in their 2005 report. The Scottish Executive has agreed to commence two pilot schemes early in 2007. The Prison Service in England continues to refuse to do so. It should be made clear that the recommendation of pilot schemes was in no sense to suggest they were 'optional' or not required by human rights law. It was rather to propose the most sensible and effective way of introducing the schemes so as to maximise acceptability and ensure appropriate 'design'.

40. **In summary**, access to healthcare in relation to HIV and hepatitis C, including appropriate and effective prevention, is directly related to human rights, and in particular to Articles 2,3,8 and 14, given the life-threatening consequences of HIV or hepatitis C infection, the vulnerability to extremely serious illness, and the difficulties, rigours and burden of treatments and their side-effects. Robust evidence from the prison needle exchange programmes which have been introduced around the world demonstrate their effectiveness in reducing needle sharing and associated harms, and the absence of any of the adverse consequences predicted. There is therefore no reasonable justification to withdraw from IDUs in prison an essential aspect of their healthcare.

CONCLUSION

41. UK Government policy denies prisoners in England access to needle exchange schemes despite the evidence of significant rates of injecting drug use in prison and elevated rates of HIV and, especially, hepatitis C amongst injecting drug users and prisoners. Outside the prison environment the Government requires accessible needle exchange as an essential component of healthcare for adult drug users. This discriminatory provision of healthcare has no reasonable or evidenced basis. The denial of access to clean needles and injecting equipment to injecting drug users in prison seriously endangers their life, health, dignity and well-being by increasing significantly the possibility of HIV and/or hepatitis C infection. NAT therefore respectfully submits that the human rights of those prisoners are breached.

Respectfully submitted this 5th day of February 2007