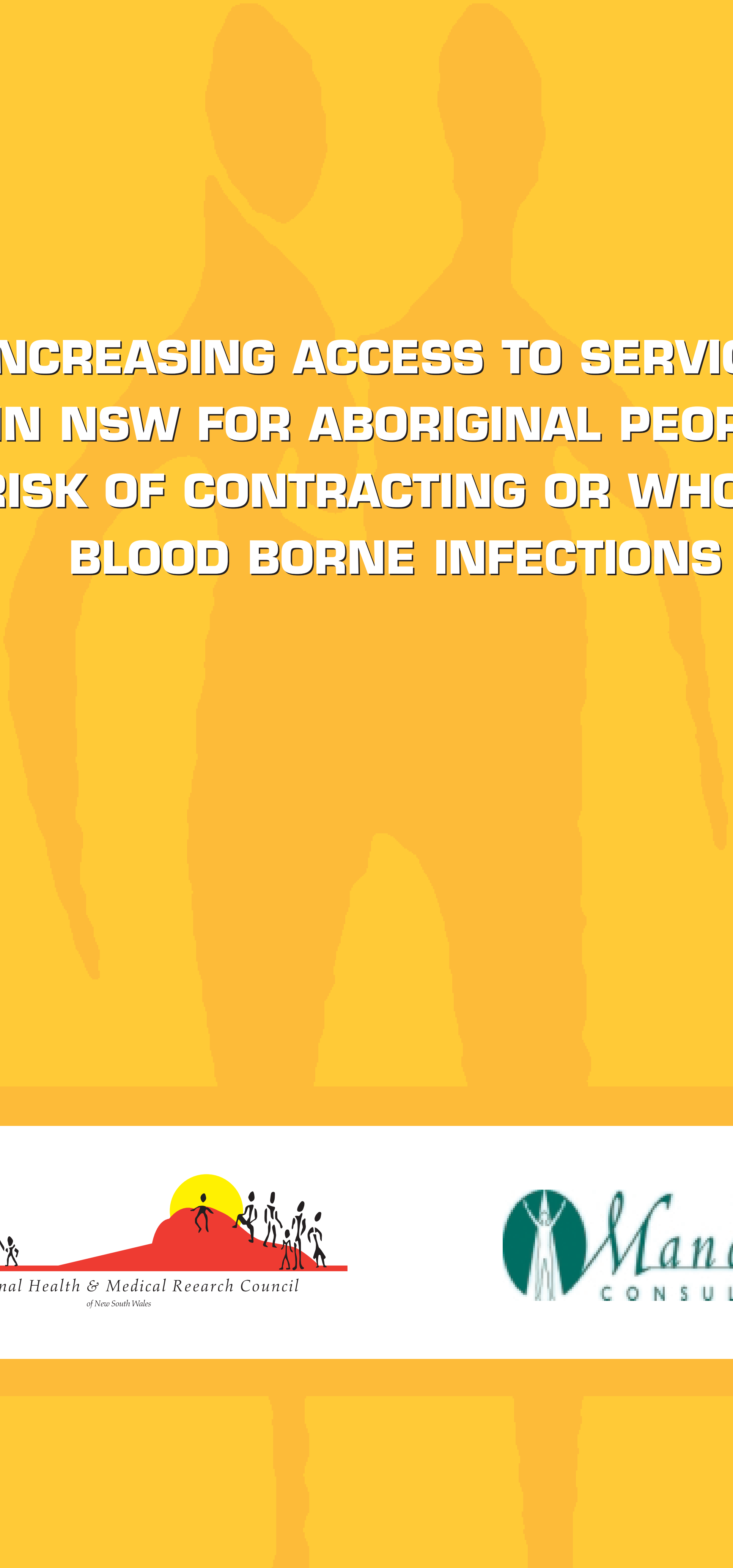

INCREASING ACCESS TO SERVICES IN NSW FOR ABORIGINAL PEOPLE AT RISK OF CONTRACTING OR WHO HAVE BLOOD BORNE INFECTIONS

Aboriginal Health & Medical Reearch Council
of New South Wales

Mandala
CONSULTING

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The AH&MRC Consultancy Service would like to thank the hundreds of people who participated in the consultations for this project, giving generously of their time, information and ideas. Their participation has helped provide our report with the authenticity which can only come from talking with people at the front line of service provision, and those who use the services.

Our thanks to the Reference Group; for their expertise and for providing valuable guidance and support at all stages of the project, especially in finalising our report.

Our thanks also to members of the Aboriginal Advisory Group of Aboriginal Sexual Health Workers, who were an excellent sounding board for us as we developed and refined our findings and recommendations.

This additional report to the summary provided to the OATSIH is a result of the commitment that the consulting team *Ruth Cotton Mandala Consulting, James Ward, Warren Lynch and Sean Appoo* had in ensuring that BBIs were comprehensively documented, enabling governments at all jurisdictional levels to address the contained overall strategic directions and recommendations.

Members of the reference groups for this project were;

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ACRONYMS

ACCHC	Aboriginal Community Controlled Health Committee
ACCHS	Aboriginal Community Controlled Health Service
ACCHRS	Aboriginal Community Controlled Health Related Service
ACON	AIDS Council of NSW
AFAO	Australian Federation of AIDS Organisations
AH&MRC	Aboriginal Health and Medical Research Council
AHS	Area Health Service
AIDB	AIDS and Infectious Diseases Branch, NSW Department of Health
AIDS	Acquired Immune Deficiency Syndrome
AHEO	Aboriginal Health Education Officer
ALO	Aboriginal Liaison Officer
ASHAC	NSW Aboriginal Sexual Health Advisory Committee
ASHW	Aboriginal Sexual Health Worker
ATSIC	Aboriginal and Torres Strait Islander Commission
BBI	Blood Borne Infection
CDEP	Commonwealth Development Employment Program
CEO	Chief Executive Officer
CHS	Corrections Health Service
D&A	Drug and alcohol
GP	General Practitioner
HAART	Highly Active Anti Retroviral Therapies
HBV	Hepatitis B virus
HCV	Hepatitis C virus
HIV	Human Immunodeficiency Virus
IDU	Injecting drug use
MOU	Memorandum of Understanding
NCHECR	National Centre for HIV Epidemiology and Clinical Research
NGO	Non Government Organisation
NIASHS	National Indigenous Australians' Sexual Health Strategy
NSP	Needle and Syringe Program
NUAA	NSW Users and AIDS Association
OATSIH	Office for Aboriginal and Torres Strait Islander Health, Commonwealth Department of Health and Ageing
PLWHA	People Living with HIV and AIDS (NSW).
STI	Sexually transmitted infections

EXECUTIVE SUMMARY

1.1 BACKGROUND AND TERMS OF REFERENCE

This project was conducted as a collaboration between the Aboriginal Health and Medical Research Council of NSW (AH&MRC) Consultancy Service and Mandala Consulting, with funding support provided from the Office for Aboriginal and Torres Strait Islander Health (OATSIH) of the Commonwealth Department of Health and Ageing.

Service providers and organisations within NSW were consulted to identify service gaps which may act as barriers for Aboriginal people both at risk of blood borne infections (BBIs) and those already living with BBIs in accessing services (education, prevention, treatment, care and management) and to propose strategies to limit these barriers. This project concentrated on the three BBIs HIV, hepatitis B and C. Particular emphasis was placed on these three BBIs because of the special risks they pose to the Aboriginal population.

The project is linked with key policy initiatives at the national and state levels, including the *NSW Hepatitis C Strategy 2000 – 2003, the NSW HIV/AIDS Statement of Strategic Directions 2002-2003* and the *National Indigenous Australians' Sexual Health Strategy 1996-97 to 2003-04 and Implementation Plan.* Project findings will help to inform the development of the *NSW Sexual Health Implementation Plan for Aboriginal and Torres Strait Islander People*, planned for 2004/2005.

The overarching ***goal*** of the project is:

> *"The enhancement of accessible and available holistic and comprehensive health services for Aboriginal and Torres Strait Islander people at risk of blood borne infections and for those already living with blood borne infections".*

The ***key tasks*** of the project were:

In consultation and collaboration with project participants and Aboriginal communities, to:

- Seek advice on and summarise gaps in services recognised to date with respect to the specific needs of Aboriginal clients who are at risk of, or who have contracted BBIs. Gaps considered included the provision of culturally sensitive health and health related services to the client groups in question, accurate data collection relating to service provision, and the ethical collection, storage, use and dissemination of such data. (Service provision covered the scope of education and prevention, health promotion, treatment and care).

- Develop proposed strategies intended to limit these service gaps.

- Present a report to the AH&MRC Board of Directors, the Director, AIDS and Infectious Diseases Branch, NSW Health Department, proposing strategies intended to enhance available and accessible holistic and comprehensive health services for Aboriginal clients who are at risk of contracting or who have blood borne infections.

The project was undertaken over a 12 month period commencing in August 2003 and concluding at the end of August 2004. *The Project Brief is at Appendix 1.*

1.2 APPROACH TO THE PROJECT

The methodology sought to be culturally sensitive through:

- Clarity of purpose, and transparency in all our dealings with an ethical framework
- Cultural awareness and sensitivity in all aspects of development and undertakings of this project
- Respect for confidentiality of all involved in this project.

The consultants were at all times cognisant of the AH&MRC *Guidelines for Research into Aboriginal Health* and *NSW Aboriginal Health Information Guidelines*. This project received the approval of the AH&MRC Ethics Committee.

The data collection process in the methodology involved the following:

- The National Centre in HIV Social Research was contracted by the consultancy team to undertake a comprehensive *literature review*. Findings from the literature review are incorporated in this report and the review is available separately on request to the AH&MRC.
  References are at Appendix 4.

- All Area Health Services (AHSs) (with the exception of Justice Health) were asked to complete a *"Fact Finder"* (a short factual survey) about their BBI service provision with the intention of obtaining basic information about service provision and special initiatives to improve Aboriginal access. *A Snapshot of the type and configuration of Services addressing BBIs in NSW is at Appendix 5.*

- C*onsultations* were held across the state and were possibly one of the most comprehensive ever undertaken in NSW for a project of this type. In all, more than 500 stakeholders were interviewed across 18 AHSs (including Justice Health), 28 Aboriginal Community Controlled Health Services (ACCHSs) and other Aboriginal Community Controlled health related services, and a dozen other agencies. Opportunities were taken for the consultants to attend statewide network meetings of Aboriginal Sexual Health Workers (ASHWs), Area Directors/Managers of Aboriginal Health, HIV/AIDS and Hepatitis C Coordinators, as well as local groups such as Needle and Syringe Program (NSP) workers. In addition clinical expertise was sought from Directors of Sexual Health and Sexual Health Physicians providing outreach to and working with Aboriginal communities across NSW. *A complete list of organisations consulted is at Appendix 3.*

- *Interview and discussion frameworks* were developed to guide all the consultations, consistent with the terms of reference. Questions were tailored to the different groups consulted. *These frameworks are at Appendix 2.*

1.3 SUMMARY OF OVERALL FINDINGS

Strategic approach

1. There has been a very strong *statewide policy response* to Indigenous peoples risk of BBIs by NSW Health (the Department and most AHSs) and statewide NGOs. Indigenous people are listed as a high priority group in all key government statewide strategies and plans, and those of most key NGOs. NSW policy approaches to HIV, hepatitis B and C are evidence-based and consistent with national strategies.

2. Much energy has been directed at developing *effective partnerships* at both statewide and Local/Area levels. The partnership between *the NSW Health Department and the AH&MRC* in relation to sexual health is well established; there is a history of shared decision making around the allocation of resources, and it is supported by an infrastructure of specific projects and joint initiatives.

   The partnership arrangements between *Justice Health and the AH&MRC* at the statewide level, and local agreements with ACCHSs, also constitute a solid infrastructure for the provision of BBI services to Aboriginal people in custodial settings.

   At the local level, there are partnerships between the majority of AHSs and ACCHSs, operating at varying levels of effectiveness that enable the effective delivery of sexual health and BBI services to Aboriginal people in NSW.

   Collaborative statewide arrangements between the AH&MRC and non-government organisations (NGOs) such as the Hepatitis C Council of NSW, AIDS Council of NSW (ACON), and the NSW Users and AIDS Association (NUAA) are at a more formative stage.

3. The impact of policy, planning and partnership activity that occurs at this strategic level however is taking *time to filter through* to front line workers and affected people. For example:

   - Strategic and business plans relating to BBIs require further work post development in some AHSs and ACCHSs, as many staff were unaware of the guiding strategies and policies relating to BBIs. The extent to which they are “owned” by all relevant stakeholders varies.
   - Many workers were unaware of the key guiding policies and strategies steering BBI education, prevention, health promotion, treatment and care.
   - Many Aboriginal Health Workers acknowledge less than optimal knowledge of BBIs and the need for training surrounding BBIs (e.g. antenatal workers unclear about vertical transmission of HCV; alcohol and other drug and mental health workers unaware of Needle and Syringe Program locations).

- Maintaining levels of awareness and knowledge of BBIs in Aboriginal communities should be an ongoing priority.

Assessment of the risk

4. In the Indigenous population, the recognition and identification of BBIs has been relatively slow and it is taking some time for a clear picture to emerge. However, it is generally agreed that HIV, hepatitis B and hepatitis C have the potential to pose significant health, social and economic risks to Aboriginal communities, both in the short and long term.

5. While the epidemiology of HIV, hepatitis B and C clearly evidences the risk factors for transmission of these diseases, there are particular characteristics unique to the Aboriginal population (in NSW) that add to their level of risk. These include the higher proportion of youth in the Aboriginal population compared to the broader population; the risks that high levels of incarceration places on Aboriginal people; the mobility of Aboriginal people; the level of knowledge of BBIs in the Aboriginal community; the increase in injecting drug use among Aboriginal people and its associated risks and harms; the high level of STIs in the Aboriginal community; the level of violence in Aboriginal communities and practices which occur in communities such as non-sterile tattooing and body piercing.

6. Many national and state BBI strategies and plans identify Indigenous Australians as a key target population for education and prevention. It is important to develop a better understanding of the complexities of this population so that prevention strategies can be targeted more precisely tailoring to the communities needs.

7. Hepatitis B is endemic in Indigenous communities. There are limited resources to assist Aboriginal Health Workers in their work in promoting the importance of testing and vaccinations to the Aboriginal community.

8. Where accurate and reliable data is available, sexually transmitted infection (STI) rates are reported up to eight times higher in Indigenous communities than the broader population. This coupled with Indigenous peoples lower access to appropriate health services poses particular risk, as the transmission of HIV is deemed easier if other STIs are present.

7. The per capita rate of HIV and AIDS diagnosis among Indigenous people was similar to that among non Indigenous people. Indigenous HIV diagnoses nationally have more than doubled between 1999 and 2003. In the Indigenous population there was a sharp increase in 2002 and a sustained increase in 2003 in the rate of new diagnoses of HIV nationally among Indigenous people[1]. This rise must also be seen in the context of an increase of 16% in the broader population of new HIV diagnoses nationally from 2001.

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[1] Newly diagnosed HIV infection in Indigenous people nationally: 1999 – 9; 2000 – 15; 2001 – 13; 2002 – 24; 2003-21. 30.3% of all diagnoses amongst Indigenous Australians were in NSW.

(NCHECR, HIV/AIDS, viral hepatitis and sexually transmitted infections in Australia, Annual Surveillance Report 2004: p. 42).

8. While the numbers are small, we know that data accuracy can be affected by limited Aboriginal identification and that testing for HIV among Aboriginal people is limited in many areas because of a number of issues associated with access to appropriate health services.

9. Unlike the non Aboriginal population where sexual contact between men accounts for the majority of HIV diagnoses, in the Indigenous population there is an *almost equal proportion of diagnoses attributed to male homosexual contact and heterosexual contact.*

10. Among Indigenous Australians diagnosed with HIV, there is a higher proportion of heterosexuals, injecting drug users, women and younger people diagnosed with HIV compared to non-Indigenous people. Together, these data have important implications for the future health of Aboriginal people.

11. In NSW there is a greater proportion of Aboriginal people with hepatitis C, attributable to injecting drug use and high rates of imprisonment. Further to this Aboriginal people are diagnosed with hepatitis C at a younger age compared to the non-Aboriginal population.

12. The seriousness of the emerging hepatitis C epidemic warrants a continued vigilance and a concerted response from all levels of health and community.

13. To help increase understanding of some of these population complexities, this project has identified the following *key areas of risk* for HIV, hepatitis B and C among Aboriginal people.

Adults and youth in correctional facilities
Young Aboriginal people, in all risk settings
Families and communities of those at risk.

RISK BEHAVIOURS
Injecting drug use
Unsafe sex [2]
Non-sterile tattooing and body piercing
Violence.

14. There is an urgent need for *ACCHSs to continue to make BBIs a priority* and respond accordingly. This involves a fuller understanding of the risk of BBIs to their community; a willingness to address issues of taboo and stigma associated with sexual health issues and BBIs; to accord sexual health and BBI a higher priority along with other general health issues; to provide supportive environments for ASHWs located in ACCHSs, and to better understand and support the harm minimisation role of Needle and Syringe Programs as a strategy for the prevention of hepatitis B, C, and HIV.

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[2] Unsafe sex is a risk factor for HIV and hepatitis B.

Access to services

15. There is a very comprehensive and readily identifiable *service infrastructure* for HIV/AIDS in NSW, but the service delivery response to hepatitis B and C is harder to capture because responsibility is located within the existing health service infrastructure, including with GPs. Justice Health has prioritised hepatitis C and is responding to the acknowledged hepatitis C epidemic with some innovative approaches. Indications from the consultations were that Aboriginal people with hepatitis C are not accessing treatment at the same level as non-Indigenous people, though this needs to be tested by research.

16. There are *many factors influencing Aboriginal access* to BBI services. General factors include the absence of ACCHSs in many parts of NSW; the perceived loss of confidentiality and privacy; transport to and from services; the decline in bulk billing by GPs; the cost of treatment; the history of services in terms of their relationship with the Aboriginal community; the largely asymptomatic nature of HIV, hepatitis B and C which may induce complacency; the stigma associated with BBIs, and the increase in injecting drug use in the Aboriginal community and associated marginalisation.

17. The perceived loss *of confidentiality and privacy* was the factor affecting access identified most frequently by staff. Closely related to this was *location of services*. A well located service should be close to reliable and regular transport, in a discrete location but not too far away from a main centre, signposted in a way that destigmatises the main role of the service, with visible indications that the service is Aboriginal friendly. Multiple access points also help (such as outreach). Locations with a high security presence, or with reception thresholds to cross, present barriers to access.

18. Other factors affecting access were the attitude, behaviour and skill of staff, the availability of Aboriginal staff, and community and worker knowledge of BBIs.

Initiatives to increase access

19. Many excellent initiatives to increase access were observed across NSW. In the body of this report, a small sample of these are detailed in areas such as partnerships, youth, engaging ACCHSs Boards of Management, and an example of a multidisciplinary sexual health team providing comprehensive holistic outreach services to the Aboriginal community.

Aboriginal Sexual Health Workers

20. The use of ASHWs constitutes a very sound model to increase Aboriginal access.

    - With 33 ASHW positions located in AHSs and ACCHSs across NSW, and a further 7 positions with statewide roles, the Commonwealth/State investment in an Aboriginal sexual health workforce is significant. ASHWs are making an important contribution to implementing the *National Indigenous Australians' Sexual Health Strategy and Implementation Plan.*

- Nevertheless, ASHWs have enormous roles and those located in rural areas particularly, are responsible for huge geographical areas and distinct cultural variations and groups. Many report feeling very stretched, lacking an adequate skills base and appropriate organisational support including gender distribution in staffing to ensure that they are able to deliver services to both sides of the community and taking in account of the specific cultural needs for gender specific roles in Aboriginal sexual health.

- ASHWs in ACCHSs tend to have greater access and flexibility in providing holistic services in a sexual health context than those located within AHSs. Therefore Local/Area Health Partnerships are important to link ASHWs working within ACCHSs to sexual health services located within AHSs ensuring broader sexual health services can be provided to the community whilst also offering external support to these workers.

- NSW Health provides a very comprehensive range of mechanisms for ASHW support at the statewide level. As the newer initiatives consolidate, the NSW ASHW Network promises to have great potential as an excellent model as a statewide support mechanism for a group of professionals. The continuation of this statewide support is vital, as is its continued responsiveness to new ASHW needs. It should be evaluated.

- Closer examination of the reasons why ASHWs feel unsupported when there are strong statewide mechanisms in place tend to point to weak support structures at the local level. ASHWs identified many areas where they felt local managers/supervisors could provide more recognition of the complexities of their role, clearer strategic direction, and support in very practical ways.

- ASHWs working within AHSs face a barrier in their workplace, as the approach to STI/BBIs is somewhat fragmented when compared with ASHWs working within an holistic whole of health and well being approach such as an ACCHS. Separating STIs/and BBIs from other health challenges facing Aboriginal people marginalises their priority in the eyes of the community. Because there are multiple factors contributing to increasing BBI risk, and multiple environments in which people at risk are found, a holistic, integrated approach to prevention and care is critical. Working more closely with health professionals and AHWs from other disciplines and service areas (such as drug and alcohol and mental health) has the potential to extend the reach and impact of BBI services for Aboriginal people.

Resources to assist ASHWs

21. While there is a wide range of resources available, more are available on HIV, than hepatitis B and C, with very little available on hepatitis B. The main issues appear to be about access and availability of existing resources (too many once-off resources with no longer term strategy for reviewing or reprinting), and the continuing need for locally developed, Aboriginal specific and appropriate resources.

22. The one-off health promotion grants available from the *NSW Collaborative Centre for Aboriginal Health Promotion* are highly valued and provide an important source of funds for special initiatives that would otherwise not be possible. However, some ASHWs have difficulty responding to such opportunities because of timelines and complex paperwork requirements. They stress the need for support and assistance in the design and development of materials, and for training in their appropriate use in a health promotion setting.

23. Many identified the need for major multi media HIV and hepatitis C campaigns similar to those of the late 1980s for HIV/AIDS (size of and not necessarily message) to provide a powerful impetus to public awareness and for their work.

Building an evidence base

24. There are considerable limitations to processes for Indigenous identification in NSW for monitoring purposes, and the extent to which data is collected. This is in relation both to notification of BBIs to track the progress of diseases in the community generally, and to monitor access to/utilisation of relevant services.

    While national and state epidemiological and surveillance bodies are able to provide a very useful picture of incidence, prevalence and risk factors pertaining to BBIs, there is much room for improvement. Although the *NSW Aboriginal Health Information Guidelines* are in place in NSW, strengthening BBI data collection processes further is likely to depend on developing specific protocols for this sensitive area.

25. Consistent with the larger literature review, very little evidence was found in the consultations of evaluations of the effectiveness of interventions. Given the size and nature of the investment in Aboriginal sexual health in NSW, it is important to continue to document and evaluate both the broader model, and the interventions themselves, many of which are very innovative.

1.4 FUTURE DIRECTIONS AND RECOMMENDATIONS

Three overarching strategic directions and eight recommendations are proposed.

Overarching strategic directions

1. A holistic, whole-of-health-and-well being approach

A holistic approach is fundamental to success in addressing the issue of Aboriginal people who have contracted or are at risk of BBIs. In this context, a holistic approach recognises that HIV/AIDS and hepatitis C cannot be addressed in isolation *from any and all* of the following:

- other sexually transmissible infections, related blood borne infections and sexuality
- issues affecting general health and the physical body
- social, cultural and emotional experiences of the people concerned.

Full implementation of a holistic approach requires moving away from a disease-specific model not just to a broader sexual health approach (this is already reflected in the *NIASHS* and the *NSW HIV/AIDS Health Promotion Plan*). It also reinforces the value for locating sexual health in an even broader whole-of-health-and-well being model as is done within the ACCHS sector.

Encouraging and supporting individuals to take responsibility for their sexual health, and for their freedom from BBIs, means that other impediments to their health and well being must be addressed. Drug and alcohol issues, mental health, maternal and child health have strong relevance to BBIs. In particular, the nexus between hepatitis C, HIV and alcohol and other drugs has a twofold importance, because of:

- The link between hepatitis C and injecting drug use, and
- The link between the use of alcohol and other drugs, disinhibition and unsafe sex.

Implementing a truly holistic approach in relation to Aboriginal health has implications for:

- The way we think about BBIs, the structures and strategies already in place. How can a holistic approach be better reflected?

- The way drug and alcohol services and sexual health services interface and work together on a day-to-day basis.

- The way health education and promotion programs are designed and delivered, so there is increased integration with general health improvement.

- The way Aboriginal Health Workers work together, and with ASHWs, and the level of knowledge Aboriginal Health Workers in other key areas have about BBIs and related services.

- In NSW Health there are substantial Aboriginal Health Workers in mental health, drug and alcohol, sexual health, and vascular health, and maternal and child health. Strengthening mechanisms for cross referral and case management helps to build bridges between workers and can be used as a vehicle for increasing the knowledge of other workers about BBIs.

- The terminology used for specific positions e.g. using “sexual health” and BBI names in job titles and service names.

2. *Focus on the major areas of risk for HIV and hepatitis C*

Focus available resources and actions more strongly on the major areas of risk for HIV and hepatitis C, within the Aboriginal community, as demonstrated in the evidence. Work with men who have sex with men must continue to be a priority, carried out in a culturally appropriate way, however an equal amount of focus and vigilance should be directed at heterosexual transmission of BBIs. The seriousness of the emerging hepatitis C epidemic warrants a concerted response at all levels. Key risk areas include:

Adults and youth in correctional facilities
Young Aboriginal people, in all risk settings
Families and communities of those at risk.

RISK BEHAVIOURS
Injecting drug use
Unsafe sex [3]
Non sterile tattooing and body piercing
Violence.

Focusing on the populations at risk and key risk behaviours has implications for:

- The way priorities are currently set, and resources are distributed.
- Giving some things lower priority in order to intensify the focus on others.
- Collecting accurate surveillance and health service utilisation data.
- Engaging other government sectors, consistent with the NSW Premiers' initiative *"Partnerships: A New Way of Doing Business with Aboriginal People".*

3. Increase Aboriginal community awareness, understanding and ownership of BBI issues.

Promote greater knowledge and understanding of the nature and urgency of the risk within Aboriginal communities so as to encourage greater ownership and responsibility for the issue of BBIs.

Increasing community awareness, understanding and ownership has implications for:

- Effectively communicating the risk without being sensationalist or alarmist.

- Influencing Aboriginal elders, especially Board members of all Aboriginal organisations.

- Practical follow up assisting communities with practical ways of taking action in response to the risk, and to access resources.

- Strong and effective partnerships, especially between ACCHSs and AHSs, and ACCHSs and NGOs such as ACON, the NSW Hepatitis C Council, and NUAA.

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[3] Unsafe sex is a risk factor for HIV and hepatitis B.

- Linking the response to BBIs with other health and well being issues especially in relation to young people, so that it becomes part of a larger response to community priorities.

- Reassuring affected people, regarding procedural safeguards to ensure confidentiality is paramount.

Recommendations

1. Getting the message out

The findings and recommendations from this project to be passed to all relevant planning and review processes (national, state and local) currently occurring, so that they can be reflected as appropriate in the directions being proposed.

2. Statewide leadership

The NSW Health Department and the AH&MRC to examine the implications of the findings from this project for:

- The types and configurations of health service delivery currently in place, and how a more holistic, whole-of-health-and-well being approach could be enhanced and promoted more broadly in relation to BBIs.

- The way resources are currently allocated, and priorities set, given the recommendation to focus on the major areas of risk within Aboriginal communities.

- The need for designated Aboriginal positions at the statewide level, as follows:
    - in the NSW Health Department (AIDB): ASHWs have identified the need for an Aboriginal-identified position;
    - Within the AH&MRC, an Aboriginal-identified Workforce Development position focussing on hepatitis C, to provide ongoing education, training development and support for ASHWs and other Aboriginal Health Workers in regards to hepatitis C, coordinate resource development, and support the development of harm minimisation strategies in both ACCHSs and AHSs.

- The range of collaborative arrangements and partnerships in place, and the way collaboration occurs:
    - across those areas of the Department with responsibility for Aboriginal health, infectious diseases, mental health, drug and alcohol, maternal and child health, health promotion, vascular health;

    - Through Local/Area Health Partnership forums;

    - with other government sectors such as education, employment, corrections, juvenile justice, consistent with *"Partnerships: A New Way of Doing Business with Aboriginal People";* and

    - with other NGOs particularly those working within the specialty areas of BBI service provision, especially the Hepatitis C Council of NSW, ACON, PLWHA and NUAA.

The NSW Aboriginal Sexual Health Advisory Committee (ASHAC) should be involved in this process at appropriate stages.

3. Building Aboriginal community awareness, understanding and ownership of BBI issues.

- The AH&MRC to develop a project plan for a major initiative aimed at increasing awareness, understanding and ownership of BBI issues in Aboriginal communities, thus strengthening capacity for communities to participate in effectively addressing issues in relation to BBIs.

The project plan is to include:

  - Target organisations and audiences, across the age spectrum.
  - Key messages and information.
  - A small resource panel of people skilled in communicating with Aboriginal people, and knowledgeable about BBIs, to develop the presentation strategy and materials, potentially from the NSW Aboriginal Sexual Health Workers Network.
  - A small team to travel around NSW over the course of a year.
  - A travel schedule.
  - The longer term continuity of the activity – how building community ownership can be made locally sustainable, such as through involving local ASHWs.

Funding for the plan and project could be derived from NIASHS allocated funding or sought from other sources.

Key messages and information to include:

  - The nature and extent of the risk, especially in relation to BBIs and Aboriginal young people.
  - A profile of key local health services.
  - Confidentiality.
  - Breaking down the stigma associated with injecting drug use, and the role of NSPs in BBI prevention.
  - Providing supportive communities for people living with HIV/AIDS, hepatitis B and C.
  - The role of ASHWs, community expectations and support.
  - Practical action communities can take in response to the issues, and how resources can be accessed.

- ACCHSs to review their current approach to BBIs, to identify areas for strengthening. This may include clarifying their own policies in relation to BBIs, consistent with national and state policies and strategies; increasing knowledge and awareness of BBIs in their local communities; ensuring all ACCHS staff have a basic knowledge of BBIs; strengthening support for their ASHW if they have one; and strengthening links with AHS sexual health services and other NGOs.

- AH&MRC to develop and consolidate links with key NGOs with statewide roles relating to BBI education, prevention and clinical services.

4. Aboriginal Sexual Health Worker Projects

- NSW Health to retain and continue initiatives to strengthen and support the ASHW model and network.

- NSW Health to continue the provision of statewide support through the various initiatives already in place or being developed. In particular:

  - ensure the establishment of two additional regional ASHW Development Coordinators; and
  - ensure responsiveness to ASHW feedback about the appropriateness of support activities, especially orientation and training.

- The NSW Health Department and AH&MRC to periodically review the distribution of ASHWs to ensure this is as equitable as possible and takes account of changing needs. The review to take account of the balance of workers in AHSs and ACCHSs, and statewide distribution including gender equity.

- The NSW Health Department and AH&MRC to obtain data on what level of financial contribution is being made by AHSs to supplement the *Aboriginal and Torres Strait Islander Sexual Health Projects.* AHSs in which there appears to be a substantial mismatch between the need and AHS response would be encouraged to review their priorities.

- The NSW Health Department to review the allocation of resources to NGOs for Aboriginal positions with sexual health responsibilities, and consider whether the number, distribution and mix of these is appropriate to priorities.

- Area Health Services and relevant ACCHSs to review the effectiveness of their service delivery model in terms of promoting access to a wider range of resources, and providing support for ASHWs. The review to be undertaken in the light of findings of this report (section 6.4) and the key elements of an effective model distilled from Macquarie Area Health Service (section 5.3.3), and to consider:

  - The role of ASHWs, along with how their priorities are set and monitored; orientation and training, and management support.

  - For rural and remote areas particularly, the scope for development of clinical role/s for ASHWs with associated competencies, to improve access to services.

  - A process for the regular audit of skills and professional development needs of ASHWs, with access to appropriate programs facilitated via funding and release.

  - Mechanisms for strengthening cross referral and case management across services and sectors.

  - How best to ensure an integrated approach to BBIs by AHSs and ACCHSs.

    - Reviewing the effectiveness of partnerships between the Area Health Services and ACCHSs, and if they are not functioning well, making improvement a shared priority.

    - Increasing the number of Aboriginal workers employed in key areas such as Needle and Syringe Programs.

    - Training and support activities to engage other AHWs in basic BBI awareness, without overloading them.

    - Scope for destigmatising terminology used for example, in names of services and buildings, and roles such as ASHWs.

5. Location of services

- Area Health Services to review the location of all services relevant to BBIs, especially NSP and sexual health services, in the light of the findings of this project (section 5.2.3).

6. Resources to support prevention and health promotion activities

- The NSW Health Department and AH&MRC to consider the need for a statewide multi media education campaign to support the focus on major areas of risk, which can be locally targeted and supported.

- A BBI Resource Committee to be established as a sub committee of the Aboriginal Sexual Health Workers Network to:

    - Share information about resources currently available and in development, and funding opportunities.
    - Collaborate on the development of shared resources.
    - Facilitate focus testing of resources.
    - Advocate for new resources, and provide advice to statewide bodies as requested.

7. Aboriginal people in correctional facilities

- Justice Health, the NSW Health Department and the NSW Department of Corrective Services to explore options for delivering BBI health promotion in a more holistic way, including within CHS clinical settings.

- Justice Health and AH&MRC to further explore and pilot models which promote continuity of care for Aboriginal people being released from prison and those moved between facilities to ensure continuity of care with local ACCHSs.

- Given its recently acquired responsibility for juvenile justice centres, Justice Health to explore options for resourcing the extension of service agreements with ACCHSs to incorporate these centres.

8. Building an evidence base

- The NSW Aboriginal Health Partnership to establish a Working Group to adapt existing data collection protocols for BBI information, so that all epidemiological and health utilisation data collections relating to BBIs comply with agreed data protocols.

- The NSW Aboriginal Health Partnership to review progress in implementing the Aboriginal Health Information Strategy, particularly in light of the need to increase Indigenous identifiers in all health service collections (inpatient, ambulatory and community health services).

- NSW Health to conduct periodic (annual or biennial) surveys of the NSP as planned, with appropriate Indigenous identifiers consistent with agreed data collection protocols.

- Consistent with the NSW Aboriginal Health Information Guidelines (1998), AHSs are to make epidemiological data on HIV, hepatitis C and STIs, available to ASHWs on an annual basis, in a form that is accessible and meaningful, and shows the changes at national, state and local levels.

- The *NSW Sexual Health Implementation Plan for Aboriginal and Torres Strait Islander People*, to include a statewide strategy for evaluating progress in implementing the *Plan*, and monitoring and evaluating the effectiveness of key interventions. Consideration should also be given to commissioning a longer-term evaluation of the impact of the ASHW model in increasing Aboriginal access to sexual health and BBI services.

2. INTRODUCTION AND BACKGROUND

2.1 BACKGROUND

It is well documented that Indigenous Australians have the worst health status of any identifiable group within Australia, “are the least healthy of all Indigenous populations within comparable developed countries, and have significantly lower level of access to appropriate health care than non-Indigenous Australians”. [4] It is also well known that the extent to which Indigenous Australians feel comfortable in accessing a health service (i.e. the absence of discriminatory attitudes and practices) and the cultural sensitivity of services are important factors influencing levels of access. On top of all this, is the fear, stigma and discrimination often associated with blood borne infections, especially HIV and hepatitis C, which further complicates service access.

As a result, workers and their services continue to seek information, resources and training programs which better enable them to increase client access to services, and improve their cultural sensitivity.

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[4] *National Strategic Framework for Aboriginal and Torres Strait Islander Health: Framework for Action by Governments (Final Draft)* November 2002, p 33-34.

This project consulted with service providers and organisations within NSW to identify service gaps which may act as barriers for Aboriginal people both at risk of BBIs and those already living with BBIs in accessing services (education, prevention, treatment, care and management) and to propose strategies to limit these barriers. The project was a collaboration between the Aboriginal Health and Medical Research Council (AH&MRC) and Mandala Consulting with funding support from the Office of Aboriginal and Torres Strait Islander Health (OATSIH) of the Commonwealth Department of Health and Ageing.

The project is linked with key policy initiatives at the national and state levels, including the *NSW Hepatitis C Strategy 2000 – 2003, the NSW HIV/AIDS Statement of Strategic Directions 2002-2003* and the *National Indigenous Australians' Sexual Health Strategy 1996-97 to 2003-04 and Implementation Plan.* Project findings will help to inform the development of the *NSW Sexual Health Implementation Plan for Aboriginal and Torres Strait Islander People*, planned for 2004.

2.2 TERMS OF REFERENCE

The overarching ***goal*** of the project is:

> "The enhancement of accessible and available holistic and comprehensive health services for Aboriginal and Torres Strait Islander people at risk of blood borne infections and for those already living with blood borne infections".

The ***target groups*** for the project outcomes are:

- Health service providers in both the public health and Aboriginal Community Controlled Health Sector.
- Aboriginal and Torres Strait Islander people who are at risk of or who have contracted blood borne infections.

The ***project participants*** are:

- NSW Health Department: the NSW Aboriginal Sexual Health Implementation Advisory Committee (ASHAC), and the AIDS and Infectious Diseases Branch (AIDB). Public health services: Area Health Services including Justice Health and other health and health related organisations working with Aboriginal clients at risk of contracting BBIs or who already have blood borne infections.
- Aboriginal community representation which specifically includes the AH&MRC, and Aboriginal Community Controlled Health Services who work with Aboriginal clients who are at risk of contracting or who have blood borne infections.
- Non Aboriginal, non-government organisations such as the Hepatitis C Council of NSW, NSW Users and Aids Association, People Living with HIV/AIDS (NSW), AIDS Council of NSW and the Australian Federation of AIDS Organisations. Where appropriate and possible, the views of Aboriginal clients who are at risk of contracting or who have blood borne infections were also sought, either directly or indirectly.

The ***key tasks*** of the project were:

In consultation and collaboration with project participants and Aboriginal communities, to:

- Seek advice on and summarise gaps in services recognised to date with respect to the specific needs of Aboriginal clients who are at risk of or who have contracted BBIs. Gaps considered included the provision of culturally sensitive health and health related services to the client groups in question, accurate data collection relating to service provision, and the ethical collection, storage, use and dissemination of such data. (Service provision covered the scope of education and prevention, health promotion, treatment and care).

- Develop proposed strategies intended to limit these service gaps.

- Present a report to the AH&MRC Directors, the Director, AIDS and Infectious Diseases Branch, NSW Health Department, proposing strategies intended to enhance available and accessible holistic and comprehensive health services for Aboriginal clients who are at risk of contracting or who have blood borne infections.

The project was undertaken over a 12 month period commencing in August 2003 and concluding at the end of August 2004.

2.3 APPROACH TO THE PROJECT

2.3.1 CULTURAL SENSITIVITY

The methodology sought to be culturally sensitive in the following ways.

Clarity, transparency and an ethical approach

An overarching principle was the need for clarity and transparency about the purpose of the project and the ethical use of any results for the positive gain of Aboriginal communities. The consultants were at all times cognisant of the Aboriginal Health & Medical Research Council's *Guidelines for Research into Aboriginal Health* and *NSW Aboriginal Health Information Guidelines*. This project received the approval of the AH&MRC Ethics Committee.

Cultural awareness and sensitivity

Collaboration between Mandala Consulting and AH&MRC ensured Aboriginal consultants were involved in this project. This was both a professional development opportunity for the persons concerned, and ensured that there was Aboriginal guidance and advice available to Mandala Consulting throughout the project.

Aboriginal Sexual Health Workers (ASHWs) and other Aboriginal health staff were offered separate meetings throughout the consultations so that they felt free to raise their issues with the consultants.

The information gathered from all the visits and conclusions reached were fed back to ASHWs through an Advisory Group of 11 Aboriginal Sexual Health Workers. This provided an opportunity for the consultants to test the validity of the findings, and to develop priorities and strategies, which are relevant and culturally sensitive, prior to consideration by the Project Reference Group.

Confidentiality

The confidentiality of information provided at interview was respected. In particular, all information relating to individuals has been de-identified; there are no Community identifiers; solicited or provided information has been confined within the structure of service delivery or gaps and deficiencies in culturally sensitive service delivery; and all records of interviews will be destroyed following de-identification of data and acceptance by the clients of the final report. This process accords with the requirements of the AH&MRC Ethics Committee.

2.3.2 STRUCTURE

The project had the following structure:

- Phase 1: **Planning** (including development of the data collection framework and tools relating to accessing identified services, or gaps in services). Conduct of a literature review.

- Phase 2: **Gathering of data**, including thorough consultations and a survey of services (“The Fact Finder”).

- Phase 3: **Analysis of data** gathered from all sources. Testing of data and refinement of strategies through an Aboriginal Advisory Group, prior to consideration by the Project Reference Group.

- Phase 4: **Preparation of draft and final reports**. The draft report was endorsed by the AH&MRC Board of Directors subject to the approval of the AH&MRC Ethics Committee. The draft report was also presented to the NSW Health Department. This report complies with the recommendations of the AH&MRC Ethics Committee.

2.3.3 LIAISON AND COMMUNICATION

A project Reference Group was established to provide overall guidance and facilitate access to relevant information and where appropriate, to consumers. Organisations represented the AH&MRC (a Director), the NSW Health Department (Aboriginal Health Branch and AIDB), AIDS Council of NSW (ACON), the Hepatitis C Council of NSW (HCC), New South Wales Users AIDS Association (NUAA), and People Living with HIV/AIDS (PLWHA) NSW.

Regular liaison and communication with AH&MRC and NSW Health Department personnel occurred throughout the project as well as with meetings of the Project Reference Group.

Key advisory committees and professional networks were periodically briefed on the progress of the project. These included the NSW Aboriginal Sexual Health Advisory Committee (ASHAC), the NSW Sexual Health Advisory Committee, NSW HIV/AIDS/Hepatitis C Coordinators, Aboriginal Health Coordinators and Aboriginal Sexual Health Workers.

2.3.4 KEY PROJECT QUESTIONS

The framework proposed for interviews ranged across the following:

In relation to access for Aboriginal people at risk of contracting or who have contracted BBIs -

- *What is happening now?*
- *What are the gaps and issues?*
- *What needs to happen in the future?*

Key areas explored included:

- Services in education, prevention, treatment, clinical care and management.
- Protocols involving client confidentiality.
- Resources and support provided to Aboriginal Sexual Health Workers to improve client access to services.
- Ways of working (such as partnerships).
- Processes for assessing the effectiveness of interventions.
- Ethical data collection, storage and dissemination relevant to the client group.

Detailed questions were developed for each of the groups to be interviewed:

- Organisations with statewide or national responsibilities that impinge on the target group.
- NSW Health Department.
- ACCHS Board members, CEOs and staff.
- AHS staff with Area-wide management or coordination responsibilities e.g. HIV/AIDS, hepatitis C, alcohol and other drugs, community health, public health, health promotion.
- Aboriginal Sexual Health Workers and other Aboriginal staff within Area Health Services.
- AHS staff with direct service delivery roles e.g. sexual health staff, HIV/AIDS, hepatitis C, alcohol and other drugs, health promotion, public health.
- Clinicians with expertise in BBI and or Aboriginal Health.

Interviewees were provided with a background paper on the project *(Project Brief, Appendix 1)*, a Framework for Discussion and an appropriate list of questions *(Appendix 2).*

Where supplementary interviews were conducted, such as to follow up issues, similar procedures were followed.

2.3.5 LITERATURE REVIEW

The National Centre in HIV Social Research was contracted by the consultancy team to undertake a comprehensive literature review encompassing the following:

- Incidence and prevalence of BBIs among Aboriginal people.
- Access to health services relevant to BBIs, specifically for Aboriginal people and relating to other Indigenous populations of comparable nations. Within the scope of service provision, education, prevention and treatment services are included.
- Ethical issues in the collection, storage and dissemination of data, including service delivery, epidemiological, and research data on BBIs among Aboriginal people.
- Interventions and service models currently operating for the target group, and demonstrated to have been effective, especially in increasing access.

Findings from the literature review are incorporated in this report and the review is available separately on request to AH&MRC.

2.3.6 THE SURVEY OF SERVICES

All AHSs (with the exception of Justice Health) were asked to complete a "Fact Finder" about their BBI service provision. *The Fact Finder (Appendix 3)* was designed to obtain basic information about:

- The strategic context in which services were provided i.e. did they have Area-specific strategies or plans for BBIs?
- Core services, both treatment and care, and education and prevention.
- Any specific action, programs or services to increase access for Aboriginal people at risk of, or who have contracted BBI, and to increase the cultural sensitivity of services.
- Any further plans to increase access for the target group.

The information thus collected was condensed into a state overview – a snapshot of relevant BBI services as at December 2003. *The Snapshot is at Appendix 5.*

2.3.7 CONSULTATIONS

The consultations undertaken for this project were possibly one of the most comprehensive ever undertaken in NSW for a project of this type. In all, more than 500 stakeholders were interviewed across 18 AHSs (including Justice Health), 28 ACCHSs and other Aboriginal Community Controlled Health Related Services (ACCHRS), and a dozen other agencies. Opportunities were taken for the consultants to attend statewide network meetings of ASHWs, Directors/Managers of Aboriginal Health, HIV/AIDS and Hepatitis C Coordinators, as well as local groups such as NSP workers. In addition clinical expertise was sought from Directors of Sexual Health and Sexual Health Physicians providing outreach to and working with Aboriginal communities across NSW. *A complete list of organisations consulted is at Appendix 4.*

3. THE CONTEXT

3.1 POPULATION

The Aboriginal and Torres Strait Islander population in NSW increased from 70,019 in 1991 to 135,319 in 2001. This increase gives NSW the largest Aboriginal and Torres Strait Islander population of any State or Territory in Australia (29.4% of the total Aboriginal and Torres Strait Islander population). Key statistics are:

- ***National Aboriginal and Torres Strait Islander population:***
  460,140 (2.4% of the total population of Australia)

- ***NSW Aboriginal and Torres Strait Islander population:***
  135,319 (2.05% of the total population of NSW)
  (29.4% of the total National Aboriginal & Torres Strait Islander population)
  - 93.6 % of total Aboriginal and Torres Strait Islander population of NSW identified as Aboriginal
  - 3.5 % of total Aboriginal and Torres Strait Islander population of NSW identified as of Torres Strait Island background.
  - 2.9 % of total Aboriginal and Torres Strait Islander population of NSW identified as both Aboriginal and Torres Strait Islander. [5]
  - Approximately 40% of the Aboriginal population in NSW live in rural and or remote areas.

Mindful of the small percentage of Torres Strait Islander people living in NSW and the importance of ensuring them access to services, reference to Aboriginal people in this report also refers to and encompasses Torres Strait Islanders.

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[5] Source ABS 2001 Census - Population Distribution Aboriginal and Torres Strait Islander Australians.

3.2 BLOOD BORNE INFECTIONS

This project concentrated on the three BBIs – HIV, hepatitis B and hepatitis C. Particular emphasis was placed on these three BBIs because of the special risks they pose to the Aboriginal community.

3.2.1 NATURAL HISTORY AND TRANSMISSION

HIV (Human Immunodeficiency Virus)

HIV is the acronym for Human Immunodeficiency Virus. HIV is a virus that affects the human immune system. HIV is the virus that causes AIDS.

How does HIV affect people?

When a person first contracts HIV, a flu like illness may occur. In most cases, HIV without treatment causes damage to the immune system within approximately ten years. As HIV disease progresses, a person may develop AIDS. An AIDS (Acquired Immune Deficiency Syndrome) diagnosis generally means that the immune system is severely compromised and that a life threatening illness may occur.

Treatments and monitoring

The course of HIV has been drastically altered in the last decade by the introduction of highly active anti-retroviral combination (HAART) therapies. The aim of therapy is to sustain an undetectable viral load that is achievable in 50-60% of patients who undertake therapy. Regular check - ups and blood tests that measure viral loads, viral activity and immune system status are required in the management of HIV patients. While there is still no vaccine for HIV, or cure for AIDS, long term survival of HIV positive people has markedly increased since the introduction of HARRT in 1994 in Australia.

Transmission of HIV occurs via the following ways:

- Sexual contact that allows the transfer of one persons body fluids to another
- through blood to blood contact and
- from mother to child.

HIV transmission is significantly reduced by:

- Safe sex practices
- Using sterile injecting equipment and never sharing injecting equipment
- HIV positive women seeking interventions during pregnancy and labour and seeking clinical advice on breast feeding
- Practicing standard and universal precautions.

Hepatitis

Hepatitis is a term used to describe inflammation of the liver. Hepatitis is caused by some viruses, alcohol, chemicals or drugs. It can manifest as either acute or chronic hepatitis. Acute hepatitis is a term used to describe a disease that evolves in a short period of time, usually about four weeks, and then the patient recovers. It rarely results in long term damage to the liver. The second and more problematic type of hepatitis is chronic hepatitis. This is an acute hepatitis from which the patient does not recover but the disease persists for more than six months. Only hepatitis B, C and D can become chronic. Chronic hepatitis causes a persistent liver injury that if not treated can lead to scarring of the liver tissue (cirrhosis) and to primary liver cancer (hepatocellular carcinoma), which may take decades to develop.[6]

Hepatitis C (HCV)

Hepatitis C is a distinct virus that causes hepatitis, and is transmitted through blood to blood contact.

Common modes of HCV transmission include:

- Sharing of injecting equipment
- Non-sterile tattooing or piercing
- Vertical transmission (before or at birth)
- Other risk activities that can involve the transfer of blood

Mother to child transmission occurs in approximately 6% of cases. Sexual transmission is considered a very low risk activity for transmission of hepatitis C.

The most commonly reported symptoms of hepatitis C include fatigue, flu-like symptoms, nausea and pain in the upper right side of the abdomen. Progression of the disease can be rapidly increased in those patients who do not have generally good health or do not lead a healthy lifestyle. .

Treatments and monitoring

Conventional medical treatment for people chronically infected with hepatitis C involves either interferon alpha-2b monotherapy or pegylated interferon and ribavirin *combination therapy.*

Very few hepatitis C patients undertake treatments in Australia. Patients are required to be assessed as to their suitability for treatment, as well as for general health monitoring and maintenance. Treatments for HCV continue to improve in both their administration to patients and advances have been made in decreasing the associated side effects of treatments. The use of combination therapy achieves a sustained viral response rate of between 45 – 80% of patients who undertake therapy depending on the genotype of the hepatitis C virus.

Liver function and antibody tests are most commonly used to monitor liver function and status.

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[6] Acknowledgment for the description of acute and chronic hepatitis is made to the National Centre in HIV Social Research (Hopwood, M and Treloar, C): The 3D Project. Diagnosis, Disclosure, Discrimination and Living with Hepatitis C, Monograph 6/2003.

Hepatitis B (HBV)

Hepatitis B is a distinct virus that causes hepatitis.

How does HBV affect people?

When first infected with HBV the body produces antibodies to try and eliminate the virus. During the first 6 weeks to 6 months the person may fell slightly ill or off colour and develop joint pains. Sometimes typical symptoms of hepatitis may occur including fatigue, yellowed eyes or skin. A very small number of people die within the first weeks or months of HBV infection. Most adults recover from HBV infections while most infected babies will develop chronic infection. Around 2-4% of infected adults will develop chronic infection. Chronic infection causes no symptoms in many people but some will develop long term liver inflammation, liver scarring and liver cancer. This often takes decades to develop. The symptoms are mild for most people though for a minority HBV can be quite debilitating.

Treatments and monitoring

Treatment is available for HBV. Liver function tests and in some cases liver biopsies are required to monitor HBV and its effect on the liver. There is now a universal vaccination for hepatitis B (often administered with hepatitis A vaccination).

Transmission of HBV

HBV is spread through sexual contact or through infected blood or sexual secretions entering someone else's blood stream. Transmission can occur via skin piercing (e.g. injecting drug use, tattooing or violence) or the sharing of toothbrushes and razors. If saliva that contains HBV pierces the skin or mucous membrane (e.g. biting) transmission may occur. Vertical transmission commonly occurs if vaccination and immunoglobulin are not administered.

*HBV is prevented t*hrough:

- Vaccination
- Safe sex
- Safe injecting, tattooing and body piercing
- Standard precautions (medical and social).

3.3 EPIDEMIOLOGY

The following key points are drawn from the Literature Review and reflect the national situation, unless specifically referenced to NSW. Surveillance data is from the National Centre in HIV Epidemiology and Clinical Research (NCHECR), which collates data from the states and territories.

3.3.1 HIV/AIDS

- In Australia as of 31 December 2003, the cumulative number of HIV diagnoses adjusted for multiple reporting was 20,580 of which an estimated 13,630 people are living with HIV. [7]

- The annual number of new HIV diagnoses declined from around 930 in 1994 to 690 in 1999 and the increased to around 780 in 2003.[8]

- NSW accounts for over half the diagnoses for HIV. This is due to the high concentration of homosexually active men in large cities in NSW, particularly Sydney. Since 2001 NSW has experienced its largest increase in HIV notifications since the epidemic was effectively bought under control in the late 1980s.

- Over the period 1994 – 2003, 185 new diagnoses of HIV in Australia were notified among Indigenous people[9] No separate identifiers were recorded for Indigenous people in the period 1984 to 1993.

- *The per capita rate of HIV among Indigenous was similar to that of non-Indigenous Australians* over the period 1994-2003 however among Indigenous women there was a significantly higher proportion of HIV diagnosis (33.7% Vs 10.1%) [10]

- Until recently, the most commonly acknowledged means of HIV transmission in the Indigenous population, as with the general Australian population, has been male homosexual contact. However Indigenous cases have significantly differed from non Indigenous cases during the period 1999-2003:

> *"… the most frequently reported route of HIV transmission was male homosexual contact in the non Indigenous population whereas in the indigenous population, male homosexual contact and heterosexual contact were reported almost equally frequently"*[11]

7,8,9,10,11 HIV/AIDS, viral hepatitis and sexually transmitted infections in Australia, Annual Surveillance Report 2004: p. 42, (NCHECR).

These significant differences in new HIV diagnosis in relation to exposure categories between Indigenous and non Indigenous people are as follows:

- Male homosexual contact is significantly lower than for the non Aboriginal population (38%v 69%)
- Heterosexual contact is significantly higher than for the non Aboriginal population (37% v 19%)
- A higher proportion of cases attributed to injecting drug use (21% vs 3%)

  - While the numbers are small, Indigenous HIV diagnoses have more than doubled between 1999 and 2003. [12]

  - NCHECR data also indicate that the rate of decline in AIDS incidence has been slower in this group than in non-Indigenous groups.

3.3.2 HEPATITIS C

- It is estimated that in 2003 about 242,000 people were living with Hepatitis C nationally. Hepatitis C is the second most commonly reported communicable disease in NSW, with 8,072 cases notified in 2001 (127.6 per 100,000) (NSW Health 2003). In 2000, of those diagnoses where ethnicity was recorded in NSW, 10% were Aboriginal (NCHECR 2001).

- Findings from the Australian NSP Survey National Data Report 1999-2003 (NCHECR, 2004) found that the proportion of injecting drug users who identified as Indigenous increased from 5% in 1995 to 8% in 2003. Of those one third reported incarceration in the previous year, a figure around twice as high as the non-Indigenous population. The proportion of injecting drug users who identified, as Indigenous could be even higher, since Indigenous injecting drug users may be less likely to attend NSPs or take part in surveys (Correll et al. 2000:56).

- "*Aboriginal and Torres Strait Islander injecting drug users may also experience discrimination and stigma from within their own communities that may inhibit access to services and support for hepatitis C*" (Commonwealth Department of Health and Aged Care 2000:49).

- Surveys undertaken by Australian Needle and Syringe Programs between 1999 and 2003 (NCHECR 2004) found a 74% prevalence of hepatitis C among Indigenous injectors, which was slightly higher to 67% prevalence of HCV among non-Indigenous injectors.

- Indigenous injectors under 25 years of age have an even higher prevalence of hepatitis C than non-Indigenous injectors (38% vs. 23%) do (Correll et al. 2000).

- Hepatitis C is a serious health problem in NSW prisons. Incarceration is identified as an independent risk factor for hepatitis C transmission. In 2001, 9% of all hepatitis C notifications in NSW were from prisoners held in NSW correctional facilities. Around 40% of all injecting drug users have a history of imprisonment.

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[12] Newly diagnosed HIV infection in Indigenous people nationally: 1999 – 9; 2000 – 15; 2001 – 13; 2002 – 24; 2003-21. 33.9% of all diagnoses amongst Indigenous Australians were in NSW. (NCHECR Annual Surveillance Report 2004: p

- Overall 59% of all inmates in NSW prisons have been diagnosed with hepatitis C with 65% of women and 40% of men compared to the 1% prevalence of hepatitis C in the broader community.

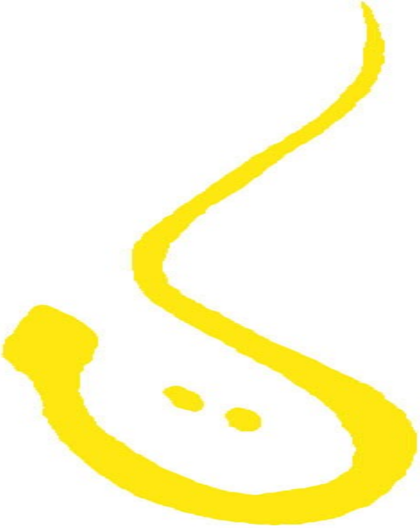
- In NSW prisons Aboriginal inmates make up 19% of the total inmate population. The rate has been increasing 1% per year for the last 5 years.

- Prisoners who inject drugs are at considerable risk of contracting hepatitis C. Indigenous people are over represented in the Australian prison system. (Crofts et al. 1996b; Major 1996). It is reported that in 2003, 90% of all young females and 40% of young males in NSW Juvenile Justice Centres were Indigenous[13].

- Half of all prisoners report a history of injecting drug use, with prison being an important point for transition to injecting drug use for Indigenous prisoners (Lane, 1993).

- High levels of injecting drug use in prison show few signs of declining while strategies preventing the spread of hepatitis C transmission are not widely implemented (Crofts et al). As well, reports suggest the transmission of BBIs may also occur through the sharing of tattooing and body piercing equipment, used sharps such as razor blades and barber clippers. (Crofts et al. 1996a; Edwards & Frances 1996).

- It should be noted that imprisonment and injecting drug use constitute the significant risk factors for hepatitis C rather than being Aboriginal per se. The link between Aboriginal ethnicity and increased hepatitis C risk is predominantly due to the high rates of injecting drug use in prison and the higher rate of incarceration among the Australian Indigenous population.



13- Department of Corrective Services – media 2004

Some projections about the long term development of hepatitis C

"Projections over the long term are difficult to determine and are sensitive to assumptions about ongoing patterns of behaviour of injecting drug users and advances in hepatitis C treatments.

In **2001** there were 210,000 people living with hepatitis C in Australia. **83,000** (or approximately **40%**) were in **NSW**.

Of those affected, 65% were aged **20-39** years and 35% were women.

During **2001** it was estimated that **16,000 new infections** occurred in Australia, an increase of **45% over 4 years** from 1997. Of the 16,000 new incidents of hepatitis C that occurred in 2001, **91%** were estimated to be the result of non-sterile injecting drug use.

In **2002** it is estimated there will be **226,000** people living with hepatitis C in Australia, rising to approximately **242,000** in **2003**.

It is estimated that in **2020**, between 321,000-836,000 Australians are likely to be living with hepatitis C.

Based on the lower, more conservative projection levels, of the **321,000 Australians living with hepatitis C** there will be:

- 81,000 who will clear the virus completely
- 171,000 chronically infected but experiencing few symptoms
- 52,000 chronically infected with moderate liver damage
- 17,000 who will develop liver disease (cirrhosis)."

(Australian National Council on AIDS, Hepatitis C and Related Diseases: Hepatitis C Virus Projections Working Group: Estimates and Projections of the Hepatitis C Virus Epidemic in Australia, August 2002)

3.3.3 HEPATITIS B

- Hepatitis B is often associated with poverty and is endemic in Aboriginal populations in both urban and remote communities. Approximately 1% of the Australian population carries HBV. The rate is higher among Indigenous people, varying from 3% to 35%. (See box below).

- Transmission has been primarily perinatal and interventions have been focused on infant and childhood vaccination.

- Hepatitis B is also associated with imprisonment and Aboriginal people are over represented in the NSW correctional system. Aboriginality is a significant marker of risk for hepatitis B amongst both male and female prisoners in NSW.

- Hepatitis B vaccinations for Indigenous infants began in NSW in 1999. In 2000, a policy of universal hepatitis B immunisation for all Australian infants was adopted following medical recommendations from the National Health and Medical Research Council. However the impact of such vaccination efforts is slow to appear. It has been estimated that it will take at least another 15 years until the effect of universal infant vaccination becomes evident.

What the literature says

It is widely accepted that Australian Aboriginal people are a high-risk population for HBV infection. In contrast, a low prevalence of HBV marker is found in the non-Aboriginal population (Patterson et al., 1993; Campbell et al., 1989). Several studies have shown, by determining the prevalence of serological markers of HBV in different Aboriginal groups around mainland Australia and the Torres Strait islands (Holman et al., 1987; Campbell et al., 1989), that the prevalence varies from 3% to 35%. Most HBV infection in Aborigines occurs in early life, either by vertical transmission from a mother , by horizontal transmission in households or as a result of tattooing or intravenous drug use in young adults (Campbell et al., 1989). A study of an urbanised NSW Aboriginal community found Indigenous people to be more than three times likely than non-Indigenous people to have serological evidence of infection with HBV (Patterson *et al*. 1993).

3.3.4 SUMMARY OF EPIDEMIOLOGY

In the Indigenous population, the recognition and identification of BBIs has been relatively slow and it is taking some time for a clear picture to emerge. In NSW, there is an incomplete set of STI data apart from HIV; however, in those states/territories where identification in data is available there continues to be substantially higher notifications.[14] Higher rates of STIs and less access to health care services places Indigenous people at particular risk of HIV infection.

The per capita rate of HIV among Indigenous was similar to that of non-Indigenous Australians over the period 1994-2003. In the same period there have been 185 cumulative HIV diagnoses among Indigenous people. The exposure categories between Indigenous and non Indigenous people differ in that a significantly higher proportion of HIV diagnoses occurs with Indigenous women compared with non Indigenous women, (33.7% vs 10.1%), a higher proportion of HIV diagnoses occur through heterosexual contact and a higher proportion of HIV diagnoses occurs through injecting drug use and a lower proportion of diagnoses occur through male homosexual contact. [15]

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[14] HIV/AIDS, viral hepatitis and sexually transmitted infections in Australia, Annual Surveillance Report 2004: p. 6 (NCHECR).

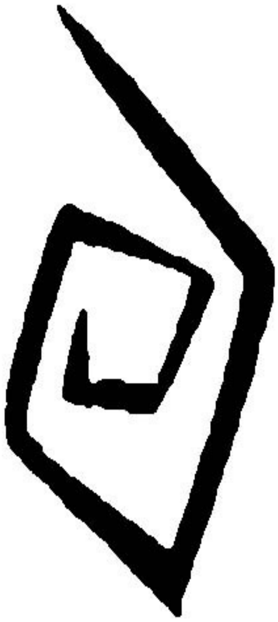
[15] HIV/AIDS, viral hepatitis and sexually transmitted infections in Australia, Annual Surveillance Report 2004: p. 5 (NCHECR).

NCHECR data also indicate that the rate of decline in AIDS incidence has been slower among Indigenous people compared with the non-Indigenous people which may indicate that Aboriginal people already diagnosed with HIV are not accessing as readily as the non Aboriginal population, or that there may be later diagnoses made within the Indigenous community.

In NSW there is a greater proportion of Aboriginal people with hepatitis C, attributed to injecting drug use and high rates of imprisonment ten times higher than the non Aboriginal population. While data is limited specific to Aboriginality with respect to hepatitis C from what is currently published there is clearly an emerging epidemic of Hepatitis C among Indigenous people.

Hepatitis B is endemic in Indigenous communities with transmission has been primarily perinatal. Hepatitis B is also associated with imprisonment and Aboriginal people are over represented in the NSW correctional system. Aboriginality is a significant marker of risk for hepatitis B amongst both male and female prisoners in NSW.

Together, these data have important implications for the future health of Aboriginal people and point to the need for increased BBI interventions and services specific to the Aboriginal population.



3.4 ASSESSMENT OF THE RISK

Many national and state strategies and plans relating to BBIs tend to identify Indigenous people as a broad target population at risk of BBIs, and a priority for action and effort. However, more effort is needed to understand the complexities of why this should be so, and why Indigenous people are at such risk.

While the epidemiology of HIV and hepatitis C clearly document the risk factors for transmission of these diseases, there are particular characteristics unique to the Aboriginal population (in NSW) that add to their being at risk. Aboriginal people experience social disadvantage at greater rates than for the non-Aboriginal population. Symptoms of both the historical and contemporary history of Australia and its treatment of Aboriginal people are that Aboriginal people are over represented in custodial settings, are frequently associated with the use and misuse of licit and illicit drugs, experience endemic poverty and lower educational outcomes. This section is an attempt to outline some of these special characteristics.

Population and young people

NSW has the highest number of Aboriginal people residing of all of the States and Territories in Australia. 45% of the Aboriginal population in NSW are aged between 15 and 44 compared to 32% in the broader community. [16] Young people are a group particularly at risk of involvement in drugs. Aboriginal youth being more marginalised and disempowered are more likely to engage in risky behaviour, including injecting drug use, unsafe sex, and experimentation with a wide range of illicit and licit substances.

Transition to injecting drug use in Australia appears to be occurring at younger ages than previously. Loxley and colleagues (1991) found that respondents under the age of 23 in a WA study had begun to inject drugs on average two years younger than did respondents over 23. This finding is supported by results from the Illicit Drug Reporting System which notes this decline in the average age of injecting drug users as well as a decrease in the age at which overdose mortality peaks. The lower age of initiation into drugs is associated with poorer knowledge of risk factors, potential harm and disease pathogenesis.

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[16] ABS 2001 Census of Population and Housing.

Incarceration

The following are risks that incarceration imposes on Aboriginal people who are incarcerated within both juvenile detention centres and adult prisons.

- Aboriginal people are incarcerated at a much higher rate than the non-Aboriginal population.

- Aboriginal people are more likely to be exposed to injecting drug use perhaps for their first time within both juvenile justice detention centres and adult prisons.
- Aboriginal people may begin injecting drugs within the corrections setting.

- Aboriginal people may be exposed to hepatitis C within the corrections setting, and perhaps unknowingly introduce hepatitis C and injecting drug use into their community upon release from the system.

- Inmates in corrective settings where injecting equipment is difficult to obtain are more likely to share highly non-sterile equipment such as syringes, spoons, filters and water.
- Inmates are also at particular risk of hepatitis B and C because of non-sterile tattooing, body piercing and related practices.

- The violence which can be characteristic of prison life also places inmates at risk of BBIs.

Low levels of knowledge surrounding BBIs within the Aboriginal community.

The consultations found a low level of knowledge of the BBIs within the Aboriginal community. Of the three BBIs, most appears to be known about HIV. However, even this knowledge seems limited and needs to be placed in the context of the particular risks that Aboriginal people face.

Injecting drug use

There is evidence in the literature[17], from workers on the ground and from community members of an increase in injecting drug use within Aboriginal communities. Many health workers reported during our consultations that they had seen an exponential rise in the numbers of members of the community injecting drugs. These drugs ranged from injecting alcohol, speed, crystal, and heroin. There is also indications to suggest that Aboriginal people who use drugs are able to switch between injecting and non-injecting drug use depending on availability at the time in the local area.

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[17] NSP Annual Report 2004

Because of the social circumstances in which many Aboriginal IDU find themselves (eg homeless, disenfranchised from their community), Aboriginal people are very likely to engage in risky behaviour, thereby placing themselves at greater risk of contracting BBIs. For example, from the available literature and from the consultations we learned that Aboriginal IDU may be:

- More likely to inject in outdoor settings, because of housing and disadvantage issues, and therefore less likely to have access to cleaning agents for injecting equipment and thus more likely to share non-sterile injecting equipment.

- More likely than others to share equipment, particularly if injecting on the street or in public spaces and facilities or in a motor vehicle, because of the cultural context of sharing.

- Likely to experience difficulties in terms of the social context of their drug use, because of disapproval within some communities, so less likely to access clean equipment, and less likely to seek out the means of prevention (such as NSPs).

Sharing injecting equipment and other items

Because Aboriginal culture is based on a system of respect and dignity there is a permeating principle that affects the way an Aboriginal person views his /her world and thus the way that they interact with other members of their families and community. Sharing injecting equipment places many people at risk of contracting BBIs because belief in sharing is the norm within the community. During the consultations, health care workers told of Aboriginal people sharing equipment because of the cultural belief system, with little or no knowledge of the risks associated with this behaviour. Some ASHWs have addressed this issue at the local level by developing strategies and campaigns based around sharing. One such campaign entitled "*cultural sharing is not always cultural caring"* has proved a popular catchy slogan for young people in that area. This slogan has been developed on health promotion resources such as wallets and key rings. Although lower risk, the sharing of common household items such as toothbrushes and razors may place Aboriginal people at risk of BBIs, particularly hepatitis C and B.

Sharing injecting equipment between Aboriginal and non-Aboriginal people is also common practice in some contexts and in the corrections setting. Strategies addressing both groups should be developed to ensure that Aboriginal community members are aware of the associated risks.

It is also well documented that Aboriginal people are more likely than non Aboriginal people to share injecting equipment in an outdoor setting. Breaking down moral judgements, stigma and discrimination within the Aboriginal community around injecting drug use will help those at risk of BBIs and those already engaging in high risk behaviour. A more supportive service and community environment will help IDUs to access services and other support and learn of the risks associated with injecting and sharing.

Sexually transmitted infections

The prevalence of STIs amongst Indigenous people is reported to be up to eight times higher than for the non-Indigenous population (Bowden *et al.* 1999; Kildea & Bowden 2000; and this is due, in part, to poor access to services experienced by many Aboriginal people (Fairley *et al.* 1997; Kildea & Bowden 2000).

The 2003 Annual Surveillance Report of HIV/AIDS in those states where reliable identifying data was available, viral hepatitis and sexually transmissible infections in Australia (NCHECR) indicates that in 2002 rates of diagnosis for chlamydia in Indigenous populations were 7 times non-Indigenous populations (957 per 100,000 compared to 137); for gonorrhoea, the rates were 1266 per 100,000 compared with 28; for syphilis 324 per 100,000 compared with 4 (80 times higher than for non-Indigenous Australians). Where the prevalence of syphilis is high, congenital syphilis is a major preventable cause of perinatal death.

Having an STI increases the risk of transmission of HIV. Particular emphasis needs to be placed on early detection programs for all STIs including HIV so as to decrease the transmission risks of HIV. The NIASHS emphasises the need for early detection, treatment, care and management of all STIs.

Tattooing and body piercing

Although lower risk activities, the high levels of non-sterile tattooing and body piercing places Aboriginal people at risk of BBIs, within both correctional and community settings.

Violence within Aboriginal communities.

Aboriginal people are at great risk of BBIs in the community and in corrections settings because of the level of violence that occurs and the possibility of exchange of blood and bodily fluids.

The nature of Aboriginal community structures and mobility of people between communities

The Aboriginal population is a particularly mobile one. The risks associated with both the introduction of injecting drug use and of BBIs are increased as people move around the state, visiting family, moving between communities and so on.

3.5 THE POLICY RESPONSE TO DATE

3.5.1 NATIONAL

The National *Indigenous Australians' Sexual Health Strategy (NIASHS) 1996/97 to 2003/04* and the *NIASHS Implementation Plan for 2001/02 to 2003/04* provide the overarching national strategic framework guiding sexual health and BBI service delivery to Aboriginal people in NSW.

The *Strategy* locates BBI prevention and transmission within a broader sexual health context, stating that HIV/AIDS and related blood borne infections such as hepatitis B and C cannot be addressed in isolation from other sexually transmissible diseases, and sexuality. The *Strategy* recognises that for Indigenous people, sexual health is linked closely to well-being, which in addition to the experiences of the physical body, recognises social, cultural, emotional and spiritual experiences.

At the national level, the *Strategy* and *Implementation Plan* link to:

- The (fourth) *National HIV/AIDS Strategy 1999-2000 to 2003-2004* [18]
- The (first) *National Hepatitis C Strategy 1999-2000 to 2003-2004* [19]
- *National Strategic Framework for Aboriginal and Torres Strait Islander Health: Framework for Action by Governments (2003).*

3.5.2 NSW

At the NSW state level, the AIDS/Infectious Diseases Branch of the NSW Health Department is responsible for the development of statewide strategic planning, policies and priorities for HIV/AIDS, hepatitis C and sexual health. It also identifies minimum service requirements in AHSs, allocates funds to both AHSs and non-government organisations (NGOs) and monitors performance.

Key policy, strategy and planning documents, which guide Area Health Services and NGOs in their service delivery responsibilities, coalesce around several areas of focus:

Sexual Health / BBI
NSW HIV/AIDS Statement of Strategic Directions 2000-2003 (currently being reviewed and redeveloped)
NSW Hepatitis C Strategy 2000-2003 (currently being reviewed and redeveloped to the *2nd NSW Hepatitis C Strategy*)
NSW Hepatitis C Care and Treatment Services Plan 2001-2003 (currently being reviewed, integrated and redeveloped into the *2nd NSW Hepatitis C Strategy*)
NSW Immunisation Strategy
NSW Aboriginal and Torres Strait Islander Sexual Health Implementation Plan (under development).

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[18] The *Strategy* has been subject to recent review.

[19] The *Strategy* has been subject to recent review.

Health Promotion

Healthy People 2005: New Directions for Public Health in NSW
NSW HIV Health Promotion Plan 2001-2003 (currently being reviewed, and redeveloped)
NSW Sexual Health Promotion Guidelines 2002
A NSW Health Promotion Plan for Hepatitis C is currently being developed.

Aboriginal Health

NSW Policy on Aboriginal Health
NSW Aboriginal Health Strategic Plan (1999)
NSW Aboriginal Health Information Strategy 1998 (including NSW Aboriginal Health Information Guidelines and Memorandum of Understanding)
NSW Aboriginal Men's Health Implementation Plan
Strategic Directions for NSW Area Managers - Aboriginal Health.

Other/technical

Core Competency Standards for Aboriginal and Torres Strait Islander HIV/Sexual Health Workers in NSW
NSW Health Notifiable Diseases Manual
Contact Tracing Guidelines for the Sexually Transmissible Diseases and
Blood borne Viruses – Circular 2000/84

As mentioned in Section 2.1, work has commenced on the development of the *NSW Sexual Health Implementation Plan for Aboriginal and Torres Strait Islander People* and findings from this project will inform the proposed *Plan*.

NSW Health is committed to the periodic review of its strategies and/or plans. In addition to the reviews indicated above, the Needle and Syringe Program is also due to be reviewed in 2004.

Brief observations on policy response

The following observations can be made as a result of an overview of NSW key policy and strategy documents:

- The policy and planning response by NSW Health to BBIs is very comprehensive and closely linked with national strategies and policies. The commitment to periodic review is commendable.

- The documents provide a sound evidence-based framework for planning, service development and review. They clearly draw on the lessons learned from experience gained at the forefront of managing BBIs in a complex public health context.

- In the relevant strategy and planning documents listed above, Aboriginal people are identified as a priority group at risk. In addition, increasing Aboriginal access to Needle and Syringe Programs has been a priority for the past 7-8 years.

- From an Aboriginal perspective, there is potential for dilution of focus as a result of the disease based approach which has led to a multiplicity of strategies and plans. The fact that the NIASHS locates BBI transmission and infection in a broader sexual health context is an important reiteration of the preference of Aboriginal people for a holistic approach to issues affecting their health and well-being. The planned development of a specific Aboriginal Sexual Health Implementation Plan for NSW, aligned with the NIASHS, will be an important means of minimising that risk.

3.6 THE PARTNERSHIP APPROACH

For this project, the concept of partnership has several dimensions.

To implement HIV/AIDS and Hepatitis C strategies

From the onset of the HIV/AIDS epidemic in the mid - 1980s, and more recently since hepatitis C has become a greater public health concern, a partnership approach has been a fundamental part of the response at both national and NSW levels. As recommended in the National Aboriginal Health Strategy (1989) (NAHS) the partnership approach is an effective, cooperative effort between all levels of government, community organisations, health professionals and administrators, researchers and affected individuals and communities. Its combined efforts are directed to combating the spread of HIV and hepatitis C and minimising their social and personal impacts.

The partnership is manifested formally and informally, through a variety of coordinating committees at national, state and local levels (too numerous to list), as well as a wide range of collaborative arrangements between services and organisations. The importance of the partnership approach is emphasised in all national, state and local policy and strategy documents on HIV/AIDS and hepatitis C.

The NSW Aboriginal Sexual Health Advisory Committee (ASHAC) is an initiative that was set up under the partnership between the Aboriginal Health and Medical Research Council of NSW (AH&MRC) and the NSW Department of Health, to provide advice on the implementation of sexual health and related services to Aboriginal people in NSW. This committee has been in place for two years and has contributed significantly to the review of existing policies and to the development of new policies and initiatives relating to sexual health and Aboriginal people in NSW.

To implement Aboriginal health strategies – statewide and locally

The NSW Aboriginal Health Partnership, which dates from 1995, provides a formal partnership forum between the NSW Health Department and the AH&MRC to progress and monitor implementation of the *NSW Aboriginal Health Strategic Plan(1999)* and address a wide range of policy, planning and implementation issues across health services at the *statewide* level. Its main goal is improved health status for all Aboriginal people to a level comparable to that enjoyed by the total community.

The process for setting priorities and decision making for implementation of the National Indigenous Australians Sexual Health Strategy involves regular meetings between representatives of the NSW Health Department and the AH&MRC.

The NSW Aboriginal Health Partnership also has expression at the *local* level, through formal *Local/Area Aboriginal Health Partnerships* between individual Area Health Services and ACCHSs serving their populations. These *Local/Area Aboriginal Health Partnerships* recognise the flexibility within the *NSW Aboriginal Health Strategic Plan* and other state strategies to develop mechanisms that best suit their individual circumstances.

Justice Health has a partnership with the AH&MRC and has developed agreements with many of the ACCHSs across the state to assist in ensuring access to culturally appropriate health services for Aboriginal inmates and for the continuity of care for Aboriginal people discharged from correctional facilities.

To integrate national, state and community controlled health sector efforts

The Aboriginal Health Framework Agreement provides a formal partnership forum between the Commonwealth Department of Health and Ageing, NSW Health, the AH&MRC and the Aboriginal Torres Strait Islander Commission (ATSIC) to enable them to work together to implement shared initiatives. While not specifically initiated under the Framework Agreement, one example of such collaboration is the NSW Aboriginal and Torres Strait Islander Sexual Health Projects, a network of Aboriginal Sexual Health Worker positions distributed across AHSs and ACCHSs. NSW Health has funded Aboriginal sexual health projects since 1989/90, and the Commonwealth (through the Office of Aboriginal and Torres Strait Islander Health, Department of Health and Ageing) began contributing Special Funding for this purpose at the beginning of the National AIDS Strategy 1993/94 to 1995/96. [20] The continuation of shared funding and effort between governments and the community sector consolidates and strengthens the partnership approach.

Other partnerships

Increasingly, at the statewide level, the number of partnerships is growing. For example,
The General Practice and Aboriginal Health Initiative arose from the NSW Health *Working Towards Healthy Communities Summit (2001*) where it was decided to develop

> "…..*a framework that demonstrates better practice models of collaboration, between the divisions of General Practice, the Area Health Services, Aboriginal Community Controlled Health Services and other partners at the grass roots level".*

Work is continuing on a Draft Memorandum of Understanding between the signatories - the AH&MRC, the NSW Health Department, the Alliance of NSW Divisions of General Practice, the NSW Rural Doctors Network, and the Commonwealth Department of Health and Ageing.

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[20] In 2003/03 NSW Health received $1.7 million from OATSIH and contributed additional funding of $2.8 million to Aboriginal sexual health.

Work is also continuing in formalising partnership arrangements between the AH&MRC and relevant NGOs involved in BBI education, prevention and treatment and clinical services. For example the AH&MRC and the Hepatitis C Council of NSW have recently developed an MOU. The MOU identifies specific strategies for the organisations to jointly address hepatitis C transmission, care, treatment and support in Aboriginal communities including enhancing relevant workforces.

There are many other partnerships in place across the state. Hopefully enough has been said here to demonstrate how working in partnership is integral to effective service delivery in a changing environment, especially in such complex areas as Aboriginal health and BBIs.

Working better together in Sydney's west

A unique local expression of the NSW Aboriginal Health Partnership can be seen in the Partnership between two AHSs, Western Sydney and Wentworth, and Daruk Aboriginal Community Controlled Medical Service. The Memorandum of Understanding was first signed in July, 1997.

Linked to the Partnership is the Aboriginal Sexual Health Project Advisory Group (ASHPAG), established in 1999 to provide support to the two ASHWs (Area and ACCHS) who work across both AHSs. ASHPAG commissioned a needs assessment *("Assessing the Sexual Health Needs of Aboriginal Communities in Western Sydney", April 1999*) and developed an Action Plan in response to that needs assessment. ASHPAG brings to the same table a diverse group which includes Area Aboriginal Health Directors, Area Health Service coordinators, Aboriginal workers, sexual health clinicians and health promotion staff. Formation of the group is in recognition that the ASHWs *"can't do it all alone",* and provides a mechanism for support, information and clinical input. It also facilitates orientation and training of ASHWs through short attachments to various services. Additionally, the ASHWs' contribution to ASHPAG is critical to the successful outcomes of the ASHPAG Action Plan.

ASHPAG is the first to acknowledge that the process has not been easy. There have been fluctuations in the Partnership itself; the workload for an AHS and ACCHS ASHW responsible for two Areas has been significant, and challenges in recruitment and retention of an ASHW are leading the group to consider alternative approaches such as establishing a training position.

"Sometimes just the continued existence of the group can feel like an achievement", said one member*. "We realise that all members can't maintain the same level of effort all the time, and the group is strong enough to accommodate this. But the long term commitment is strong, and that is what matters".*

3.7 OVERVIEW OF CURRENT SERVICE ARRANGEMENTS

Each AHS is required to be self sufficient in service provision for HIV/AIDS, hepatitis C and B and sexual health through meeting minimum service requirements specified by the NSW Health Department. In relation to HIV/AIDS, hepatitis B, C and sexual health specifically, AHSs are responsible for the planning, coordination and provision of treatment, care and support, health promotion and prevention.

While the treatment/care and health promotion strategies are slightly different for each of the BBIs, the following *commonalities* can be noted.

- In every AHS, coordination across the whole spectrum of service provision for both diseases (and sexual health generally) is provided by an *Area Coordinator*.

- Under the *Aboriginal and Torres Strait Islander Sexual Health Projects*, a network of ASHWs is distributed across all AHSs and located in some ACCHSs. The role of the ASH workforce is to provide community based BBI and STI prevention messages, information, education and promotion according to the needs of their specific area or community. Section 6 provides more detail about the distribution of ASHWs and how this role is being carried out.

- Each AHS has been encouraged to develop a broad range of *sexual health services* appropriate to the needs of the population it serves. It is notable that NSW has the most comprehensive network of sexual health services in Australia. The primary role of sexual health services involves:

    - the provision of screening, ambulatory care, treatment and support, health promotion and prevention services for people with STIs/BBIs; and

    - STI/BBI control and surveillance in collaboration with Public Health Units and ASHWs, whether located in AHSs or ACCHSs.

- In rural areas, sexual health services provide a focus for expertise and an infrastructure for the delivery of ambulatory services for people living with HIV/AIDS, hepatitis B and C. Aboriginal people are identified as a key target population of sexual health services. Treatment and care, and prevention and health promotion, are fully integrated in sexual health services.

- Each AHS is also to be self sufficient in *drug and alcohol services* for its population, consistent with the *NSW Drug Treatment Services Plan*. Given the connection between injecting drug use and hepatitis C and HIV/AIDS, close service linkages continue to be important.

- NSW has an extensive network of *Needle and Syringe Program (NSP)* outlets, and again, each Area is required to be self sufficient in this regard. NSPs are a critical prevention strategy for both HIV/AIDS and hepatitis C. Aboriginal people have been identified as a priority under the NSP for several years.

- *NGOs* play a significant role in the provision of information and education to people living with HIV/AIDS, hepatitis B and C, their partners and carers, and in their support and advocacy roles. These include ACON, the Hepatitis C Council of NSW, NUAA, and PLWHA.

3.7.1 HIV/AIDS

A considerable amount of work has been recently completed or under way as this report is released with respect to service delivery arrangements associated with HIV/AIDS. The NSW AIDS Infectious Diseases Branch is currently developing the *NSW HIV/AIDS Strategy 2004/2005-2007/2008.* This plan will identify strategic priorities for HIV health promotion, treatment, care and support services and research. These are intended to focus the activities of HIV/AIDS services on strategic priorities and will improve the measurement of the impact of service delivery on health outcomes.

In 2004 the NSW Health Department commissioned a *HIV/AIDS Care and Treatment Services Needs Assessment* recognising that the needs of PLWHA have changed in recent times. This assessment provided recommendations and a strategic framework for providing HIV care and treatment service models for the next triennium. Several of the recommendations included in this assessment, both directly and indirectly relate to service provision for Aboriginal populations. This review will inform the *NSW HIV/AIDS Strategy 2004/2005-2007/2008.*

The duration of the HIV/AIDS epidemic and the comprehensive policy and funding response by NSW Health has resulted in the establishment of a strong service delivery infrastructure for treatment, care and support, health promotion and prevention. That infrastructure is a mix of mainstream and specialist services, and is largest in the higher prevalence Areas. Some key features are outlined below:

- NSW *hospitals* have had their roles delineated into 6 levels of service (1-6), with the higher levels reflecting an increasing degree of complexity.

- Seven hospitals in many of the AHSs have been designated as providing the highest (Level 5/6) HIV/AIDS service – St Vincent's, Prince of Wales, Royal Prince Alfred, Westmead, Liverpool, John Hunter and Royal North Shore. These hospitals are located in Areas of moderate to high prevalence and receive referrals of more complicated cases from other Areas.

- All other Areas are required to be self sufficient in hospital inpatient and outpatient, palliative care and community health up to Level 4.

- A number of services also provide *statewide* HIV/AIDS functions – these include the Albion Street Centre, the AIDS Dementia and HIV Psychiatry Service (ADAHPS), Sydney and Parramatta Sexual Health Services, the HIV/AIDS Dental Program, the Paediatric HIV Service, the Transfusion Related AIDS and Infectious Diseases Service, the Haemophilia Service, and the Institute of Forensic Medicine.

- The *NGO s*ector has a major role in providing community based accommodation services providing step-down, respite and supported longer-term accommodation. In addition, there is a range of community care services, both government and NGO, accessed by people with HIV/AIDS.

- *GPs* have an increasing role in providing primary health care as people with HIV/AIDS are living longer and more effective treatments become available. Anti retroviral prescribing rights are available to GPs trained in HIV medicine across NSW.

- While antiretroviral therapy can be prescribed in the community (ie by GPs), the patient then has to attend a hospital pharmacy to obtain supplies. This is a requirement of the Commonwealth, which funds these drugs under the Highly Specialised Drugs Program.

Health promotion and prevention

Surviving our Success: NSW HIV/AIDS Health Promotion Plan 2001-2003 has expired and has recently been evaluated. This strategy provided strategic directions, established priority target populations, principles and priorities as well as a detailed action plan for the health promotion effort by NSW Health and NGOs. As with *HIV/AIDS Care and Treatment* review the *HIV/AIDS Health Promotion Plan Evaluation* will inform the *NSW HIV/AIDS* S*trategy 2004/2005-2007/2008.*

Priority issues in the NSW HIV/AIDS Health Promotion Plan were:

- Unprotected anal intercourse among gay and other homosexually active men.
- Post exposure prophylaxis (PEP)
- Serodiscordant relationship
- Treatment and health issues (for people living with HIV/AIDS)
- Aboriginal and Torres Strait Islander Australians' sexual health
- Illicit drug use
- HIV and sexually transmissible diseases
- Vaccines
- Testing and late diagnosis.

The NSW Health Department provides leadership, infrastructure and funding to ensure the *Strategy* is effectively implemented. However structures and responses within AHSs will differ depending on the needs of the local community, capacity to respond, local program experience and evaluation and regional epidemiology.

3.7.2 HEPATITIS C

Care and treatment

From the outset of the hepatitis C epidemic, it was determined that the most appropriate response for NSW was to locate responsibility for care, treatment, prevention and health promotion within the existing health service infrastructure, and reorient it accordingly. A central thrust of the NSW *Hepatitis C Care and Treatment Services Plan 2001-2003* is recognition of the need to extend the number of people who are able to effectively deal with the care and treatment needs of people with hepatitis C and to enhance the role of existing players.

One of the main reasons for this approach is that most people infected do not know they have hepatitis C. Symptoms do not usually present until many years, even decades, after infection occurs. 75% of people who are exposed to the hepatitis C virus develop some form of chronic infection and are able to transmit the virus (ANCAHRD, 2002).

The model of care that has been developed in NSW seeks to balance the changing needs of affected people at different stages of the evolution of the disease (see the box below). Key features of the model of care are:

- Primary care services for people with hepatitis C are principally provided by GPs including those employed by ACCHSs and sexual health services.

- Pre-treatment assessment and provision and monitoring of drug treatments [21] is provided by hospital based specialist units and specialists in private practice. These services may also be provided by specialists in ambulatory settings such as the Albion Street Clinic. The Australasian Society for HIV Medicine trains GPs to provide drug treatments as S100 prescribers, with specialist guidance. Some shared care between specialists and GPs occurs.

- Highly specialised care and treatment for persons with advanced disease is provided by hospital based specialist units.

- Testing, health information and education, care and support services is expected to be available from a wide range of locations.

- NGOs (especially the Hepatitis C Council of NSW) have a critical role in providing information, education, care, support and advocacy.

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[21] Conventional medical treatment for people chronically infected with hepatitis C involves either interferon alpha-2b monotherapy or interferon and ribavirin combination therapy. In October 2003 the Commonwealth approved combination therapy for funding under Section 100 of the National Health Act 1953, through the Pharmaceutical Benefits Scheme. Previously interferon was the only drug approved under Section 100 for management of chronic hepatitis C.

Prevention and health promotion

The 2nd *NSW Hepatitis C Strategy* is currently in draft format. This strategy aims to provide a framework and set direction for the surveillance, control, treatment, management and prevention of hepatitis C and the care and support of people with hepatitis C in NSW.

The key goals of the strategy are to

- minimise the transmission of hepatitis C,
- improve the health status of people with hepatitis C and
- minimise the negative health social and economic impact of hepatitis C.

The draft strategy provides extensive guidance on prevention and health promotion. Priority groups identified as being at high risk of hepatitis C are identified as:

- People who inject drugs
- Prisoners and young offenders
- Aboriginal and Torres Strait Islander people
- Young people
- Health care workers
- People living in rural and regional areas
- People with medically acquired infection
- People from a non-English speaking background
- People with dual disorders
- Pregnant women
- People with existing or co-existing illness
- Gay men and lesbians.

A strong emphasis is placed on prevention in the *Strategy*, particularly on the role and contribution of NSPs. No separate education and prevention plan appears to have been developed, as set out in the *Strategy,* although one is planned for 2004 and the Strategy itself contains quite detailed action plans. Unlike the *HIV/AIDS Health Promotion Plan,* it is not clear what mechanisms have been put in place to ensure implementation. As with HIV/AIDS, structures and responses within AHSs will differ depending on the needs of the local community, capacity to respond, local program experience and evaluation and regional epidemiology.

3.7.3 THE FACT FINDER ON SERVICES

As part of the data collection for the project, AHSs were asked to complete a short survey about their BBI service provision specific to the local/area Aboriginal communities. The survey was designed to obtain basic information about:

- The strategic context in which services were provided i.e. did they have Area-specific strategies or plans for BBIs?

- Core services, both treatment and care, and education and prevention.

- Any specific action, programs or services to increase access for Aboriginal people at risk of, or who have contracted BBIs.

- Any specific action, programs or services to increase access to increase the cultural sensitivity of services.

- Any further plans to increase access for the target group.

This information was sought primarily to assist the consultants prepare for their meetings and reduce the need to gather factual information in the interview setting. A summary *Snapshot of NSW Services,* as approved by the contributing Areas*,* is at Appendix 5.

While following sections of this report will synthesise findings from the consultations about efforts being made to increase Aboriginal access, and the gaps, it is helpful to make some brief observations about the information collected through the survey.

- All AHSs were able to refer to a *strategic framework* within which BBI services were delivered, and the great majority (but not all) had Area-specific plans, as well as referring to statewide plans and strategies. The range of plans was interesting – they included broad communicable diseases plans, disease-specific plans, sexual health plans, Aboriginal health plans, health promotion plans and clinical service plans.

- *Sexual health services* featured prominently in the returns as core services, as did *NSPs*.

- Very few surveys mentioned *drug and alcohol services* as part of their core service structure, although all AHSs are required to be self sufficient in such services.

- Reference was made by several Areas to *outpatient liver clinics*.

- *Partnerships* were often quoted as examples of specific initiatives to increase access.

- The great majority (but not all) were able to list various *initiatives* to increase Aboriginal access and/or the cultural sensitivity of services. There was a considerable variety in the initiatives, which focused mainly on education and prevention, but did include treatment and care services.

4 SERVICE PROVISION

4.1 STRATEGIC APPROACH TO BBI

4.1.1 AREA HEALTH SERVICES

The consultations

The 17 public health organisations within NSW known as Area Health Services are responsible for the planning, co-ordination and delivery of local health services. Of the 17 AHSs, nine are classified as metropolitan services with the remaining eight being rural services. The consultants for this project visited every rural AHS and 8 of the metropolitan AHSs to meet with relevant staff. Consultations were also held with Justice Health Service, which is also technically an AHS. All AHSs were invited to complete a comprehensive “Fact Finder” that sought information about the range of BBI services they provided and any specific action, programs or services to increase access for Aboriginal people at risk, or who have contracted BBI.

The consultants sought to meet with as many staff within AHSs who work directly or indirectly with Aboriginal people at risk of BBIs and those already living with BBIs.

During AHS consultations the consultants met with three main groups of staff:

- Staff with Area wide responsibilities (eg Directors of Sexual Health; HIV/AIDS/Hepatitis C Coordinators; Directors of Public Health, Health Promotion, Alcohol and other Drugs, Community Health; Sexual Health Physicians.

- Aboriginal health staff (ALOs, ASHWs, AHEOs, and any other Aboriginal staff within AHSs).

- Other staff with direct service delivery roles to the Aboriginal groups that this report focuses on eg staff in Needle and Syringe Programs, sexual health services, drug and alcohol services, health promotion.

There was an overwhelming amount of interest and input into this project by the latter two groups, with their sessions being well attended in almost every AHS visited.

Disappointing however were participation levels by the first group of staff, those with area wide responsibilities. Only a handful of AHSs had good representation of available staff during the consultations, with Central Sydney AHS, Macquarie AHS, and Mid North Coast AHS being exceptional in this regard.

The low participation by senior staff was disappointing in several ways.

Firstly, the same process, endorsed by AIDB, was used for organising all consultations. Generous follow up of each AHS was provided by the field consultants.

Secondly, for many of the staff employed within the AHS, it suggested either a perceived lack of support for their roles in what is recognised as a difficult area of work or was possibly indicative of the perceived level of priority given to Aboriginal health.

At the same time, the consultants recognise the multiple demands that are placed on all AHS staff and that it is not always possible to respond to all requests to participate in meetings.

Strategic approach

Many of the AHSs have developed *a local strategic plan* that gives overall direction and guidance with regard to Aboriginal people accessing sexual health/BBI services. In addition almost all AHSs have developed an Aboriginal Health Strategic Plan specific to the local area, with sexual health/BBIs identified as an area of priority. These plans provide a framework with strategic direction for the work of ASHWs and other clinicians within Sexual Health. Some staff however expressed disappointment that these plans were not revisited throughout the year and that they had to remind their colleagues about the plan/strategy parameters that they were working within.

Of the three BBIs, *HIV has been the priority for many of AHS staff*. However, there appears to be *a shift in focus* in workload toward the treatment and care of hepatitis C diagnosed patients. This has came about as a result of a couple of factors: first, the number of newly diagnosed patients, and second, changes in treatment regimes for hepatitis C with the availability of new options. In areas where there are correctional facilities, hepatitis C is a major focus for staff workloads, while in rural and remote areas, the emphasis is on hepatitis C and B. This is largely due to the smaller numbers of HIV positive patients in most rural AHSs.

Area Health staff expressed concerns about *the lack of major awareness campaigns* targeting hepatitis C. Many discussions were held around the awareness campaigns that focussed on HIV in the early days of the epidemic, but staff would like to see a major campaign focussing on hepatitis C similar in proportion to the advertising campaigns of the late 1980s. This would help staff by providing a more powerful impetus for their local initiatives to improve access to services for at risk populations.

It was noted that newer combination therapies for hepatitis C could result in an increase in patient numbers because of fewer side effects from the newer drugs and because patients did not need to attend as frequently for their treatment. Treatment advances in the future will see more patients accessing services not only because of the benefits to patients but also because eligibility for treatment may be expanded.

Most AHSs have developed *Local/Area Aboriginal Health Partnerships* that aim to improve access by the Aboriginal population across the full range of services (AHS and ACCHS). The level of functioning of those Partnerships appeared to vary. Maintaining an effective Partnership needs ongoing work to ensure that once individuals within ACCHSs or AHSs move on, the Partnerships can be sustained.

The consultants observed that in some instances, the working groups under the Partnerships had lapsed and required attention to rejuvenate them.

Strong collaboration between the ACCHSs and the AHS was noted in some cases. For instance, there is a clear demonstration of an effective Local/Area Aboriginal Health Partnership on the Mid North Coast where the AHS Executive meets with ACCHS CEOs and Board members on a regular basis to improve service provision for the Aboriginal community in that area. The Partnership took an active role in the arrangements for the project consultations, and met with the consultants at the outset of their visit. The high level of representation on the Executive contributes to Aboriginal health being seen as a high priority for the AHS on the Mid North Coast.

Generally, AHSs recognised the *difficulties that they have in accessing the Aboriginal community* particularly when there are periods without Aboriginal staff employed in key roles within the area. There is much time expended in forming relationships with the Aboriginal community but only with persistence do these relationships endure. Much work remains to be done in accessing Aboriginal communities particularly in those Areas where there is a negative history of service provision for the Aboriginal community.

Many AHSs have conducted *cultural awareness courses* for non-Aboriginal staff in sexual health to raise awareness of the sensitivities around BBIs for the Aboriginal population.

4.1.2 ABORIGINAL COMMUNITY CONTROLLED HEALTH SERVICES

In NSW there are more than forty Aboriginal Community Controlled Health Services in NSW providing primary health care services to local Aboriginal communities. ACCHSs play an important primary care role in the treatment, care and management of Aboriginal people who have contracted BBIs. This involves the provision of education and information, prevention, early clinical detection, support and referral as well as ongoing clinical and holistic management of clients. ACCHSs are an integral component of the myriad of services that are required to address BBIs within the Aboriginal population.

The consultants met with 28 ACCHS across the state. In each of the ACCHSs the consultants met with a variety of staff ranging from Board of Directors, CEOs, ASHWs, drug and alcohol workers, medical officers, registered nurses and other staff members who were invited or interested in the consultations. Participation rates from each of the services were generally good. Many of the services put a significant amount of time into organising the meetings and staff generally had plenty to say regarding BBIs. In the ACCHSs we tended to hold a single meeting with all staff in attendance rather than separate groups as we did within the AHSs. This was because of the smaller numbers working in ACCHSs and because the majority of staff working within the services are Aboriginal.

ACCHSs have a range of initiatives in place to address BBIs. Mostly these initiatives are provided by ASHWs and generally in a holistic whole of health and well being approach. ACCHSs are participating in the NSW Aboriginal Sexual Health Projects and 16 of the 33 ASHW positions are located in those services. The advantage of staff employed within ACCHSs is that staff are generally well supported by their line managers to be able to provide active outreach to the community in the most appropriate manner possible. This same luxury is not afforded to many of the ASHWs working within AHSs as limitations of government employment sometimes limit their flexibility in accessing the community.

Partnerships between ASHWs located within ACCHSs and AHS sexual health clinics remain an important component of addressing BBIs. Within ACCHSs there appears to be greater flexibility within the organisational structure of an ACCHS that allows for different AHWs and other staff to cross over roles and responsibilities in a BBI context. This model is not so apparent within AHSs.

Many ACCHS staff felt pleased that had an opportunity to provide input into what is seen as an area of concern for staff within ACCHSs. They were pleased that not only had they been consulted, but also that Aboriginal people had conducted the consultations. Many staff they felt that it was timely to begin stimulating discussions about BBIs particularly hepatitis C.

Partnerships

Partnerships between AHSs and ACCHSs are essential if there is to be a coordinated response to BBIs within Aboriginal communities, especially hepatitis C. Section 3.5 of this report describes the various levels of the partnership approach in NSW. The NSW Aboriginal Health Partnership provides the platform for Local/Area Aboriginal Health Partnerships to be developed that allow for local shared health planning and coordinated responses to BBIs within the Aboriginal population. Around the state there are many examples of partnerships between ACCHSs and AHSs, some working better than others. Supporting and developing effective partnerships, and sustaining them over the long term is recognised as a challenge, which needs commitment and persistence, by all parties.

Many of the ACCHS have developed partnerships with Justice Health to work in local corrections and juvenile justice facilities. However some of these partnerships require fine tuning and services need to be expanded. ACCHS staff need to be able to deliver comprehensive services and programs broader than the small number of initiatives that are working well at present such as the Aboriginal Vascular Health program within corrections facilities.

Leadership

Ongoing leadership within ACCHSs is crucial if the incidence of BBIs is to be limited, particularly around the difficult issues of injecting drug use within communities. Aboriginal leaders both within ACCHSs and external to Aboriginal health need to make a sustained committed effort to attempt to curb new transmissions of BBIs. For example the issue of hosting needle and syringe programs within ACCHSs requires considered thought and leadership.

By acknowledging that injecting drug use is an issue in some Aboriginal communities, and actively participating in providing the means of prevention (such as NSPs), or providing moral support for AHSs or NGOs doing so, leaders are directly helping to reduce the transmission rates of BBIs within communities.

The unique structure of ACCHSs means they are particularly good at accessing the Aboriginal community. Aboriginal staff employed within services usually have familial and or cultural links into the community and thus are more effective at developing and implementing programs within the Aboriginal community. Although BBIs and sexual health are sensitive issues in the Aboriginal community, there has been considerable work done particularly by ASHWs in broaching the subject of BBIs within communities.

However more effort and support mechanisms are required if ASHWs and other staff within the ACCHS are to continue breaking down the stigma, moral judgements and discrimination faced by those at risk of BBIs and those already living with BBIs.

The need was also identified for those in leadership and management roles in ACCHSs to ensure that ACCHS staff with responsibility for sexual health/BBIs are working within a locally developed framework that is both strategic in its intent and approach, both short and long term. ACCHS staff require a framework to work within that strategically addresses BBIs to alleviate fragmented approaches to prevention, education, treatment, care and management of BBIs. Such a framework would also have implications for other ACCHS staff, in terms of their basic knowledge and awareness of BBIs, so that a holistic approach can be enhanced and built upon. Some of the ACCHSs have yet to develop and endorse appropriate strategies, either in partnership with mainstream services or as a ACCHS BBI - specific strategy. The consultants found that this had implications for the way ASHWs set their priorities, the extent to which that they felt supported and supervised in their work, and the level of priority accorded to sexual health.

Developing such strategies takes time and resources, both of which present challenges to ACCHSs. As such any initiative that aims to direct resources at BBIs should encompass a component which will allow ACCHSs to employ or access specialist staff to assist in the development and in the monitoring of any BBI strategic plan.

ASHWs working within ACCHSs have reported that at times they have experienced greater expectations from the community leadership with regards to the work that they were undertaking. ASHWs felt that the responsibility is broader than any one individual and it would be more useful in the longer term for the leadership to maintain pressure on the broader health system, including assisting ACCHSs in partnership.

Justice Health

Justice Health in NSW (formerly Corrections Health Service) is responsible for the provision of health services to detained persons in 29 correctional centres, eleven periodic detention centres, two transitional complexes, eight police cell complexes, seven court complexes, nine juvenile detention centres, the adult drug court and the pilot Correctional Centre Release Treatment Scheme.
Justice Health has had responsibility for providing health services to juvenile detention centres since February 2003.

The NSW Inmate Census of 30th June 2001 indicated that there were 8780 inmates including periodic detainees within NSW. There were 1244 Aboriginal inmates at 30th June 2001 (14%). [22] The number of Aboriginal inmates has increased by 1% each year over the last five years.

HCV

Justice Health acknowledges that NSW correctional facilities are dealing with a serious hepatitis C epidemic, with 64% of women and 40% of men inmates infected. [23] This compares with a 1% prevalence in the broader Australian community. [24] In NSW there are up to 4,000 people with hepatitis C in prison at any one time.

It is well documented that incarceration is an independent risk factor for the transmission and dissemination of hepatitis C. Risk factors for transmission of hepatitis C in correctional settings are the sharing of IDU equipment, tattooing and body piercing equipment, violence and the sharing of domestic utensils such as barbering equipment and toothbrushes.

The adult inmate surveys indicate that Aboriginal people are younger than the general inmate population, are more likely to have a prior adult imprisonment, and are less likely to have been imprisoned for a serious offence.

Whilst Aboriginal people are over represented within the NSW prison setting (19% of all inmates) Aboriginal inmates are also more likely to serve less time incarcerated compared to the general inmate population, with the median length of stay being 23 months for Aboriginal males and 11 months for Aboriginal females compared with 47 months and 20 months for non Aboriginal males and females respectively. This has implications for the way that Aboriginal inmates are able to access early detection and ongoing treatment and care services for BBIs within this setting.

These factors are compounded by the fact that many Aboriginal prisoners may be exposed to injecting drug use for their first time while incarcerated and thus may have started injecting drugs while in prison. This has implications for the broader Aboriginal population as when inmates are released they are not only a source of introducing injecting drug use within the community but also they are potentially a source of hepatitis C infection. Thus a new problem is created where one previously did not exist.

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[22] Corrections Health Service Corporate Plan 2003 – 2008.

[23] Corrections Health Service Corporate Plan 2003 – 2008.

[24] Corrections Health Service: *Hepatitis C: the challenges, the responses – Strategic Directions 2003 – 2006*

There are further important implications for the continuity of care, especially as many people end up in the correctional system because of multiple health problems that have not been adequately addressed in the past. Adding another health issue demonstrates the need for models of continuous care to ensure that Aboriginal people are linked in effectively to their local ACCHS upon release from the correctional setting.

One of the identified key groups at risk of BBIs is Aboriginal youth. Aboriginal juveniles are 19 times more likely to be detained than non - Aboriginal people are. In 2003, the numbers of Aboriginal male youth accounted for 40% of male youth detained in the juvenile justice settings and Aboriginal girls accounted for 90% of all girls in juvenile justice settings. Preliminary data from the Young People in Custody Health Survey indicate HCV prevalence of 9.1% among juvenile detainees in NSW. [25] Aboriginal youth must obviously be a focus of attention with regard to health promotion, education, and treatment and clinical services. There is an urgent need to develop service agreements between ACCHSs and juvenile justice centres that will enable these initiatives to occur in the most culturally appropriate manner.

Elements of the response to hepatitis C by Justice Health

- Justice Health has recently developed a strategic document titled *Hepatitis C: the challenges, the responses – Strategic Directions 2003 – 2006 to* direct their efforts in reducing the risk of hepatitis C for all inmates.

- Justice Health has a comprehensive targeted screening program (rather than mandatory screening) for BBIs that seeks to provide treatment and care to those at high risk of BBIs. This directs resources in an efficient manner. Inmates are assessed as to whether they are at high risk and then offered screening, with appropriate follow up and referral. The program is designed to improve the inmates' capacity to reduce the risk of becoming infected and/or reinfected during their term, to reduce risks to others and to ensure better care and management of inmates. The high turnover of inmates and movement through the correctional system is a constraint to the program; a prerequisite is some certainty that the inmate will be around to obtain the results. Justice Health advises that approximately 36% of inmates are currently screened for BBIs and STIs.

- Specialist hepatitis C clinics are held in each of the state's 29 correctional facilities, providing and monitoring treatment. Specialists are now visiting 12-13 centres, and there are 3 centres where liver biopsies are done.

- Justice Health has a partnership with the AH&MRC which provides a framework for local service delivery agreements with individual ACCHSs across the state. These are in place with all ACCHSs that are within distance of correctional facilities. Eighteen of the 28 correctional facilities in NSW have access to visiting ACCHS staff, including GPs. These agreements provide an important mechanism for providing culturally appropriate services to inmates. Justice Health estimates that 84% of Aboriginal men and 94% of women in custodial settings have access to such services.

- There is an Aboriginal Health Unit in Justice Health with a Manager and one staff member.

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[25] Corrections Health Service Corporate Plan 2003 – 2008.

- Justice Health has recently received permission to deliver condoms and dental dams through their clinics. Condom vending machines are in place although access can be problematic. There are no specific Justice Health funds to facilitate Aboriginal health promotion and education programs resulting in a somewhat fragmented approach to health care delivery for Aboriginal inmates. This contravenes the philosophy of the ACCHS sector in ensuring the delivery of a holistic whole of health and well being approach for Aboriginal people. The Department of Corrective Services provides drug and alcohol and related services to inmates of its facilities.

HIV/AIDS

The number of known HIV positive inmates has increased by 20% between 2000 –2003, reflecting the longer survival of people with HIV/AIDS in the general community. Currently there are 34 inmates known to have HIV, within the NSW correctional system.

Justice Health offers two specialist on-site clinics per month (at Silverwater and Long Bay Complexes). These clinics are part of a comprehensive service provided by the Sydney Sexual Health Service through a funded Memorandum of Understanding between South Eastern Sydney Area Health Service and Justice Health. Other components of this MOU are telephone support for Justice Health staff, and clinical assessment of inmates residing at remote correctional centres.

A statewide network of public health/sexual health nurses provides ongoing monitoring and support to inmates with HIV/AIDS. This network is supported by the Clinical Nurse Consultant Sexual Health (Justice Health).

Inmates requiring low-dependency hospital management are admitted to B Ward at the Long Bay Hospital. Those requiring more intensive care are admitted to local community hospitals, or if classified as high-security, will be admitted to “The Annex” at the Prince of Wales Hospital. End-stage AIDS patients would usually generate early release on compassionate grounds. There has been no call on palliative care services in the three-years under review.

Justice Health does not have specific HIV/AIDS allied health services, although there is enhanced access to dental services within Justice Health.

All inmates can access sexual health services through the Targeted Screening Program within the Population Health Clinical Stream. Those diagnosed as HIV positive are offered care and treatment (as listed above). The Targeted Screening Program assesses risk and appropriate testing for a range of blood borne viruses and sexually transmitted infections.

Mental health and drug and alcohol services are available to all inmates, with HIV positive inmates offered priority access.

The Department of Corrective Services has an HIV Health Promotion Unit responsible for education and health promotion programs for inmates.

Access issues in correctional facilities

- As described above, Aboriginal people returning to their community from correctional facilities may introduce the practice of injecting, as well as unknowingly transmit hepatitis C. It is important therefore that they be quickly linked with local health services, from both treatment and prevention perspectives. Since inmates may be incarcerated in facilities far distant from their homes, the association they may have had with an ACCHS near the facility will not necessarily help on return home where a different service is involved. The time immediately following release is a unique opportunity to provide support, education and encourage access to services – however, this opportunity is often lost.

- One good example of how this issue is being addressed is in the Bulgarr Ngaru Medical Aboriginal Corporation in Grafton, where a position of Aboriginal Community Inmate Health Coordinator has been established. Its role is to identify Aboriginal people from the Hastings and Clarence regions in correctional faculties across NSW and help them access health and welfare related services during and after their incarceration. This will include linking them and their families with their local community health services, and provide opportunities for health promotion, prevention and education regarding the risks associated with BBIs.

- A related issue is the process for transferring inmate information from Justice Health to, for example, ASHWs, and the sensitivity of doing so. A model with informed consent from the inmate may be a way to get around the issue.

- Justice Health advises that Aboriginal inmates are accessing services within correctional facilities less than the non Aboriginal inmates. Exact reasons are not known, but it is likely that visibility and concerns about confidentiality breaches may be factors.

- Partnerships that exist between ACCHSs and Justice Health are widespread and diverse in their effectiveness- as with other partnerships, some are working more effectively than others. Those that are not fully effective in their responsibilities need to be analysed and identified issues be addressed by both parties.

- Since Justice Health has taken over responsibility for juvenile justice centres, partnership arrangements with ACCHSs in respect of adult correctional facilities need to be now extended to these centres. There will of course be resource implications.

- The reality of prison life is that sharing of injecting equipment does occur. An underground system brings with it many risks associated with BBI transmission. Education and prevention in these circumstances is a challenge, but still needs to pursued. In particular, provision of the means of prevention (eg sterile equipment, condoms) continues to be a public health protection concern. The political and cultural sensitivity of these issues is of course acknowledged.

- Justice Health does not have specific resources to provide health promotion within clinical settings. A need was identified for a more holistic approach to health promotion as it is provided by the Department of Corrective Services, collaborating more closely with Justice Health.

4.2 FACTORS INFLUENCING ACCESS

4.2.1 GENERAL

Access to ACCHSs and other culturally sensitive services

The National Aboriginal Health Strategy identified in 1989 that Aboriginal peoples' access to health care across NSW was less than optimal. It is well documented that Aboriginal people access health services far less than the general population. Despite many reports that have confirmed the key role that ACCHSs play in improving access to services, there are still many areas in NSW where ACCHSs do not exist or do so with limited potential to expand and service the communities they are meant to be servicing.

Aboriginal people particularly in rural and remote areas have poorer access to GPs particularly in the current climate where numbers of bulk billing GPs in those areas decline. Limited access to culturally sensitive services places Aboriginal people at further risk of not accessing medical treatment and care.

The cost associated with treatment for BBIs is also another prohibitive barrier to Aboriginal people accessing treatment and care by specialist services, as well as drugs for treatments where these are not provided by the public sector.

Access to services by Aboriginal people is also directly affected by services' history within the Aboriginal community. For instance, does the service have a history of real or perceived breach of confidentiality? Are the service priorities reflective of community needs? Has the service established rapport with the Aboriginal community, and have general support from it? How long has it been providing services, and has it achieved credibility and trust over time?

Clinical history of BBIs

The three major blood borne infections (hepatitis B, C and HIV) share one thing in common – the mode of transmission via blood or bodily fluids. The pathogenesis and natural history of BBIs also share commonalties in that each can present as an acute infection but may progress slowly with few symptoms. This clinical history has many implications for Aboriginal people. For example:

1. Unless Aboriginal people are accessing clinical services, many may remain infected without ever knowing their health status in relation to BBIs.

2. People who are unknowingly infected with HIV, hepatitis B or C may disregard their status while the virus is progressing slowly. Thus people may continue to engage in risk taking behaviours, including unsafe sex, dangerous levels of drinking and injecting drug use. At the same time they may be transmitting BBIs to others in the community without knowing their status.

3. Once a person is infected with hepatitis B, C and/or HIV, many people may assume "*that's it*" - they are infected. They don't necessarily appreciate, for

example the effects of hyper mutability, and the creation of quasispecies of the three viruses, causing an accelerated progression of disease.

4. Co-infection of both hepatitis C and HIV can lead to an accelerated development of cirrhosis and end stage liver disease, as can hepatitis B and HIV.

General stigma associated with BBIs

There is negative stigma associated with each of the BBIs within the Aboriginal community. From the consultations we learned that moral judgements can be placed on others of different sexual orientation or those involved in a risk taking activity, such as injecting drug use, in the community. For instance, if a person is HIV positive they may be judged as "gay" even though the rate of transmission is reported equally frequently for both heterosexual and homosexual transmission within the Aboriginal community. If a person is hepatitis C positive, then they may be assumed to be a current IDU, though infection may have been acquired long ago, or via other routes of transmission such as transfusions or sharing of household items such as razors or toothbrushes.

What the literature says

Some of the cultural sensitivities that may be misunderstood by non-Indigenous health service providers include the separation of 'men's business' and 'women's business', and the expectation that issues of sexuality and sexual health will not be discussed in a mixed environment (Forrest 1995: 14). Sexual identity can also mean quite different things in an Indigenous setting. For example, Indigenous men who have sex with men may not identify as gay, and may not be identified by others in their community according to their sexuality (Gallagher 1999: 14).

Injecting drug use and Aboriginal communities

There is enough evidence now to suggest that the pattern of drug use within Aboriginal communities are changing dramatically as with other identified communities both nationally and globally. Injecting drug use among Aboriginal people is now in the public domain and what was confined to certain areas and communities is now widespread, no matter the geographical location. While numbers may be small in some areas, the potential for epidemics of the three BBIs to occur in these areas is nevertheless there.

What used to be limited to inner urban areas is spreading not only to outer metropolitan areas but also to rural and remote communities. This was confirmed through the extensive visits and consultations conducted for this project.

Each of the NSP surveys over recent years has indicated that Aboriginal people comprise around 8% of clients at NSP outlets across NSW. Aboriginal people are injecting drugs in rural and remote communities - not only opioids drugs but also injecting alcohol and other stimulants including amphetamines.

Sharing is an integral component of Aboriginal culture, as discussed in section 3.3, and poses additional special risks. However, during the consultations, we heard many stories of one person within an IDU group that would access NSP services on behalf of other users and then distribute the equipment across in a communal setting. Thus a positive cultural practice can be a negative public health practice. Once an IDU is accepted within their community, there are fewer obstacles in accessing programs such as NSPs.

Aboriginal community understanding and ownership of the issues at hand

The cultural and social marginalisation of IDUs within their community further increases the likelihood of drug related harm including transmission. It marginalises them from accessing services because of the perceived notions of them not being part of the community or if Aboriginal leaders are openly expressing intolerance of IDU within their communities. This further marginalises IDUs within communities.

As drug use is changing within Aboriginal communities, service provision needs to reflect the changes. This has implications for leadership from within the Aboriginal community to keep abreast of the changing nature of IDU, the need for ensuring a caring and supportive environment for all community members and the need to be informed of current medical interventions addressing BBIs.

4.2.2 CONFIDENTIALITY

The perceived fear of loss of confidentiality and loss of privacy were the barriers to access most frequently identified by staff in all of the consultations. Sexual health issues are arguably one of the most difficult areas to work in within the Aboriginal community and the sensitivities associated with confidentiality within health services compound this.

Aboriginal Community Controlled Health Services were established to provide holistic health care for the Aboriginal community in a supportive environment and this works no better than in a sexual health context where people are able to access the services anonymously and without fear of judgement because of the range of health services an ACCHS is able to provide. However, there is still a perception that confidentiality can be compromised because of the greater capacity for Aboriginal people to be recognised. Many ACCHSs have implemented a range of initiatives to ensure that strictest confidentiality and privacy practices prevail for all clients.

However, this does not eliminate members of the community other than ACCHS staff perceiving that privacy in sensitive areas of health care are vulnerable. Whilst this is an established myth it still needs to be addressed to enable sustained effective sexual health services within the Community

The location of mainstream sexual health and harm minimisation services such as NSP services and the related issues of signage of services and attitudes of staff is even more critical due to the one dimensional aspect of services provided to ensure access is equitable for Aboriginal people.

The location of services has important implications for the way that Aboriginal people access such specific services. If a service is deemed to be in a place that is highly visible then people may feel exposed not only to staff within the service, but also vulnerable to other community members who may be perceived to breach privacy or be seen to assume the particular purpose of their visit to the service. Service location issues are discussed further in section 5.2.4.

There is a commonly misunderstood fact that staff within ACCHS and other health services are able to freely discuss patient details with each other resulting in a possible breach of privacy. However, during our consultations the above was identified as a potential areas for concern in accessing health services.

In addition another issues regarding privacy and confidentiality was raised concerning clients disclosing their own status in social settings (for example within drinking circles) and possibly without remembering that they have done so. Word spreads around the community and unfortunately blame is often placed with the health service. It was identified during the consultations that many practitioners may be failing to provide clients with proper and adequately understood *pre and post test* counselling including practices surrounding disclosure.

4.2.3 LOCATION

Location is a key factor in anyone accessing health services, and this is particularly for Aboriginal people due to socioeconomic and cultural factors. It is well documented that people residing in rural and remote areas have lower health status and have less access to quality, comprehensive services than people in urban areas. Approximately 35% of the NSW Indigenous population live outside of Sydney, Newcastle, Wollongong and Canberra [26] – accounting for a significant proportion of that population with limited access to support and specialist BBI services. For example, in rural and remote areas, sexual health services are often the focal point for HIV/AIDS specialist treatment and care. However, there is often only one service, located in a large regional centre, thus requiring extensive travel with implications for cost, time and available transport.

The specific location of services, for instance within a town or centre, has major implications for Aboriginal access. Examples noted during the consultations that may inhibit access to services included:

- NSPs in emergency departments – the hospital is often located on the outskirts of a town making access difficult particularly after hours and during weekends when public transport has ceased or has a limited service; security personnel are often prominent; other Aboriginal people may be waiting; police may be coming and going especially after hours.

- Methadone clinics (requiring daily attendance) may often be located in hospitals (again, not always very accessible – where a hospital is particularly inaccessible, this causes further hardship for people already marginalised – alternatives are needed).

- NSP vending machines may located in highly visible sites (usually to deter vandalism), such as in the front of a community health centre, or at the side in full view of staff- again alternative sites are needed. Similarly we noted that many of the available vending machines were out of service for many months at a time.

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[26] ABS 2001 Census of Population and Housing - Population Distribution Aboriginal and Torres Strait Islander Australians.

- Community health services located near other agencies that are highly accessed by Aboriginal community members. One such example was locating the local community health centre right opposite Centrelink. This may present as a barrier for Aboriginal use of the service, because of the high client traffic, and Aboriginal sensitivity to being judged as an IDU or to be seen as accessing sexual health services.

- D&A units and sexual health clinics located in hospital areas (sometimes on third or fourth floors) where there may be one or more access barriers such as reception and/or security. Such services may largely be invisible and little known. At the same time, a high level of visibility and identifying signage, may also be a deterrent.

- Access seems to be enhanced where the buildings are separate, discreetly signed (perhaps using a surrogate name rather than "Sexual Health Clinic"), in a lower traffic/visibility central location (such as one street back from the centre).

- Little knowledge by the Aboriginal community of services, especially those provided by community health centres. In some cases noted, the services were so discreet few people knew about them.

- Transport continues to be a factor influencing access for Aboriginal people, including compliance with treatment regimes. Aboriginal health workers are often criticised for being transport providers, but this is often the key factor influencing whether an Aboriginal person attends a service or not.

CHECKLIST FOR WELL LOCATED SEXUAL HEALTH AND HARM MINIMISATION SERVICES

- Close to reliable and regular transport.
- Discrete location, away from other high traffic/visibility gathering points and services.
- Without obvious proximity to security or law enforcement services;
- Minimal reception barriers to be crossed.
- Signposted in a way that destigmatises the main role of the service.
- Multiple access points – outreach (foot, van, car, and other shopfront locations).
- Visible indications that the service is Koori friendly eg naming, posters, use of colours, symbols.

4.2.4 STAFF

The staff in a service have a primary responsibility for ensuring that Aboriginal people feel comfortable accessing the service. The following are particularly important:

- Welcoming, respectful and equitable treatment for everyone approaching the front desk or counter, especially on first visits.
- Maintaining confidentiality.
- Refraining from being judgemental as to why the client is accessing the service – this can be expressed in many subtle ways.
- Access to male and female practitioners.
- Access to visiting specialists.
- Access to Aboriginal staff is almost always an advantage. However, in some circumstances, services may have to accept that this may be a barrier to some in a community and so alternative access modes may need to be considered. The need has been identified for more Aboriginal workers in NSPs.
- Pharmacies are important providers of injecting equipment and methadone, and substantially increase access. However, the attitude of counter staff is critical as to whether Aboriginal people will access that supplier.

4.2.5 COMMUNITY AND WORKER KNOWLEDGE

Throughout all consultations the consultants found that there was generally a low level of knowledge concerning BBIs throughout the broader Aboriginal community particularly among those are not directly or indirectly involved in health service delivery. This related to what the diseases are, how transmission occurs, what the risk behaviours are, symptoms and treatment. Of the three BBIs in focus for this report, HIV was the one that most community members had some knowledge about, even though many misconceptions were noted. There seemed to often be confusion about hepatitis B and C both within the community and within the Aboriginal health workforce. At times hepatitis C was quoted as having been vaccinated against when there is no such vaccination for hepatitis C.

Other examples included the lack of knowledge of the risks associated with birthing and vertical transmission of Hepatitis C and difficulties in identifying where to get information about these risks.

There was a general perception that there was more knowledge among IDUs about the risks associated with transmission of HIV and hepatitis C. Several studies have suggested that the longer people inject drugs the greater their level of knowledge is surrounding transmission and pathogenesis. Similarly this is often the case in correctional facilities.

An area of concern highlighted by many workers regarding hepatitis C was that once people were infected they could then share injecting equipment without further risk to themselves as they were already positive to hepatitis C without too many disabling symptoms when actually transmission to others is a huge risk.

When community knowledge of BBIs is low, it is more difficult to convince communities and their leaders of the urgency of a situation, or the need for action. It is important to ensure that Aboriginal workers in all health fields have a sound basic knowledge of BBIs so they can take opportunities to educate and refer to ASHWs as they are dealing with other health issues.

4.3 INITIATIVES TO IMPROVE ACCESS

In the course of gathering data for the project, the consultants heard about many initiatives to improve Aboriginal access. The Snapshot (Appendix 5) provides an overview of initiatives notified to the project. For this report we have selected some examples in areas of endeavour where efforts are likely to be effective in increasing access for Aboriginal people – although this cannot be known for sure without evaluation. Of course, in making this selection, we may have omitted many others equally of interest. Nevertheless, we hope this brief discussion will stimulate readers to think about and implement new initiatives to increase access for Aboriginal people.

Initiatives are described below in the following areas:

- Partnerships
- Engaging the Boards of ACCHSs
- A multidisciplinary sexual health team providing comprehensive outreach services to the Aboriginal community
- Supporting clients
- Outreach services.

4.3.1 PARTNERSHIPS

On the Mid North Coast there is an excellent example of how a Local /Area Aboriginal Health Partnership can work effectively across a large geographical area.

The partnership is between the AHS and ACCHSs at Kempsey, Taree and Coffs Harbour. Members of the Local Area Aboriginal Health Partnership are Chairpersons and CEOs of each of the ACCHSs, the Chair of the AHS Board and the Area CEO, plus the Aboriginal Health Coordinator. They meet every two months to discuss and resolve Aboriginal health service delivery issues.

While most AHSs have similar partnerships, not all function well at all times. In this case, leadership by a new Area CEO, genuine commitment by ACCHSs to the partnership and belief that its processes can and will work are critical success factors.

This Partnership forum was the only one that invited the consultants to meet with them in their regular meeting and the Area CEO the only one to do likewise. All showed great interest in the project and its potential to assist them improve Aboriginal access to BBI services. To our knowledge, Mid North Coast and Western Sydney AHSs are the only AHSs with an Aboriginal person on the Executive. Giving Aboriginal issues this level of priority at the highest levels of Area administration sends an important signal across the health service and is picked up by other staff.

4.3.2 ACCHS BOARD ENGAGEMENT

ACCHS Board members are elected community members who are influential in shaping the direction and priorities of the local ACCHS. Because of their expertise in health, Board members can also influence opinion in the Aboriginal community, especially in sensitive areas such as sexual health and injecting drug use.

Board members, who are informed, are able to act and persuade others into implementing harm minimisation strategies and are able to understand the complexities of BBI prevention, are critical to ensuring the full range of programs and services, and the necessary supportive community environment

A good example of a project to engage a group of ACCHS Boards in strategies to increase access for those most at risk of BBIs in the community is in the Far West AHS. Funding was received from the Council of Australian Governments (COAG) through the NSW Health Department to conduct an NSP “road show” for health workers and Board members in ACCHSs in the Far West, and to develop some appropriate resources. The objective was to increase knowledge of Board members of ACCHSs of NSPs and the key role they play in harm minimisation of BBIs, and thus create a more supportive community environment for people to access them.

The “road show” involved local AHEOs, the AHS sexual health team and a local ASHW and was promoted in four Far West Aboriginal communities. While the outcomes are expected to be increased access of NSP by Aboriginal people, and more ACCHSs willing to host NSP within their services, this will need to be monitored. Such an initiative is also likely to need follow up and reinforcement so the outcomes are sustained over time.

4.3.3 A MULTIDISCIPLINARY SEXUAL HEALTH TEAM PROVIDING COMPREHENSIVE OUTREACH PROGRAMS TO THE ABORIGINAL COMMUNITY

The way services are structured, managed and delivered, and the way health professionals work together as a team, can be a huge influence on how clients feel about accessing the service, as well as the quality of care and service they receive from it.

Macquarie Area Health Service has a comprehensive sexual health team which provides services across a large geographical area. It services the whole population and two ASHWs (male, female) allow a special focus on Aboriginal sexual health.

Its key features are (in relation to Aboriginal access):

- Multidisciplinary – medical, nursing, ASHWs
- A visiting sexual health physician.
- The HIV/AIDS/Hepatitis C Coordinator plays a crucial role in strategic direction and priorities of service, developing skills of ASHWs (clinical, and skills required to work within a mainstream service).
- Two ASHWs – male and female.
- Every member of staff is given the opportunity to be involved in decision making.
- Role modelling and mentoring is essential to staff development.

- Staff are encouraged to try things that they haven't done before, with appropriate support.
- There is a genuine commitment to building staff capacity in relation to skills acquisition and knowledge. Thus training is about giving knowledge to back up competencies rather than just teaching a skill (eg they know and understand what they are testing for and not just taking a urine sample).
- ASHWs are trained to do comprehensive sexual health assessments of clients, including referral. They also do venipuncture, PCR screening, and pre and post test counselling. Ongoing training, including new skills, is provided based on periodic skills audits.
- A comprehensive set of operating procedures has been developed for ASHWs providing outreach services.
- ASHWs and other staff are respected for their life experience as well as health experience.
- A policy that no new outreach service can commence until a comprehensive consultative process has been completed.

It should be noted that most AHSs are funded for only one ASHW, in this Area extra funding is provided from the Area's overall budget to enable the permanent employment of both a male and female ASHW.

4.3.4 YOUTH

Aboriginal youth require particular attention and priority because of their risk of contracting BBIs.

The consultants learned about many good initiatives across NSW that have been developed locally to improve access for this group. Following are some examples.

"WAY COOL"

In Wellington, in central NSW, staff of the Community Health Service in partnership with the Wellington Aboriginal Corporation Health Service, the Police and Community Health Club, the Community Development Employment Program, the Wellington branch of the Sydney City Mission and the Far West AHS worked together to run a program specifically for Aboriginal youth at risk.

The program is called ***"WAY COOL",*** an acronym for *"Wellington Active Youth Community Options on Life".*

Participants were 16-20 years of age and were recruited "from the street", from services, and from CDEP. A steering committee was set up with facilitators from each of the services represented. The program runs once a week for 3 months, with an education and prevention focus. Participants could be picked up to attend and transported home. Activities include:

- Education sessions on subjects such as drug and alcohol issues, sexual health, legal issues, mental health and culture. Speakers include current and past injecting drug users as well as people who are positive to hepatitis C and HIV.

- Visits to rehabilitation centres, youth centres and gaols.

- Regular overnight trips that aimed to build self-esteem, with a trip at the completion of the course.

- Sport and BBQs.

The program maintains a 90% attendance/retention rate and there have been some positive outcomes associated with this program including the employment of some of the participants of this program the health sector and in particular one in the Wellington Aboriginal Corporation Health Service.

Riverina Youth Group

Riverina Youth Group (RYG) is an initiative of the Riverina Medical and Dental Health Aboriginal Corporation, located in Wagga Wagga. The Board of Management recognised that they have an important role in ensuring a positive future for youth in the community.

The youth group has its own committee made up of seven local youth members selected by their peers that meets every two weeks. The committee aims to make RYG as friendly and accessible as possible in a relaxing learning and interactive environment.

Each afternoon between 3.30 p.m. and 7 p.m. approximately 30 youth (both sexes) attend the centre to participate in a number of activities and programs. A range of educational activities and skills development programs is available. Activities include sports, traditional dance, art and crafts, the Internet and tutorials, use of the Police and Community Youth Club (PCYC) facilities, board games and a play station. Education and skills development programs focus on important issues for youth such as drug and alcohol issues, employment, education, sexual health, the justice system, life skills and cultural awareness. RYG also has a number of field trips.

To become a member there is a $2 annual membership fee that contributes to afternoon tea and PCYC membership. Members receive a package that includes a membership card, t-shirt and information on services available to youth within the community.

The benefits of this group are that the youth are attending a non-threatening environment still under the umbrella of the local ACCHS. Youth are arguably the most difficult group within the community to engage in health services. Through this project a large group is attending the ACCHS on a daily basis making them much better prepared and informed of health issues pertinent to their own age group.

Other examples:

> ***Mens' Camp*** – Katungul Aboriginal Corporation Community and Medical Services (Narooma) conducts camps for up to 30 young men most at risk, twice a year (15 per camp). There are 2 week and 8 week camps, with medical appointments beforehand (eg for Nicorette patches). The camps involve fishing and other recreational activities, in an education and self-esteem building process, which covers areas such as sexual health, drug and alcohol, and diabetes issues. The groups stay no longer than 3 days in one spot, and message sticks are used throughout the trip. Elders are involved in cultural teaching, and extended families are invited to join the group for one night. Employment agencies are invited to talk with the young men. There is

evidence that participants feel more comfortable accessing services and tend to do so more frequently after the camp.

Girl Power – At Moruya, Southern AHS delivers a program that empowers young Aboriginal women and engages them in education about risk taking behaviours and the risks associated with this. The program is called *Girl Power* and is designed for young Aboriginal women who are using alcohol and other drugs. Although the majority of young women are not dependent on a substance, there is evidence among some of high risk behaviours, for example, intoxication, unprotected sex, and domestic violence.

The program aims to:

- Target young Aboriginal women between the ages of 12 and 18
- Provide education on alcohol and other drugs
- Promote harm minimisation strategies
- Explore self esteem – body image, sex
- Discuss healthy relationships
- Gain an understanding of goal setting and problem solving strategies.

During the development of *Girl Power*, a consultation process was conducted with women Elders to ensure program content was culturally appropriate and delivered in a sensitive manner. Those Elders where then invited back as guest speakers throughout the 6 week program.

The participants used a variety of artistic media such as collage, journal work and dance to explore society's values and express their emotions. At the end of each program the young women produced an installation that represented what they had learnt during the six week course which was displayed in a public area.

Outcomes:

- Court Diversion - 2 girls diverted from incarceration
- Self identification of problematic substance use and behaviours
- Referral made to appropriate treatment
- Enhanced self esteem led to re-evaluation of relationships
- Self reported reduction and cessation of alcohol and other drug use
- 97% retention rate.

Evaluations from this program:

> *" It made me feel better about myself in the group but once I left I was back to reality".*
>
> *"It was informative at the same time fun, so it was even better"*
>
> *"It was cool to talk about the stuff you usually can't",*

The *Girl Power* program has now been delivered successfully on eight occasions throughout the Eurobodalla and Bega Shires.

4.3.5 SUPPORTING CLIENTS

The Sydney-based Kirketon Road Centre is a primary health care facility within South East Sydney Area Health Service, located at Kings Cross. Fifteen per cent of its clients are Aboriginal IDUs, and 30% of the clients on its Methadone Access program are Aboriginal. On their first visit, Aboriginal clients are linked up with an Aboriginal project coordinator, and there is a regular Aboriginal group meeting every week. Between 6 -12 regularly attend the support group meetings. Clients identify the issues they want to be discussed. Guest speakers/role models come and address the group, for example David Gulpilill recently did so. The Centre has identified major barriers for preventing the spread of hepatitis C: Many Aboriginal injectors hide their practices, making them vulnerable to the virus; Aboriginal clients have few family and elders with whom to discuss health and drug use, and most are disenfranchised from their own communities. They need more non-judgmental education programs; and there are very few Aboriginal resources written in plain language (Orcher 2001).

4.3.6 OUTREACH SERVICES EMPLOYING ABORIGINAL STAFF

Outreach services, especially by Aboriginal workers (with/without non-Aboriginal clinicians) offer great potential for reducing access barriers, especially relating to location and transport. ACCHSs (and NGOs such as ACON and NUAA) tend to have greater flexibility than AHSs in providing outreach services to the community, and do so. In the Northern Rivers AHS, a proposal to locate an ASHW in ACON Lismore is aimed at increasing Aboriginal access through more outreach services. This is an example of a strategy that should be evaluated to see what improvements do in fact occur.

The consultants observed many examples of ASHWs providing education or clinical services, for example through CDEP programs, schools, Aboriginal sports festivals, and Land Councils. Riverina ACCHS and Biripi have other access points in the community and town, respectively. South Western Sydney AHS (and others) have outreach NSP workers and the ASHW delivers outreach services to a number of different sites.

What the literature says

Plummer and Forrest (1999) insist that it is “wrong to suggest that Aboriginal people do not access mainstream services very well. Mainstream services generally do not reach out to marginal groups and are not designed with this in mind” (Plummer & Forrest 1999: 51). Culturally sensitive and appropriate services and systems of delivery are key determinants of access to services (Shipp 2002) and the provision of these is likely to require ‘special arrangements’ (Plummer & Forrest 1999; Fagan 2001). Others also suggest that to improve uptake of sexual health services by rural Indigenous men the concept of ‘outreach’ should include models other than clinical provision including going to where men already meet (Smith & King 1998; Willis *et al.* 2002a).

The structure of locally available health services has been seen to influence the prevalence of Indigenous STIs (Miller *et al.* 2003). The importance of local community control and participation in the development and delivery of programs (National Aboriginal Health Strategy Working Party 1989; Australian Federation of AIDS Organisations 1998) is consistently noted throughout the literature. The NIASHS outlines the principles that underpin effective partnership processes (Australian National Council on AIDS 2002: 15).

5 ABORIGINAL SEXUAL HEALTH WORKERS

5.1 BACKGROUND – DISTRIBUTION AND FUNDING

A network of ASHW positions has been set in place across NSW, with sexual health funding from NSW Health and the Commonwealth Department of Health and Ageing. There are currently some 33 positions, 17 located in AHSs and 16 in ACCHSs. An additional 7 positions have statewide roles – 4 in ACON, 2 in the AH&MRC and 1 in a regional coordination position (ASHW Development Coordinator – North Coast [27]). In addition, at least one AHS (Macquarie) has funded a second position for that Area although there may be more than this AHS.

The number of workers per Area and the actual location of the positions (AHS or ACCHSs) were negotiated in the NSW Aboriginal Health Partnership. Working within available resources, decisions about the number of workers per Area were made taking into account geography, population, unique local factors and STI rates. In terms of location, a broadly equitable distribution of workers between AHSs and ACCHSs is sought by the Partnership. Currently, there is one more ASHW position in AHSs than ACCHSs.

Funding is provided to ACCHSs for salary, overheads and goods and services. Funding provided to AHSs is seen as a substantial contribution to meeting the cost of employing an ASHW, and AHSs are expected to add to that as part of their responsibility for the health of their whole population. The extent to which this is done varies considerably.

From time to time, ASHWs are able to access one off funding from a range of sources to enable them to conduct specific initiatives and programs. Recent examples include funding through the NSW HIV/AIDS Health Promotion Plan, and COAG grants channelled through the NSW Health Department.

The table over the page presents information on the distribution of NSW Health Department funded ASHW positions by AHS, Aboriginal population and geographical area (the last for rural AHSs only). As was evident in the consultation visits, the fact that these positions are funded and established does not necessarily mean they are all filled and operational. Recruitment of Aboriginal staff to work in the sensitive field of sexual health is inevitably difficult. Staff turnover is more likely where a worker is isolated and unsupported. Resignations may be planned or sudden; in either case, prompt action needs to be taken to avoid long periods with unfilled positions. Both AIDB and AH&MRC need to be proactive in supporting AHSs and ACCHSs with recruitment and in improving the work environment where repeated staff turnover is occurring. The ASHW Development Coordinator (North Coast) is already demonstrating how this can be done to good effect.

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[27] The NSW Health Department is considering the scope to establish similar positions for the south of the state, and the metropolitan area.

Table 1: ASHW distribution by AHS Aboriginal population and geographical area

(January, 2004)

AHS	Aboriginal population [28]	Geographical area (sq km)	Number of ASHW FTEs [29]
RURAL			
New England	10,292	98,000	2.5 (1.5A, 1C)
Far West	6,508	270,000	3 (3C)
Macquarie	7,766	116,400	3 (2A, [30] 1C)
Greater Murray	5,831	113,854	1 (1A) [31]
Mid Western	5,103	59,835	1 (1A)
Mid North Coast	7,170	22,000	3 (2C, 1A)
Northern Rivers	6,445	24,555	3 (2A, 1C)
Southern	3,365	52,214	2 (1A, 1C)
Hunter	8,508	25,000	1 (1C)
Illawarra	5,710	5,653	2.5 (1.5A, 1C)
Central Coast	3,395	1,900	1 (1A)
METROPOLITAN			
Central Sydney	3,168		4 (2A, 2C)
South Eastern Sydney	5,695		2 (2A)
South W Sydney	8,647		2 (1A, 1C)
Western Sydney Wentworth	11,920		2 (1A, 1C)
Northern Sydney	1,690		Nil
STATEWIDE			
ACON			4 (gay, lesbian, sistergirl, sex worker Outreach project Officer)
AH&MRC			2 (Sydney)
Regional Coordination			1 (Coffs Harbour)

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[28] ABS Census of Population and Housing, 1996.

[29] A: located in AHS, C: located in Aboriginal Community Controlled Health Service.

[30] One of the two positions is funded directly by Macquarie AHS.

[31] Greater Murray is funded for 1.5 ASHW positions but has chosen one Aboriginal nurse position.

5.2 ROLE OF ABORIGINAL SEXUAL HEALTH WORKERS

The NSW Health Department documentation describing the *Aboriginal Sexual Health Projects* outlines the role of the position of ASHWs as follows:

> *"The position works in partnership and provides a liaison role between Aboriginal and Torres Strait Islander communities and their relevant services and sexual health services in both the public and private or community controlled sectors within an area of NSW.*

The position assists in reducing the incidence of sexually transmitted infections, HIV and hepatitis C within Aboriginal and Torres Strait Islander communities in the area, by conducting HIV/AIDS, hepatitis C and sexual health education and prevention programs for Aboriginal and Torres Strait Islander families, injecting drug users, gay/lesbian/transgender people, inmates, youth and other individuals through workshops, camps, home visits, counselling and consultations.

The position assists other workers, services and agencies, both Aboriginal and Torres Strait Islander and non-Aboriginal and Torres Strait Islander, in providing clinical treatment, counselling, contact tracing, venipuncture, obtaining urine samples or providing advice. "

The objectives of the projects are to:

- liaise with Aboriginal and Torres Strait Islander organisations, health workers, school groups and community elders to assist in the development of culturally appropriate information;
- advocate and lobby for Aboriginal and Torres Strait Islander people to have access to mainstream services;
- minimise adverse social and political impact of HIV, hepatitis C and STIs by providing culturally appropriate services, treatment and education to the target group;
- promote and provide preventative resources such as condoms and injecting drug use equipment;
- provide a safe and confidential environment;
- improve the quality of life expectancy through adequate treatment and care;
- assist other workers, services and agencies, both Aboriginal and Torres Strait Islander and non-Aboriginal and Torres Strait Islander, in providing clinical treatment, counselling, contact tracing, venipuncture, obtaining urine samples or providing advice;
- provide regular information regarding treatments for HIV, hepatitis C and STIs;
- ensure HIV and hepatitis C positive Aboriginal and Torres Strait Islander clients have access to the range of treatment and care available;
- break down the barriers of geographical isolation which some HIV and hepatitis C positive Aboriginal and Torres Strait Islander people experience;
- enable the Aboriginal and Torres Strait Islander communities to care and support family or friends who are currently caring for someone with HIV/AIDS or hepatitis C through education and resources;

- maintain the continued development of peer support groups for HIV and hepatitis C positive Aboriginal and Torres Strait Islander people;
- minimise the impact on carers by providing emotional and physical support;
- assist individuals and groups in dealing with issues around discriminative practices that surround HIV, hepatitis C, STIs and sexuality; and
- increase the availability of culturally specific and appropriate resources that pertain to HIV, hepatitis C and sexual health.

The positions are to develop and maintain partnerships with the following:

- mainstream service providers;
- Aboriginal and Torres Strait Islander communities;
- specialist sexual health service providers;
- Aboriginal community controlled health services;
- Aboriginal and Torres Strait Islander HIV/sexual health workers network; and
- AIDS/Infectious Diseases Branch, NSW Health.

This information forms the basis of a generic role description which AHSs and ACCHSs adapted to suit local circumstances and priorities. The main point of adaptation is whether the ASHW is required to undertake/assist in clinical matters such as venipuncture, taking urine samples and pre and post test counselling. It is more likely that ASHWs in rural Areas will have a clinical role than in metropolitan ones, where more ready access to services is available, but this is by no means universal.

5.3 ISSUES AFFECTING ROLE AND DISTRIBUTION

As can be seen from the above description, the *role* of the ASHW is complex and wide ranging in terms of specific responsibilities. Some of the issues raised by ASHWs in relation to the size and scope of their role include:

- Difficulties at times in setting priorities across a complex portfolio of responsibilities.

- A large geographical area covering distinct populations with unique cultural needs

- High expectations from the community.

- Often a gender imbalance in the distribution of ASHWs required to cover areas.

- A tendency for anything with the slightest link to Aboriginal sexual health to be referred to them by other health workers.

- The often low level of knowledge of BBIs in the community and among some other health workers.

- Cultural taboos and stigma around sexual health issues and BBIs. In some AHSs and ACCHSs, there may be a relatively low priority given to sexual health issues, given the overwhelming amount of already existing morbidity and mortality.

- Tension between the scope of the role and salary levels, depending on whether AHSs are contributing to the salary.

Despite the fact that NSW has the highest number of Aboriginal sexual health workers in Australia, rural workers in particular have large geographical areas to cover. For example, New England AHS has 3 workers to cover an Aboriginal population of 10,292 over 98,000 square kilometres. Table 1 provides information about the distribution of ASHWs. While the difficulties of distributing the positions equitably are obvious, and the Partnership has done its best with the resources, the fact remains that the jobs are large ones, both in terms of role and geography.

5.4 SUPPORT FOR ABORIGINAL SEXUAL HEALTH WORKERS

5.4.1 STATEWIDE SUPPORT

NSW Health and AH&MRC are building a strong mix of support mechanisms for ASHWs at the statewide level.

NSW Aboriginal Sexual Health Workers Network Training Meeting

NSW Health has acknowledged and supported the need for all Aboriginal sexual health workers to come together annually for training, updates, networking and to provide advice on relevant issues that pertain to Aboriginal sexual health in NSW.

The NSW Aboriginal Sexual Health Workers Network Training Meeting is held annually over 3 days. The first day of the meeting is agenda driven and is committed to worker issues, needs and current developments in Hepatitis C, B and HIV and sexual health strategies specific to Aboriginal people. The remaining days are specifically set aside for professional development and/or project presentations. These meetings are highly valued by ASHWs and have been running for nine years.

NSW Health Workforce Development Program in Hepatitis, HIV and Sexual Health

The NSW Health Workforce Development Program provides financial assistance to the Aboriginal Sexual Health Workers Network to undertake study or training for the purpose of developing or upgrading their skills in HIV/AIDS, sexual health or hepatitis. The program also provides seeding grants for the purpose of training or educating staff in the organisation, volunteers or staff from other organisations.

The program provides an HIV/AIDS, sexual health and hepatitis training directory which is updated every six months outlining all related courses, workshops and forums being conducted in NSW.

Regional Development Coordinators

Under the NSW Aboriginal and Torres Strait Islander Sexual Health Development Project, an ASHW Development Coordinator has been appointed for the Northern NSW Rural AHSs. The project is being conducted in partnership with NSW Health (AIDB) and the AH&MRC. The role of the Coordinator is to provide support to ASHWs in the north of the state, located in both AHSs and ACCHSs. This is achieved through identifying information and training needs of the ASHWs, developing training programs and workshops in line with ASHW needs, supporting ASHWs at a local level to set up outreach clinical sexual health services and urine testing services, and producing and distributing the Aboriginal and Torres Strait Islander STI Education Kit (with the existing presentation team).

The potential of this model is being demonstrated for providing more local, hands-on coordination and support for ASHWs, as well as assisting in the development of resources. The NSW Health Department plans to establish similar positions for the southern and metropolitan areas of NSW.

Placement Program

This new initiative provides placement opportunities to Aboriginal Sexual Health Workers through the NSW Health Workforce Development in Hepatitis, HIV and Sexual Health Program.

The placements aim to provide ASHWs with an opportunity to gain an overall view and another perspective away from their current work environment into sexual health, harm minimisation and STI screening. The placements also aim to enhance and add to the skills of the workers in order to provide a comprehensive sexual health service to the Aboriginal community in their area. In addition the placements, which will occur within specialist sexual health centres and clinics, will provide workers with an opportunity to gain valuable skills that they may not encounter within their current working environment.

Placements will also provide beneficial opportunities for the enhancement of knowledge and skill levels to ASHWs undertaking the AH&MRC Aboriginal Health College's Diploma of Community Services (Case Management) with a focus on Aboriginal Sexual Health.

NSW Distance Learning Package, Diploma of Community Services (Case Management) with a focus on Aboriginal Sexual Health

The AH&MRC Aboriginal Health College has developed a distance learning package for Aboriginal Sexual Health Workers. The aim of the package is to support the *Core Competency Standards for Aboriginal and Torres Strait Islander Sexual Health Workers in NSW*, which were finalised and distributed in 1999. The Core Competencies and the Distance Learning Package have been developed to assist workers and organisations in the management of performance, provide a generic framework to guide workers' work and to provide accredited training and qualifications in the field of Aboriginal sexual health. The course is has gained national accreditation with Vocational Education Training Advisory Board at the Diploma level.

The Standards consist of 4 Core Clusters:

- Networking and Advocacy;
- Case Management;
- Promotion and Education; and
- Managing the work environment

The Distance Learning Package and the accompanying curriculum, address the above 4 core cluster units as well as general units from the *National Aboriginal Health Workers Competency Standards.*

The Distance Learning Package is being implemented by a Course Co-ordinator based at the Aboriginal Health College currently located with the AH&MRC secretariat in Redfern. The Course Coordinator is responsible for ensuring that ASHWs undertaking the distance learning package are provided with local lecturers, preceptors, assessors, mentors and support in line with the objectives of the course.

NSW Aboriginal Sexual Health Training and Resource Development Project

This new project will develop training programs and resources in line with the needs of the NSW network of Aboriginal and Torres Strait Islander Sexual Health Workers.

The training programs will include the Aboriginal STI Education Kit currently offered by NSW Health and support/develop any other training needs and resources identified by the Network, and other statewide Aboriginal Sexual Health Projects/Programs. This project will be located with the AH&MRC.

Area Quarterly Network Meetings

The Area HIV/AIDS Coordinators in consultation with the Area Aboriginal Health Coordinators provide and coordinate quarterly area network meetings for government and non-government health workers providing sexual health services to Aboriginal people or communities.

5.4.2 SUPPORT ISSUES

Despite the enormous amount of support offered by NSW Health with AH&MRC for ASHWs there are still ASHWs who feel isolated and unsupported within their daily workplaces. Many feel they don’t have sufficient support from either their colleagues or managers. This is the case whether located in AHSs or ACCHSs.

The literature documents most of the issues confronted by ASHWs and our consultations have confirmed this picture (see box below). The question must be asked: despite significant statewide support and development opportunities, what are the underlying reasons for many ASHWs feeling – at times - unsupported?

Part of the answer lies in the widespread tendency for anything linked to Aboriginal sexual health to be referred to the ASHW. At the same time, insufficient attention is given to thinking through the opportunities for partnering with other related health areas and optimising resources. Examples might include ASHWs working more closely with other Aboriginal and non-Aboriginal health workers, such as drug and alcohol workers, NSP staff, mental health teams and health promotion staff.

While ASHW working with sexual health staff should be a given, especially in rural and remote areas, this is not always easy for ASHWs, because of factors of geographical isolation, and relationships between AHS and ACCHS staff and where working parties under Local/Area Aboriginal Health partnerships are not operating at all levels efficiently.

Another part of the answer to the question of why ASHWs feel unsupported lies in the local work environment. Practically all the issues identified in the consultations relate to this in one way or another. They include non recognition by local managers of:

- The complexities that ASHWs are confronted with when working in a community. For example, community politics, the time required to develop trust and rapport with communities, community expectations of the ASHW, their individual relationship with each community.

- The need to work within a holistic model of care, including the need to work with other AHWs in a team (which also enables peer support).

- The need for an appropriate budget for delivery of programs and services, and to know what that budget is.

- Regular assessment of professional development needs (skills audit) in the context of role requirements, and the need for a budget/release to implement the plan.

- The need to work out of hours to meet community access needs.

- Lack of clarity at times in direction from managers, and negotiation, about priorities and guidance regarding implementation of specific initiatives – both in AHSs and ACCHSs.

- Monitoring of business plans (more than once a year) and the capacity to take account of changing/new needs.

- Within ACCHS, the need for an appropriate structure around ASHWs which recognises the importance of a strong focus on sexual health (including BBIs) while at the same time working within a holistic environment.

- Flexibility to be able to deliver services to the Aboriginal community in a way that suits their needs.

- The importance of ASHWs of being able to deliver clinical services where these aren’t readily accessible/available. Assistance with negotiating role delineation (and territoriality) with other clinicians and team members, the development of clinical skills, supervision etc

- Funds/release to participate in statewide support.

WHAT THE LITERATURE SAYS

A strong primary care workforce is a prerequisite for effective action in Indigenous sexual health and there is a huge need to increase Indigenous participation in the workforce (Sibthorpe *et al.* 1998).

Indigenous health workers are central to the development and delivery of health services that meet the specific needs of the Indigenous population (Australian Federation of AIDS Organisations 1998). For example, Smith & Beever contended that Aboriginal men in Central Australia have a low uptake of services in part because of a lack of male practitioners working in clinics (2001: 16). Factors preventing Aboriginal health workers from attaining a key role in the health service include the standard of training they receive, low literacy and numeracy, and a lack of participation in decision making within the service (Hecker 1997).

Shipp's report on Indigenous Sexual Health and Wellbeing in South Australia (2002) identifies ongoing support and professional development for workers trained in sexual health as a key area of need. Indigenous workers, particularly those operating in rural and remote areas, are undervalued and largely under supported. This not only exacts a heavy personal toll from those workers but also hinders the understanding and identification of sexual health activity among the groups they tend to. Indigenous workers have a low status in terms of the professional recognition of their work by other agencies (Shipp 2002: 9). Sibthorpe *et al* (1998) identified a need to develop certification and recognition of the wide range of non-course based training being undertaken.

Workers themselves need to be consulted about the most effective ways to support them in their work (Shipp 2002). There are also issues around obtaining funding for these workers because of breakdowns in the communication and the dissemination of information relating to training and support, for instance information regarding training at state or national level does not always reach the workers (Shipp 2002: 10). The capacity of health workers in remote community demands the proper recognition of their pivotal role, and requires the progression of workers who feel marginalised, undervalued and under-utilised to feeling valued, essential and empowered (Australian National Council on AIDS 2002: 10).

No mention is found of the NSW Aboriginal sexual health workforce in the literature. A significant innovation of this nature warrants documentation and assessment, both for internal service improvement purposes and wider dissemination of the model.

5.4.3 HEALTH PROMOTION RESOURCES

This section concerns resources specifically to help ASHWs carry out their role, especially in education, information and health promotion and prevention.

There has been a considerable investment in HIV Aboriginal - specific resources over a long period, over the national, state and local levels. They include videos, pamphlets, posters etc.

In relation to hepatitis C, there does not appear to have been the same national and statewide investment on Aboriginal - specific resources, though there has been considerable activity at the local level, with statewide funding support. The health promotion grants available from *The Collaborative Centre for Aboriginal Health Promotion (NSW)* from time to time are highly valued and provide an important source of funding for special initiatives that otherwise would not be possible.

Virtually no resources were noted in relation to hepatitis B.

The consultants were provided with many examples of excellent resources in the course of the project. While it is not our purpose to list these, four very recent additions are worth noting - ***"HIV/AIDS and Us Mob"*** (an AFAO/NAPWA/ANCAHRD publication), and a graphic ***pictograph/wall hanging with facilitators notes on HCV prevention*** (Northern Rivers AHS);

A pack of cards titled ***"Play Your Cards Right"*** *which feature education messages regarding BBIs and STIs developed in collaboration between three metropolitan AHSs and two ACCHS in the south and western suburbs of Sydney;* and

Health promotion messages printed on wallets and key rings telling the story ***"cultural sharing is not always cultural caring"*** Other resources the ASHWs have found effective include Streetwize comics, and resources from QLD were often cited as effective resources that carry health promotion messages.

Resources issues

- A key issue seems to be about be *access and availability of existing resources* for ASHWs (knowing about them, obtaining them, and knowing how to use them to best effect as part of a properly planned strategy). Opportunities are not always taken to share resources developed in one AHS with others, where relevant, thus saving effort and funds. The need for more guidance was often identified about how to use the materials eg the type of audience/environment in which to show sensitive videos; the preparation needed. There may be a training need here, as well as the need for a mechanism for sharing information about and improving access to resources that are already available.

- Many ASHWs stated that when resources are developed that are appropriate that they are often *one off resources* with no further capacity for reprinting and/or reviewing the content. Hence the strategies are often short lived. Again, this points to the need for a broader resources strategy, and should be kept in mind for the statewide resource development initiatives currently in train (refer section 6.4.1).

- ASHWs often mentioned some other states' health promotion resources as good examples that could be adapted to a NSW context. Queensland's resources are particularly commended. These could be reviewed and assessed by an expert group and Queensland Health approached to negotiate permission for NSW Health to adapt and print selected resources.

- ASHWs identified the need for more locally developed Koori-friendly materials. However many ASHWs stressed the need for support in the production of such resources. They found it difficult to develop resources within their full time jobs, given the mammoth task involved in community consultations, development and design of resources, trial and evaluation of such resources. Development of resources requires special expertise in design and development as well as advice on disease-specific health promotion content. Such assistance may not be readily available to all ASHWs. Funds can easily be wasted without combining that specialist input with ASHWs expert in communicating with Aboriginal people and in the knowledge of health issues affecting their community.

- This was especially the case for those ASHWs working within ACCHSs where the infrastructure for design, development and production of such resources is not available in-house. It is important that ASHWs working within ACCHSs be offered support to develop local resources that may be available to ASHWs working within AHSs. This potentially could be a role for the statewide ASHW Development positions.

- While the periodic availability of health promotion grants is highly valued, some ASHWs expressed concern about their capacity to respond to these opportunities, both in terms of having the necessary skills (eg developing the concepts, completing the substantial paperwork) and meeting the timelines.

- In the early days of HIV there was a major health prevention campaign that addressed the community at large. To date there has not been a similar investment in hepatitis C prevention within the Indigenous community, although there have been smaller campaigns, mainly targeted toward those in the community at most risk. During this project we heard frequent calls for *a comprehensive campaign* similar in status to the HIV Grim Reaper campaign for hepatitis C. This investment in health promotion, prevention and education should enhance knowledge regarding hepatitis C and HIV.

- Often the power of broad communication strategies such as television were underestimated as potential modes of health promotion/prevention communication particularly in rural and remote areas where television advertising rates are much cheaper than in urban areas.

What the literature says

The central aim of health promotion efforts is that of empowerment. Enabling individuals and communities to increase control over the determinants of their health enhances their capacity to improve it. However, empowerment requires more than the production of leaflets. Furthermore workshops and other education forums should be sites of dialogue and serve as opportunities for newly developing sexual health services to ‘hear’ as much as to ‘tell’.

The Australian Charter for Indigenous Health Promotion (Australian Indigenous Health Promotion Network - draft) states that health promotion with Indigenous people must involve appropriate forms of consultation with local community members at all stages, from design through implementation and evaluation. This also requires a recognition of, and respect for, different ways of learning and sharing. It is not only Indigenous agencies and individuals that lack sufficient information; mainstream services also need more education about issues specific to Aboriginal peoples’ relationships to health services (Plummer & Forrest 1999; Australian National Council on AIDS Hepatitis C and Related Diseases 2000).

ANCHARD identifies the need to ‘not only provide information on reducing risks but also support broader behaviour change within communities in order to inhibit the spread of HIV/AIDS and other blood borne infections (ANCARD Working Party on Indigenous Australians' Sexual Health 1997: 6). Factors affecting access to this information and support will be dependent on location, gender and risk context.

6.BUILDING AN EVIDENCE BASE

6.1 THE CONTEXT

The review of the *National Indigenous Australians' Sexual Health Strategy* conducted in 1999/2000 found that the evidence base to support planners at all levels to implement effective sexual health strategies is incomplete. In supporting this finding, the Indigenous Australians' Sexual Health Committee (IASHC) of ANCAHRD proposed

> *"…extending the conventional definition of 'evidence' to legitimise and incorporate the knowledge and experience of individuals and organisations working at the grass roots. Such evidence includes the results of in-house monitoring and evaluations and well documented observations over a period of time. In many cases, evidence collected at the community level can identify immediate priorities and provide a basis for action. IASHC also emphasises the continuing need for evidence accumulated through conventional, scientifically rigorous research…..".* [32]

The *National Indigenous Australians' Sexual Health Strategy Implementation Plan* for 2001/02 to 2003/04 provides a useful framework for thinking about the activities that together contribute to the evidence base that informs decision making in Indigenous health. There are three broad streams - monitoring, research and evaluation. This project is primarily concerned with monitoring, and evaluation.

6.2 MONITORING

The Implementation Plan describes monitoring as

> *"…the tracking of programs and epidemiological evidence to enable better and more responsive planning and service delivery. Planners will have access to a variety of information sources including epidemiological data, internal service statistics, results of population-based screening programs and, particularly in the case of community level planners, the evidence accumulated through the long term experience, knowledge and observations of its members."* [33]

6.2.1 EPIDEMIOLOGICAL DATA COLLECTION

Epidemiological data collection systems are used in the health care system to provide an understanding of disease profiles in the community. These systems can play a vital role in telling us where diseases are, what communities are particularly affected, and how diseases are being spread. They are very important in ensuring that strategies for dealing with BBIs are well directed.

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[32] ANCAHRD: *The National Indigenous Australians' Sexual Health Strategy. Implementation Plan for 2001/02 to 2003/04 p. 21.*

[33] ANCAHRD: *The National Indigenous Australians' Sexual Health Strategy. Implementation Plan for 2001/02 to 2003/04 p. 21.*

Epidemiological data collection in relation to Aboriginal sexual health remains a sensitive issue, although there is increasing agreement on the value of and need for such data. Key issues remain in relation to collection methods, ownership of information, confidentiality and privacy, access to data and the ultimate use of data.

Epidemiological data on HIV/AIDS and hepatitis C are collected at a range of levels:

- NSW Health collects and reports on data on newly reported cases of HIV, AIDS, hepatitis B and C along with other notifiable diseases under the NSW Public Health Act.

- The National Centre in HIV Epidemiology and Clinical Research collects and reports on de-identified data from the States and Territories on HIV, AIDS, and hepatitis C.

- The National Notifiable Diseases Surveillance system monitors the incidence of an agreed list of communicable diseases through national collation of data from the States and Territories.

The accuracy and reliability of epidemiological data on BBIs amongst Aboriginal people depends on ***accurately identifying Indigenous people***. This is the case whether collecting epidemiological data, or data about whom is accessing services.

There are considerable limitations to processes for Indigenous identification in NSW in relation to notification of BBIs. This is despite that fact that all NSW Health Department forms and databases for notifiable diseases have the capability to collect Indigenous status. It is a priority of the AH&MRC and the NSW Health Aboriginal Health branch to address inadequate identification of Aboriginal in all health data. An initiative is under way between the ABS, NSW Government Departments including NSW Health to establish more accurate and reliable data relating to Aboriginal people.

In relation to BBIs when a doctor requests a laboratory test for HIV, hepatitis B or C, a pathology form approved by the Health Insurance Commission (HIC) is completed and sent to the laboratory. The pathology request forms do not have an Indigenous identifier.

In NSW, the laboratory is required to notify the AHS Public Health Unit of positive results.

Public Health Units follow up notifications of HIV and AIDS with the doctor. The availability and accuracy of Indigenous status is totally reliant on whether the doctor has collected that information in the first instance.

Public Health Units do not routinely follow up Hepatitis C, so Indigenous status is rarely recorded in NSW Health forms and data bases.

Hepatitis B follow up by Public Health Units is discretionary. When the laboratory results indicate a chronic infection, no follow up occurs. When follow up does occur, it is with both the doctor and the case, so recording of Indigenous status will be better than hepatitis C but is not complete.

6.2.2 HEALTH SERVICES UTILISATION DATA COLLECTION

Without accurate data there is little capacity to monitor changes in health status, evaluate access to health services and the response of health services to address needs, or to quantify resources expended on health services and programs.

In NSW, the same limitations apply to the quality of data collection on access to services, or health service utilisation. Again, the reliability and accuracy of data collected depends on accurately identifying Indigenous status.

A key priority of the (former) Aboriginal Torres Strait Islander Health and Welfare Information Unit (ATSIHWIU) of the Australian Bureau of Statistics was to promote and evaluate standard Indigenous identification procedures which could be adopted by health services across Australia. In NSW, one of the main strategies of the Aboriginal Health Information Unit of the NSW Health Department has been the development and implementation of the *Collecting Patient Registration Information Training Program*. Initially the program is targeting NSW Health staff in hospitals where it is estimated that the NSW Inpatient Statistics Collection under reports Aboriginal and Torres Strait Islander origin by 60-70%. [34]

Much more work remains to be done to comprehensively and continuously implement the Program across NSW, not only in hospitals but also in ambulatory and community health services. Evaluating the impact of the Program will also be important.

Currently NAGATSIHID is developing National Guidelines and Principles for the Routine Collection of Standardised Data on Aboriginal and Torres Strait Islander Health, to apply to all data in government repositories and agencies. These national protocols, excluding mandatory reporting requirements, will provide ethical guidelines for issues relating to ownership, custodianship, de-identification, and optional Community anonymity and privacy issues. Separate guidelines were developed in 1997 for the collection and use of data from ACCHS although resourcing of this project has yet to eventuate. As HIV, hepatitis B and C are mandatory notifiable diseases other measures may be necessary to ensure appropriate identification of Aboriginal people occurs. It would appear that complementary processes are required to provide and maintain accurate data in BBIs within the Aboriginal population and further work should be done to progress these issues in NSW.

From a BBI perspective, Indigenous access to NSPs is an important source of data to monitor access. In NSW, NSP data collection forms do not have the capability to collect Indigenous identification. This data has been collected successfully through major national surveys of NSPs, and the NSW Health Department plans to conduct periodic program audits that would provide a more efficient means of collecting such data. Time limited surveys of specific NSP sites have been conducted (such as in Western Sydney Area Health Service) to monitor Aboriginal and other access patterns.

ACCHSs have a range of systems in place to collect patient data, some of which are linked with recall systems. However, these systems tend to be designed for patient management rather than service utilisation and management purposes. However, the ACCH sector is developing a comprehensive sentinel data collection process within its own service coverage with expressed intentions that this data is available at each jurisdictional level, including regional and local areas.

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[34] NSW Health: Collecting Patient Registration Information Training Program, p. 9.

Yet within this planned essential process confidentiality and individual and Community privacy are paramount.

A small number of AHSs (e.g. South Eastern Sydney, Mid North Coast and Northern Rivers) have established good data collection systems, monitoring both epidemiology and access to services. South East Sydney has invested substantially in a Minimum Data Set aimed at collecting comprehensive data from its extensive HIV/AIDS, sexual health and related services.

While area health services, planning units and other senior people in AHSs may have access to quality local epidemiological data, this does not always filter through to the service delivery level. The lack of local information is a potential impediment to health workers having a sense of priority or urgency, and being able to communicate that to their managers, the Aboriginal community and their partners. They are also handicapped because they have no way of determining whether their efforts are having any impact.

6.3 EVALUATING THE EFFECTIVENESS OF INTERVENTIONS

Considerable effort and resources are going into BBI prevention and health promotion activities across NSW. However, this project found little evidence of processes to evaluate the effectiveness of interventions. Evaluation can have several aims, including:

- Assessing the extent to which interventions meet their stated objectives.
- Building the evidence base of what we know works in delivering programs and services, especially those targeting Aboriginal people.
- Documenting and disseminating models that work well at the local level.
- Informing future service planning locally and statewide.
- Providing information about what gaps still exist, what still needs to be done, and how current programs and services can be improved.
- Providing feedback to stakeholders and managers about the outcomes of initiatives.
- Providing a basis for further planning and advocacy for resources.

It may be that the absence of any statewide strategy that supports evaluation, and the development of capacity and skills to undertake it locally, means that evaluation is a low priority.

Gaps in the literature

- The literature review commissioned for this project highlights that little work has focussed on Aboriginal access to BBI services, especially recent attempts at engaging mainstream health to increase Aboriginal access. There is considerably more literature on sexual health including STIs among Aboriginal and Torres Strait Islander people than on BBIs, and literature on HIV is often subsumed under the rubric of sexual health. Other gaps in the literature identified by our review include:
- Little data on implementation of health strategies (though more of their development); few measurable goals and monitoring systems identified.
- Lack of information about the situation in urban populations and those “in-between” areas where there are fewest Aboriginal -specific services.
- Lack of literature on recent responses by mainstream services to Aboriginal needs and the effects of those interventions on access to those services.
- Extant impact research focuses on risk factors and individual behaviour. Little in the literature that considers acting on risk contexts – such as prisons.

6.4 ETHICAL ISSUES

The notion of ownership of information has special significance, rights and responsibilities of access and use for Aboriginal peoples

Western ethical protocols may not protect Aboriginal health data, and Aboriginal people and others have expressed concern about the continuing lack of consultation about the purpose and nature of the collection, storage and dissemination of health information about them. Todd *et al* (2000) argue that many Aboriginal communities have been the subject of data collection without apparent benefit; that Aboriginal health personnel often carry the burden of data collection; that collection of data may only benefit academic researchers and may either be of a poor quality or has not been used to increase the health of Aboriginal people; and that Aboriginal people may not access health services if they believe information is being gathered about them. [35]

Thus there has been a growing necessity for guidelines on the collection and use of data on Aboriginal peoples. As well as a need for specific protocols on the ownership and use of Aboriginal health information, there has also been a dearth of practical advice about how to collect information in a sensitive and culturally appropriate way.

In NSW work has been undertaken by the NSW Aboriginal Health Partnership to improve the range and quality of Aboriginal health information in NSW. The NSW

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[35] Todd, A. L., Frommer, M. S. Bailey, S, & Daniels, J.L (2000). Collecting and using Aboriginal health information in NSW. Australian and New Zealand Journal of Public Health, 24(4), 378-81.

Aboriginal Health Information Strategy (1998) includes an agreement (Memorandum of Understanding) between the NSW Health Department and affiliated Aboriginal Community Controlled Health Services regarding ownership and sharing of data, and confidentiality and privacy guidelines. The agreement aims to ensure that health information will be managed ethically and in a culturally appropriate manner.

The *NSW Aboriginal Health Information Guidelines* form part of the Strategy. They detail principles to enhance the well being of Aboriginal communities through the ethical, meaningful and useful collection, storage and dissemination of data. These principles state that:

- information about the health of Aboriginal peoples and the services they receive must be used to benefit Aboriginal health and health services
- analysis, interpretation and reporting of information should be collaborative
- privacy of Aboriginal peoples and health services must be protected
- free and informed consent to collection of information should be obtained
- there is a diversity of unique information needs among health service providers
- value in information gathered must outweigh cost
- the burden of data collection to Aboriginal peoples must be minimised
- utilisation rather than collection of data should be maximised
- parties should share information that may assist in planning, management and delivery of Aboriginal health services
- information collection reviews should take place to ensure relevance to service delivery and compliance with agreed information requirements.

The AH&MRC has developed ethical guidelines for research and the collection of data in Aboriginal health. The cultural basis underlying this position can be found in the National Protocols for the Routine Collection of Standardised Data on Aboriginal and Torres Strait Islander Health (NACCHO 1997)

The data collected from Aboriginal peoples about blood borne infections and the types of sexual behaviour and drug use that may surround these are of a highly sensitive nature and may used in sensationalist ways by the media. While there are no specific Australian guidelines or protocols on the collection of Aboriginal information on blood borne infections, a sound foundation exists in the form of the current *NSW Aboriginal Health Information Guidelines.*

Further work can now to be done to adapt existing protocols for BBI information, so that all epidemiological and health utilisation data collections relating to BBIs comply with agreed data protocols.

Ethical BBI data collection

One research project that has tackled some of the culturally specific and sensitive ethical issues in the collection of data on blood borne infections is a study of the health and well being of young Koori people in Melbourne (Holmes *et al.* 2002). This project was initiated and carried out by the Victorian Aboriginal Health Service Health Promotion and Research Unit. This study team established their own Institutional Ethical Committee according to the guidelines of the NHMRC, and registered with the Council. It consisted of an elder, three men and three women from the Aboriginal community, a lawyer and a medical practitioner with research experience. The Committee not only scrutinised the research design, but also monitored the conduct of the study. Before approval was granted three-half day meetings were held to discuss issues such as privacy and consent, and control of research findings.

7 SUMMARY OF OVERALL FINDINGS

7.1 STRATEGIC APPROACH

1. There has been a very strong *statewide policy response* to Indigenous risk of BBIs by NSW Health (the Department and most AHSs) and statewide NGOs. Indigenous people are listed as a high priority group in all key government statewide strategies and plans, and those of most key NGOs. NSW policy approaches to HIV, hepatitis B and C are evidence-based and consistent with national strategies.

2. Much energy has been directed at developing *effective partnerships* at both statewide and Local/Area levels. The partnership between *the NSW Health Department and the AH&MRC* in relation to sexual health is well established; there is a history of shared decision making around the allocation of resources, and it is supported by an infrastructure of specific projects and joint initiatives.

    - The partnership arrangements between *Justice Health and AH&MRC* at the statewide level, and local agreements with ACCHSs, also constitute a solid infrastructure.

    - At the local level, there are partnerships between the majority of AHSs and ACCHSs, operating at varying levels of effectiveness.

    - Collaborative statewide arrangements between the AH&MRC and non government organisations (NGOs) such as the AIDS Council of NSW (ACON), the NSW Users and AIDS Association (NUAA) and the NSW Hepatitis C Council are at a more formative stage.

3. However the impact of policy, planning and partnership activity that occurs at this strategic level is taking *time to filter through* to front line workers and affected people. For example:

    - Strategic and business plans relating to BBIs require further work post development in some AHSs and ACCHSs as many staff were unaware of the key guiding policies and strategies relating to BBIs. The extent to which they are “owned” by all relevant stakeholders varies.

    - Many workers were unaware of the key guiding policies and strategies steering BBI education, prevention, health promotion, treatment and care.

    - Many Aboriginal health workers acknowledge less than optimal knowledge of BBIs and the need for training surrounding BBIs (eg antenatal workers unclear about vertical transmission of HCV; alcohol and other drug and mental health workers unaware of Needle and Syringe Program locations).

    - Maintaining levels of awareness and knowledge of BBIs in Aboriginal communities should be an ongoing priority.

7.2 ASSESSMENT OF THE RISK

4. In the Indigenous population, the recognition and identification of BBIs has been relatively slow and it is taking some time for a clear picture to emerge. However, it is generally agreed that HIV, hepatitis B and hepatitis C have the potential to pose significant health, social and economic risks to Aboriginal communities, both in the short and long term.

5. The prevalence of STIs amongst Indigenous people is reported to be up to eight times higher than for the non-Indigenous population (Bowden *et al.* 1999; Kildea & Bowden 2000; and this is due, in part, to poor access to services experienced by many Aboriginal people (Fairley *et al.* 1997; Kildea & Bowden 2000). Having other STIs increases the risk of transmission of HIV. Particular emphasis needs to be placed on early detection programs for all STIs including HIV so as to decrease the transmission risks of HIV. The NIASHS emphasises the need for early detection, treatment, care and management of all STIs.

6. Over the period 1994 – 2003, 185 new diagnoses of HIV in Australia were notified among Indigenous people[36] No separate identifiers were recorded for Indigenous people in the period 1984 to 1993.

7. The per capita rate of HIV among Indigenous was similar to that of non-Indigenous Australians over the period 1994-2003 however among Indigenous women there was a significantly higher proportion of HIV diagnosis (33.7% Vs 10.1%) [37]

8. Until recently, the most commonly acknowledged means of HIV transmission in the Indigenous population, as with the general Australian population, has been male homosexual contact. However Indigenous cases have significantly differed from non Indigenous cases during the period 1999-2003:

   > *"… the most frequently reported route of HIV transmission was male homosexual contact in the non Indigenous population whereas in the indigenous population, male homosexual contact and heterosexual contact were reported almost equally frequently"*[38]

9. These significant differences in new HIV diagnosis in relation to exposure categories between Indigenous and non Indigenous people are as follows:

   - *Male homosexual contact is significantly lower than for the non Aboriginal population (38%v 69%)*
   - *Heterosexual contact is significantly higher than for the non Aboriginal population (37% v 19%)*
   - *A higher proportion of cases attributed to injecting drug use (21% vs 3%)*

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[36] HIV/AIDS, viral hepatitis and sexually transmitted infections in Australia, Annual Surveillance Report 2004: p. 42, (NCHECR).

[37] HIV/AIDS, viral hepatitis and sexually transmitted infections in Australia, Annual Surveillance Report 2004: p. 5 (NCHECR).

[38] HIV/AIDS, viral hepatitis and sexually transmitted infections in Australia, Annual Surveillance Report 2004: p. 5 (NCHECR).

10. While the numbers are small, Indigenous HIV diagnoses have more than doubled between 1999 and 2003. [39]

11. NCHECR data also indicate that the rate of decline in AIDS incidence has been slower in this group than in non-Indigenous groups.

12. The seriousness of the emerging hepatitis C epidemic now warrants a continued vigilance and a concerted response. In NSW there is a greater proportion of Aboriginal people with hepatitis C, attributable to injecting drug use and high rates of imprisonment. Further to this Aboriginal people are diagnosed with hepatitis C at a younger age compared to the non-Aboriginal population.

13. In 2000, of those diagnoses where ethnicity was recorded in NSW, 10% were Aboriginal (NCHECR 2001).

14. Findings from the Australian NSP Survey National Data Report 1999-2003 (NCHECR, 2004) found that the proportion of injecting drug users who identified as Indigenous increased from 5% in 1995 to 8% in 2003.

15. Hepatitis C is a serious health problem in NSW prisons.

16. In NSW prisons Aboriginal inmates make up 19% of the total inmate population. The rate has been increasing 1% per year for the last 5 years.

17. Incarceration is identified as an independent risk factor for hepatitis C transmission. In 2001, 9% of all hepatitis C notifications in NSW were from prisoners held in NSW correctional facilities. Around 40% of all injecting drug users have a history of imprisonment.

18. Overall 59% of all inmates in NSW prisons have been diagnosed with hepatitis C with 65% of women and 40% of men compared to the 1-% prevalence of hepatitis C in the broader community.

19. Hepatitis B is endemic in Indigenous communities. There are limited resources to assist Aboriginal Health Workers in their work in promoting the importance of testing and vaccinations to the Aboriginal community. Approximately 1% of the Australian population carries HBV. The rate is higher among Indigenous people, varying from 3% to 35%. (See box below).

20. Transmission of hepatitis B has been primarily perinatal and interventions have been focused on infant and childhood vaccination.

21. Hepatitis B is also associated with imprisonment and Aboriginal people are over represented in the NSW correctional system. Aboriginality is a significant marker of risk for hepatitis B amongst both male and female prisoners in NSW.

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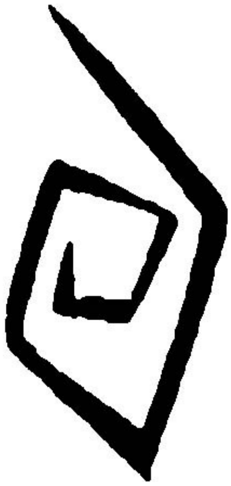
[39] Newly diagnosed HIV infection in Indigenous people nationally: 1999 – 9; 2000 – 15; 2001 – 13; 2002 – 24; 2003-21. 33.9% of all diagnoses amongst Indigenous Australians were in NSW.
(NCHECR Annual Surveillance Report 2004: p

22. While the epidemiology of HIV, hepatitis B and C clearly evidences the risk factors for transmission of these diseases, there are particular characteristics unique to the Indigenous population (in NSW) that add to their level of risk. These include the higher number of Aboriginal youth than in the broader community; the risks that high levels of incarceration places on Aboriginal people; the mobility of Aboriginal people; the level of knowledge of BBIs in the Aboriginal community; the increase in injecting drug use among Aboriginal people and its associated risks; the high level of STIs in the Aboriginal community; the level of violence in Aboriginal communities and practices which occur in communities such as non-sterile tattooing and body piercing.

23. Many national and state BBI strategies and plans identify Indigenous Australians as a key target population for education and prevention. It is important to develop a better understanding of the complexities of that population so that prevention strategies can be targeted more precisely tailoring to the communities needs.



24. To help increase understanding of some of these population complexities, this project has identified the following *key areas of risk* for HIV, hepatitis B and C among Aboriginal people.

Adults and youth in correctional facilities
Young Aboriginal people, in all risk settings
Families and communities of those at risk.

RISK BEHAVIOURS

Injecting drug use
Unsafe sex [40]
Non-sterile tattooing and body piercing
Violence.

25. There is an urgent need for *ACCHSs to continue to make BBIs a priority* and respond accordingly. This involves a fuller understanding of the risk of BBIs to their community; a willingness to address issues of taboo and stigma associated with sexual health issues and BBIs; to accord sexual health and BBI a higher priority along with other general health issues; to provide supportive environments for ASHWs located in ACCHSs, and to better understand and support the harm minimisation role of Needle and Syringe Programs as a strategy for the prevention of hepatitis B, C, and HIV.

7.3 ACCESS TO SERVICES

26. There is a very comprehensive and readily identifiable *service infrastructure* for HIV/AIDS in NSW, but the service delivery response to hepatitis B and C is harder to capture because responsibility is located within the existing health service infrastructure, including with GPs. *Justice Health* has hepatitis C as a major priority and is responding to the acknowledged hepatitis C epidemic with some innovative approaches. Indications from the consultations were that Aboriginal people with hepatitis C are not accessing treatment at the same level as non-Indigenous people, though this needs to be tested by research.

27. There are *many factors influencing Aboriginal access* to BBI services. General factors include the absence of ACCHSs in many parts of NSW; the perceived loss of confidentiality and privacy; transport to and from services; the decline in bulk billing by GPs; the cost of treatment; the history of services in terms of their relationship with the Aboriginal community; the largely asymptomatic nature of HIV, hepatitis B and C which may induce complacency; the stigma associated with BBIs, and the increase in injecting drug use in the Aboriginal community and associated marginalisation.

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[40] Unsafe sex is a risk factor for HIV and hepatitis B.

28. The perceived loss *of confidentiality and privacy* was the factor affecting access identified most frequently by staff. Closely related to this was *location of services*. A well located service should be close to reliable and regular transport, in a discrete location but not too far away from a main centre, signposted in a way that destigmatises the main role of the service, with visible indications that the service is Aboriginal friendly. Multiple access points also help (such as outreach). Locations with a high security presence, or with reception thresholds to cross, present barriers to access.

29. Other factors affecting access were the attitude, behaviour and skill of staff, the availability of Aboriginal staff, and community and worker knowledge of BBIs.

7.4 INITIATIVES TO INCREASE ACCESS

30. Many excellent initiatives to increase access were observed across NSW. In the body of the report, a small sample of these are detailed in areas such as partnerships, youth, engaging ACCHSs Boards of Management, and an example of a multidisciplinary sexual health team providing comprehensive holistic outreach services to the Aboriginal community.

7.5 ABORIGINAL SEXUAL HEALTH WORKERS

31. The use of ASHWs constitutes a very sound model to increase Aboriginal access.

32. With 33 ASHW positions located in AHSs and ACCHSs across NSW, and a further 7 positions with statewide roles, the Commonwealth/State investment in an Aboriginal sexual health workforce is significant. ASHWs are making an important contribution to implementing the *National Indigenous Australians' Sexual Health Strategy.*

33. Nevertheless, ASHWs have enormous roles and those located in rural areas particularly, are responsible for huge geographical areas and distinct cultural variations and groups. Many report feeling very stretched, lacking an adequate skills base and appropriate organisational support including gender distribution in staffing to ensure that they are able to deliver services to both sides of the community and taking in account of the specific needs for gender specific roles in Aboriginal sexual health.

34. ASHWs in ACCHSs tend to have greater access and flexibility in providing holistic services in a sexual health context than those located within AHSs. Therefore Local/Area Health Partnerships are important to link ASHWs working within ACCHSs to sexual health services located within AHSs ensuring broader sexual health services are provided to the community whilst also offering external support to these workers.

35. NSW Health provides a very comprehensive range of mechanisms for ASHW support at the statewide level. As the newer initiatives consolidate, the NSW ASHW network promises to have great potential as an excellent model for ASHW statewide support. The continuation of this statewide support is vital, as is its continued responsiveness to new ASHW needs. It should be evaluated.

36. Closer examination of the reasons why ASHWs feel unsupported when there are strong statewide mechanisms in place tend to point to weak support structures at the local level. ASHWs identified many areas where they felt local managers/supervisors could provide more recognition of the complexities of their role, clearer strategic direction, and support in very practical ways.

37. ASHWs working within AHSs face a barrier in their workplace, as the approach to STI/BBIs is somewhat fragmented when compared with ASHWs working within a holistic whole of health and well being approach such as an ACCHS. Separating STIs/and BBIs from other health challenges facing Aboriginal people marginalises their priority in the eyes of the community. Because there are multiple factors contributing to increasing BBI risk, and multiple environments in which people at risk are found, a holistic, integrated approach to prevention and care is critical. Working more closely with health professionals and AHWs from other disciplines and service areas (such as drug and alcohol and mental health) has the potential to extend the reach and impact of BBI services for Aboriginal people.

7.6 RESOURCES TO ASSIST ABORIGINAL SEXUAL HEALTH WORKERS

38. While there is a wide range of resources available, more are available on HIV, than hepatitis B and C, with very little available on hepatitis B. The main issues appear to be about access and availability of existing resources (too many once-off resources with no longer term strategy for reviewing or reprinting), and the continuing need for locally developed, Aboriginal specific and appropriate resources.

39. The one-off health promotion grants available from The Collaborative Centre for Aboriginal Health Promotion from time to time are highly valued as they provide an important source of funds for special initiatives that would otherwise not be possible. However, some ASHWs have difficulty responding to such opportunities because of timelines and complex paperwork requirements. They stress the need for support and assistance in the design and development of materials, and for training in their appropriate use in a health promotion setting.

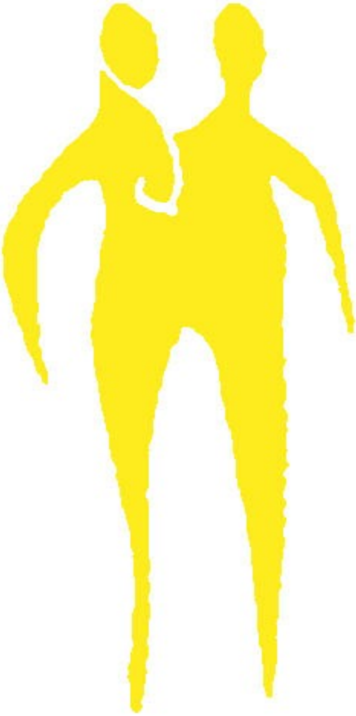
40. Many identified the need for major multi media HIV and hepatitis C campaigns similar to those of the late 1980s for HIV/AIDS (size of and not necessarily message) to provide a powerful impetus to public awareness and for their work.

7.7 BUILDING AN EVIDENCE BASE

41. There are considerable limitations to processes for Indigenous identification in NSW for monitoring purposes, and the extent to which data is collected. This is in relation both to notification of BBIs to track the progress of diseases in the community generally, and to monitor access to/utilisation of relevant services.

42. While national and state epidemiological and surveillance bodies are able to provide a very useful picture of incidence, prevalence and risk factors pertaining to BBIs, there is much room for improvement. Although the *NSW Aboriginal Health Information Guidelines* are in place in NSW, strengthening BBI data collection processes further is likely to depend on developing specific protocols for this sensitive area.

43. Consistent with the larger literature review, very little evidence was found in the consultations of evaluations of the effectiveness of interventions. Given the size and nature of the investment in Aboriginal sexual health in NSW, it is important to continue to document and evaluate both the broader model, and the interventions themselves, many of which are very innovative.



8 FUTURE DIRECTIONS AND RECOMMENDATIONS

Three overarching strategic directions and eight recommendations are proposed.

8.1 OVERARCHING STRATEGIC DIRECTIONS

1. A holistic, whole-of-health-and-well being approach

A holistic approach is fundamental to success in addressing the issue of Aboriginal people who have contracted or are at risk of BBIs. In this context, a holistic approach recognises that HIV/AIDS and hepatitis C cannot be addressed in isolation *from any and all* of the following:

- other sexually transmissible infections, related blood borne infections and sexuality
- issues affecting general health and the physical body
- social, cultural and emotional experiences of the people concerned.

Full implementation of a holistic approach requires moving away from a disease-specific model not just to a broader sexual health approach (this is already reflected in the *NIASHS* and the *NSW HIV/AIDS Health Promotion Plan*). It also reinforces the value for locating sexual health in an even broader whole-of-health-and-well being model as is done within the ACCHS sector.

Encouraging and supporting individuals to take responsibility for their sexual health, and for their freedom from BBIs, means that other impediments to their health and well being must be addressed. Drug and alcohol issues, mental health, maternal and child health have strong relevance to BBIs. In particular, the nexus between hepatitis C, HIV and alcohol and other drugs has a twofold importance, because of:

- The link between hepatitis C and injecting drug use, and

- The link between the use of alcohol and other drugs, disinhibition and unsafe sex.

Implementing a truly holistic approach in relation to Aboriginal health has implications for:

- The way we think about BBIs, the structures and strategies already in place. How can a holistic approach be better reflected?

- The way drug and alcohol services and sexual health services interface and work together on a day-to-day basis.

- The way health education and promotion programs are designed and delivered, so there is increased integration with general health improvement.

- The way Aboriginal Health Workers work together, and with ASHWs, and the level of knowledge Aboriginal Health Workers in other key areas have about BBIs and related services. In NSW Health there are substantial Aboriginal Health Workers in mental health, drug and alcohol, sexual health, vascular health, and maternal and child health. Strengthening mechanisms for cross referral and case management helps to build bridges between workers and can be used as a vehicle for increasing the knowledge of other workers about BBIs.

- The terminology used for specific positions e.g. using “sexual health” and BBI names in job titles and service names.

What the literature says

The grounds on which health is prioritised impact on access and uptake of services (Miller *et al.* 2003). The literature on Aboriginal conceptions of health would imply that services that frame health messages within a disease-based notion of health as a matter pertaining to the individual have little chance of convincing people that their services are a priority - or relevant to well-being.

Smith *et al* (1999) report that successful health promotion for Indigenous people will involve:

- ‘disguising’ sexual health promotions within a holistic focus on general health
- separating interventions for men and women
- delivering the programs in informal ‘outreach’ settings such as in people’s homes, places of public congregation, community gatherings, local communities, or alternatively, in institutional settings, such as schools or prisons
- involving local community members, particularly elders, in developing and implementing initiatives
- using simple and appropriate language and Indigenous designs in materials
- establishing trust about confidentiality and privacy.

The research points to a variety of issues related to addressing injecting health issues. These include support programs for families of users (Shoebridge *et al.* 1998; South Australian Police (SAPOL) report 1999) and the need for Indigenous Needle and Syringe Programs that provided information, education, and support, alongside health services (Smith & Newton 1997). It is believed that holistic approaches to treatment are most appropriate (South Australian Police (SAPOL) report 1999), including cultural centres where Indigenous users can learn about their culture, values and spirituality (Edwards *et al.* 1999).

2. *Focus on the major areas of risk for HIV and hepatitis C*

Focus available resources and actions more strongly on the major areas of risk for HIV and hepatitis C, within the Aboriginal community, as demonstrated in the evidence. Work with men who have sex with men must continue to be a priority, carried out in a culturally appropriate way, however an equal amount of focus and vigilance should be directed at heterosexual transmission of BBIs. The seriousness of the emerging hepatitis C epidemic warrants a concerted response at all levels. Key risk areas include:

Adults and youth in correctional facilities
Young Aboriginal people, in all risk settings
Families and communities of those at risk.

RISK BEHAVIOURS

Injecting drug use
Unsafe sex [41]
Non sterile tattooing and body piercing
Violence.

Focusing on the populations at risk and key risk behaviours has implications for:

- The way priorities are currently set, and resources are distributed.
- Giving some things lower priority in order to intensify the focus on others.
- Collecting accurate surveillance and health service utilisation data.
- Engaging other government sectors, consistent with the NSW Premiers' initiative *"Partnerships: A New Way of Doing Business with Aboriginal People".*

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[41] Unsafe sex is a risk factor for HIV and hepatitis B.

What the literature says

Section 3.2 of this report summarises the epidemiological data that supports this approach.

The *2002 Review of the National Hepatitis C Strategy 1999-2000 to 2003-04: The Road Not Taken* found that the strategy had not succeeded in controlling the hepatitis C epidemic in Australia. The report identified a number of factors contributing to this failure. Those that have a particular relevance to hepatitis C among Indigenous peoples are a need for a greater focus on risk contexts and settings - not just individual behaviours and risk factors; a need for more resources; and a failure to grapple with the complexities of treatment and care, and drug laws and policies.

Families and communities of those at risk have been included as a priority because the literature finds that support for informal care networks is needed. In many instances, Aboriginal people living with HIV and AIDS are being cared for by family and community networks (Australian National Council on AIDS Hepatitis C and Related Diseases 2000: 5). Caring for people in environments where there are significant social and economic burdens places additional stress on people already dealing with substantial pressure (ANCARD 2000:44). Although desiring to care for and support their own people infected with HIV/ AIDS, these communities lack access to basic knowledge and resources to do this adequately (Australian National Council on AIDS Hepatitis C and Related Diseases 2000: 7). Although some Indigenous health services have worked closely with their communities to develop innovative and locally relevant care and support resources, there is still much to be achieved (Australian National Council on AIDS Hepatitis C and Related Diseases 2000).

3. Increase Aboriginal community awareness, understanding and ownership of BBI issues.

Promote greater knowledge and understanding of the nature and urgency of the risk within Aboriginal communities so as to encourage greater ownership and responsibility for the issue of BBIs.

Increasing community awareness, understanding and ownership has implications for:

- Effectively communicating the risk without being sensationalist or alarmist.
- Influencing Aboriginal elders, especially Board members of all Aboriginal organisations.
- Practical follow up: assisting communities with practical ways of taking action in response to the risk, and to access resources.

- Strong and effective partnerships, especially between ACCHSs and AHSs, and ACCHSs and NGOs such as ACON, the NSW Hepatitis C Council, and NUAA.

- Linking the response to BBIs with other health and well being issues especially in relation to young people, so that it becomes part of a larger response to community priorities.

- Reassuring affected people, regarding procedural safeguards to ensure confidentiality is paramount.

What the literature says

The structure of locally available health services has been seen to influence the prevalence of Indigenous STIs (Miller *et al.* 2003). The importance of local community control and participation in the development and delivery of programs (National Aboriginal Health Strategy Working Party 1989; Australian Federation of AIDS Organisations 1998) is consistently noted throughout the literature.
Confidentiality, anonymity and privacy are central concerns with regard to Aboriginal access to all sexual health services, particularly diagnoses and treatment (Plummer & Forrest 1999; Fagan 2001). Fagan reads this need for confidentiality in the context of a history of traumatic dispossession, state intrusion into peoples lives and past approaches to STI management that have been coercive and punitive to individuals (Fagan 2001: 59). Issues of anonymity and confidentiality when accessing Aboriginal Medical Services that may be staffed by members of local Indigenous communities become more complex (Junga-Williams 1998: 13).

There is a need for Aboriginal community involvement and ownership, and specifically involvement of Indigenous injectors, to support self-determination and ensure ownership of services, projects or programs (Larson 1996; Shoebridge *et al.* 1998; South Australian Police (SAPOL) report 1999; Arabena 2000).

There has been a consistent undervaluing and under-funding of programs designed by and for Indigenous gay men, lesbians and transgender people (Forrest 1995: 13). The sexual health needs of Indigenous gay men and sister girls might be overlooked by Aboriginal Medical Services that tend to focus on the wider health issues of Indigenous communities, and can also get overlooked by AIDS Councils that may be inexperienced in delivering appropriate services for Indigenous people (Costello 1999).

8.2 RECOMMENDATIONS

1. Getting the message out

- The findings and recommendations from this project to be passed to all relevant planning and review processes (national, state and local) currently occurring, so that they can be reflected as appropriate in the directions being proposed.

2. Statewide leadership

The NSW Health Department and the AH&MRC to examine the implications of the findings from this project for:

- The types and configurations of health service delivery currently in place, and how a more holistic, whole-of-health-and-well being approach could be enhanced and promoted more broadly in relation to BBIs.
- The way resources are currently allocated, and priorities set, given the recommendation to focus on the major areas of risk within Aboriginal communities.
- The need for designated Aboriginal positions at the statewide level, as follows:
- in the NSW Health Department (AIDB): ASHWs have identified the need for an Aboriginal-identified position;
- Within the AH&MRC, an Aboriginal-identified Workforce Development position focussing on hepatitis C, to provide ongoing education, training development and support for ASHWs and other Aboriginal Health Workers in regards to hepatitis C, coordinate resource development, and support the development of harm minimisation strategies in both ACCHSs and AHSs.

The range of collaborative arrangements and partnerships in place, and the way collaboration occurs:

- across those areas of the Department with responsibility for Aboriginal health, infectious diseases, mental health, drug and alcohol, maternal and child health, health promotion, vascular health;
- Through Local/Area Health Partnership forums;
- with other government sectors such as education, employment, corrections, juvenile justice, consistent with *“Partnerships: A New Way of Doing Business with Aboriginal People”;* and
- with other NGOs particularly those working within the specialty areas of BBI service provision, especially the Hepatitis C Council of NSW, ACON, PLWHA and NUAA.

- The NSW Aboriginal Sexual Health Implementation Advisory Committee (ASHAC) should be involved in this process at appropriate stages.

3. ***Building Aboriginal community awareness, understanding and ownership of BBI issues.***

The AH&MRC to develop a project plan for a major initiative aimed at increasing awareness, understanding and ownership of BBI issues in Aboriginal communities, thus strengthening capacity for communities to participate in effectively addressing issues in relation to BBIs.

The project plan is to include:

- Target organisations and audiences, across the age spectrum.
- Key messages and information.
- A small resource panel of people skilled in communicating with Aboriginal people, and knowledgeable about BBIs, to develop the presentation strategy and materials, potentially from the NSW Aboriginal Sexual Health Workers Network.
- A small team to travel around NSW over the course of a year.
- A travel schedule.
- The longer term continuity of the activity – how building community ownership can be made locally sustainable, such as through involving local ASHWs.

Funding for the plan and project could be derived from NIASHS allocated funding or sought from other sources.

Key messages and information to include:

- The nature and extent of the risk, especially in relation to BBIs and Aboriginal young people.
- A profile of key local health services.
- Confidentiality.
- Breaking down the stigma associated with injecting drug use, and the role of NSPs in BBI prevention.
- Providing supportive communities for people living with HIV/AIDS, hepatitis B and C.
- The role of ASHWs, community expectations and support.
- Practical action communities can take in response to the issues, and how resources can be accessed.

- ACCHSs to review their current approach to BBIs, to identify areas for strengthening. This may include clarifying their own policies in relation to BBIs, consistent with national and state policies and strategies; increasing knowledge and awareness of BBIs in their local communities; ensuring all ACCHS staff have a basic knowledge of BBIs; strengthening support for their ASHW if they have one; and strengthening links with AHS sexual health services and other NGOs.

- AH&MRC to develop and consolidate links with key NGOs with statewide roles relating to BBI education, prevention and clinical services.

4. *Aboriginal Sexual Health Worker Projects*

- NSW Health to retain and continue initiatives to strengthen and support the ASHW model and network.

- NSW Health to continue the provision of statewide support through the various initiatives already in place or being developed. In particular:

    - ensure the establishment of two additional regional ASHW Development Coordinators; and
    - ensure responsiveness to ASHW feedback about the appropriateness of support activities, especially orientation and training.

- The NSW Health Department and AH&MRC to periodically review the distribution of ASHWs to ensure this is as equitable as possible and takes account of changing needs. The review to take account of the balance of workers in AHSs and ACCHSs, and statewide distribution includes gender equity.

- The NSW Health Department and AH&MRC to obtain data on what level of financial contribution is being made by AHSs to supplement the *Aboriginal and Torres Strait Islander Sexual Health Projects.* AHSs in which there appears to be a substantial mismatch between the need and AHS response would be encouraged to review their priorities.

- The NSW Health Department to review the allocation of resources to NGOs for Aboriginal positions with sexual health responsibilities, and consider whether the number, distribution and mix of these is appropriate to priorities.

- Area Health Services and relevant ACCHSs to review the effectiveness of their service delivery model in terms of promoting access to a wider range of resources, and providing support for ASHWs. The review to be undertaken in the light of findings of this report (section 6.4) and the key elements of an effective model distilled from Macquarie Area Health Service (section 5.3.3), and to consider:

    - The role of ASHWs, along with how their priorities are set and monitored; orientation and training, and management support.

    - For rural and remote areas particularly, the scope for development of clinical role/s for ASHWs with associated competencies, to improve access to services.

    - A process for the regular audit of skills and professional development needs of ASHWs, with access to appropriate programs facilitated via funding and release.

    - Mechanisms for strengthening cross referral and case management across services and sectors.

    - How best to ensure an integrated approach to BBIs by AHSs and ACCHSs.

  - Reviewing the effectiveness of partnerships between the Area Health Services and ACCHSs, and if they are not functioning well, making improvement a shared priority.

  - Increasing the number of Aboriginal workers employed in key areas such as Needle and Syringe Programs.

  - Training and support activities to engage other AHWs in basic BBI awareness, without overloading them.

  - Scope for destigmatising terminology used for example, in names of services and buildings, and roles such as ASHWs.

5. Location of services

- Area Health Services to review the location of all services relevant to BBIs, especially NSP and sexual health services, in the light of the findings of this project (section 5.2.3).

6. Resources to support prevention and health promotion activities

- The NSW Health Department and AH&MRC to consider the need for a statewide multi media education campaign to support the focus on major areas of risk, which can be locally targeted and supported.

- A BBI Resource Committee to be established as a sub committee of the Aboriginal Sexual Health Workers Network to:

    - Share information about resources currently available and in development, and funding opportunities.
    - Collaborate on the development of shared resources.
    - Facilitate focus testing of resources.
    - Advocate for new resources, and provide advice to statewide bodies as requested.

7. *Aboriginal people in correctional facilities*

- Justice Health, the NSW Health Department and the NSW Department of Corrective Services to explore options for delivering BBI health promotion in a more holistic way, including within CHS clinical settings.

- Justice Health and AH&MRC to further explore and pilot models which promote continuity of care for Aboriginal people being released from prison and those moved between facilities to ensure continuity of care with local ACCHSs.

- Given its recently acquired responsibility for juvenile justice centres, Justice Health to explore options for resourcing the extension of service agreements with ACCHSs to incorporate these centres.

8. Building an evidence base

- The NSW Aboriginal Health Partnership to establish a Working Group to adapt existing data collection protocols for BBI information, so that all epidemiological and health utilisation data collections relating to BBIs comply with agreed data protocols.

- The NSW Aboriginal Health Partnership to review progress in implementing the Aboriginal Health Information Strategy, particularly in light of the need to increase Indigenous identifiers in all health service collections (inpatient, ambulatory and community health services).

- NSW Health to conduct periodic (annual or biennial) surveys of the NSP as planned, with appropriate Indigenous identifiers consistent with agreed data collection protocols.

- Consistent with the NSW Aboriginal Health Information Guidelines (1998), AHSs are to make epidemiological data on HIV, hepatitis C and STIs, available to ASHWs on an annual basis, in a form that is accessible and meaningful, and shows the changes at national, state and local levels.

- The *NSW Sexual Health Implementation Plan for Aboriginal and Torres Strait Islander People*, planned for 2004, to include a statewide strategy for evaluating progress in implementing the *Plan*, and monitoring and evaluating the effectiveness of key interventions. Consideration should also be given to commissioning a longer-term evaluation of the impact of the ASHW model in increasing Aboriginal access to sexual health and BBI services.

9 APPENDIX 1: PROJECT BRIEF

Project Brief: Increasing access to services for Aboriginal people at risk of blood borne infections and those who have blood borne infections

This project is being conducted under the auspice of the NSW Aboriginal Health Partnership, with funding assistance from the Commonwealth Department of Health and Ageing.

Project Consultants

James Ward and Warren Lynch (staff of the Aboriginal Health and Medical Research Council of NSW) in association with Ruth Cotton (Mandala Consulting).

Project Goal

To enhance the accessibility and availability of appropriate services including education, prevention and treatment services for Aboriginal people who are at risk of or have contracted blood borne infections (BBIs).

Key areas to be explored include:

- ethical data collection, storage and dissemination relevant to the client group;
- protocols involving client confidentiality;
- services in education, prevention and treatment;
- resources and support provided to Aboriginal Sexual Health Workers to improve client access to services;
- ways of working (such as partnerships); and
- assessment of the effectiveness of interventions.

The project findings will help to inform the development of the *NSW Sexual Health Implementation Plan for Aboriginal and Torres Strait Islander People.*

Project Period

August 2003 to August 2004.

Project Structure

Phase 1:Planning
Includes establishing frameworks for gathering information, a comprehensive literature review, scheduling and arranging consultations, establishing a Project Reference Group.

Phase 2: Consultation
Consulting as widely as possible across all 17 Area Health Services, Corrections Health and most of the Aboriginal Community Controlled Health Services within NSW as well as with consumers and other key stakeholders with state-wide roles.

Phase 3: Analysis and further advice

Analysis and processing of data collected, as the consultations proceed and at the conclusion of the consultation phase. Establishment of a Project Advisory Group (see below).

Phase Four: Documentation
Report preparation and review process, including briefing of parties to the NSW Aboriginal Health Partnership.

Key Tasks

- Seek advice and summarise gaps with respect to specific needs of Aboriginal clients who are at risk of or who have contracted BBIs through a wide consultative process and current literature review.
- Develop proposed strategies intended to limit these service gaps.
- Prepare a comprehensive report containing proposed strategies to enhance availability and accessibility of education, preventative and clinical services for Aboriginal clients who are at risk of or who have contracted BBIs.

Guiding Principles

- Aboriginal cultural sensitivity during consultations and at all phases of the project.
- Respect for confidentiality of information provided at interview.
- A wide consultative process.
- Clarity and transparency of processes.

Project Reference Group

Established to provide overall guidance and facilitate access to relevant information and where appropriate, to consumers. Organisations represented will include the AH&MRC, the NSW Health Department, the AIDS Council of NSW, the Hepatitis C Council, the NSW Users and AIDS Association, and the People Living with HIV and AIDS Association.

Project Advisory Group

A group of Aboriginal Sexual Health Workers to work with the project consultants in developing and refining priorities for the future.

Further Information

Available from James Ward, AH&MRC, tel. 02 96981099, email jward@ahmrc.org.au.

10 APPENDIX 2: FRAMEWORKS FOR INTERVIEWS

INTERVIEW AND DISCUSSION FRAMEWORKS PROJECT ON INCREASING ACCESS TO SERVICES FOR ABORIGINAL PEOPLE AT RISK OF OR WHO HAVE BBIs

These interview frameworks are intended *as guides* only.

Not everyone will be able to answer all questions, and some will be explored in greater depth than others, depending on the local situation. It will help if, before the interviews*, interviewees have identified the areas* where they wish to contribute most.

The consultants would like to have *a flexible, informal conversation* around the key issues/questions rather than going through them by rote.

Confidentiality:

In the report of the project, ***individuals will not be identified****.* However, the *information* provided *will* be used in the report. Generally it will be analysed with all the other data collected, for instance to identify *common themes and findings* across an Area Health Service, or across NSW.

Occasionally, in the report, a direct quote may be used from the interviews, but the person speaking will ***not*** be identified.

The consultants may use case studies of initiatives that are proving particularly successful or are of value to others. In this case, the description used will be checked with the responsible person.

The framework we propose is to ask questions about -

- What is happening now?
- What are the gaps and issues?
- What needs to happen in the future?

… in relation to access for Aboriginal people at risk of contracting or who have contracted BBI.

Key areas to be explored include:

- ethical data collection, storage and dissemination relevant to the client group;
- protocols involving client confidentiality;
- services in education, prevention and treatment;
- resources and support provided to Aboriginal Sexual Health Workers to improve client access to services;
- ways of working (such as partnerships); and
- assessment of the effectiveness of interventions.

AHS STAFF WITH AREA-WIDE MANAGEMENT OR CO-ORDINATION RESPONSIBILITIES

Eg HIV/AIDS and Hep C Coordinators, Aboriginal Health Directors/Coordinators, Directors of Sexual Health, Drug and Alcohol, Mental Health, Public Health etc.

Overall Area approach and map of service provision

1. **What *overall approach or strategy* does the AHS have in relation to Aboriginal people at risk or who have contracted BBIs?** What key *partnerships* are important (at the broader/Area level)?

2. Clarify and confirm **the outline of *education, prevention and treatment* services** provided by the AHS in the "Fact Finder", and list of relevant policy/planning documents.

Access

<u>Please differentiate between Hepatitis B and C, and HIV/AIDS.</u>

3. What are your views about **the *extent* to which the risk of BBIs, or BBI infection, is affecting Aboriginal people in this Area?** What is the basis for those views (eg data, anecdotal information)?

4. What are your views **about the extent to which people in the target group are *accessing* services now?** What *specific services* are being accessed? Are some being accessed more than others – if so, which ones? Any ideas about what *factors* might be important in increasing access?

5. Would you like to talk about **any initiatives, services or programs that are *working well* in terms of increasing access?** (or have worked well in the past). If so – would it be a useful case study for the project report, of interest to others? (NB: Arrange to obtain more detailed information; check if any written documentation is available).

6. What do you see as **the main *barriers* to access, or *gaps* in service provision?**

7. What do you think **needs to happen *in the future* to address these barriers to access** and in what services or areas specifically?

Aboriginal Sexual Health Workers

8. How do you see **the main role or contribution of the Area Aboriginal Sexual Health Worker? What resources and support are provided** (eg mentoring/supervision, peer support, support from other workers, funds/infrastructure, links to related areas such as public health, health promotion, skills transfer, training, education materials appropriate to the client group, networking opportunities).

Client confidentiality

9. How is ethical implementation of Area-wide policy/practice about maintaining client confidentiality ensured? Are there particular issues in relation to Aboriginal people?

Effectiveness

10. Is there any Area-wide approach to monitoring or evaluating the *effectiveness* of services, interventions or programs? If so, can we discuss?

Other issues

11. Are there any other issues you would like to raise?

AREA HEALTH SERVICE STAFF WITH DIRECT SERVICE DELIVERY ROLES

Eg staff in HIV/AIDS, Hep C, alcohol and other drugs, health promotion, public health, mental health etc.

PLEASE BRING EXAMPLES OF ANY INFORMATION OR EDUCATIONAL MATERIALS DEVELOPED FOR USERS OF YOUR SERVICE.

Representation

1. What services are represented here today? (Check)

Access

Please differentiate between Hepatitis B and C, and HIV/AIDS.

2. What are your views about **the *extent* to which the risk of BBIs, or BBI infection, is affecting Aboriginal people in this Area?** What is the basis for those views (eg data, other information)?

3. What are your views about **the extent to which people in the target group are *accessing* services now?** What *specific services* are being accessed? Any ideas about what *factors* might be important in increasing access? For example, what services have Aboriginal workers employed?

4. Would you like to talk about **any initiatives, services or programs that are *working well* in terms of increasing access?** (or have worked well in the past). If so – would it be a useful case study for the project report, of interest to others? (NB: Arrange to obtain more detailed information; check if any written documentation is available).

5. What do you see as the **main *barriers* to access**, or *gaps* in service provision?

6. **What needs to happen in the future** for these barriers to access to be *addressed*, and in what services or areas specifically? Would you like to make suggestions?

Client confidentiality and data

7. **What arrangements are in place to maintain *client confidentiality***, in the various services represented here today?

8. **What *data collection activities* do your services participate in** that would contribute to understanding the incidence of BBI in the client target group? How accurate is the data, in your view? What factors affect accuracy?

9. Are there any examples of **data collection to *monitor Aboriginal access* to programs or services, or to evaluate their effectiveness?** If so, would this example be useful for case study purposes? (NB arrange to obtain detailed information; check if documentation is available).

ABORIGINAL SEXUAL HEALTH WORKERS
Located in AHSs and AMSs

Please differentiate between Hepatitis B and C, and HIV/AIDS.

1. **How do you see your *role*?** For example is it mainly education, or providing direct services, or coordination of other services?

2. **What have you been seeking to achieve *(your priorities)*** over the past year or so?

3. When we talk about Aboriginal people at risk of diseases like HIV/AIDS and Hepatitis B/C, or who have already got these conditions, **how do you rate the priority of (a) Hepatitis B (b) Hepatitis C (c) HIV/AIDS?** What information helps you make this assessment?

4. What do you think about ***what is being done overall*** **for this target group now?** Is it enough? Is it working?

5. What are the **main *barriers* to improving access?** Are there *gaps*?

6. Are there examples of **things that are *working particularly well now, or in the past*?** Can we talk more about this?

7. **What *resources and support are available to you* in your role** (eg mentoring/supervision, peer support, support from other workers, funds/infrastructure, links to related areas such as public health, health promotion, skills transfer, training, education materials appropriate to the client group, networking opportunities). Are there *gaps* – if so, what are they?

8. **What other services or programs do you *work closely with*** eg cross referral, interagency meetings, partnerships? How does that help improve access?

9. **Are there things you would *like to be able to do but can't* at the moment?** Why? What needs to happen for more to be done?

10. What about getting ***information*** **to people at risk** – what is the best way to do this? Is there anything needing to change in the Area to improve the way this happens – if so, what specifically?

11. Are there *other important issues* you would like to raise?

CORRECTIONS HEALTH SERVICE (CHS)

Please differentiate between Hepatitis B and C, and HIV/AIDS.

Overall Area approach and map of service provision

1. **What *overall approach or strategy* does CHS have in relation to Aboriginal people at risk or who have contracted BBIs?** Is this reflected in any policy documents or strategic plans? What key *partnerships* are important (at the broader/Area level)?

2. **Can you briefly describe what services are in place for inmates generally at risk of BBI, or who have contracted BBI?**

3. **Have any special initiatives been implemented specifically targeting Aboriginal people in Correctional facilities?**

Access

4. What are your views about **the *extent* to which the risk of BBIs, or BBI infection, is affecting Aboriginal people in Correctional facilities?** What is the basis for those views (eg data, anecdotal information)?

5. What are your views **about the extent to which people in the target group are *accessing* services now?** What *specific services* are being accessed? Are some being accessed more than others – if so, which ones? Any ideas about what *factors* might be important in increasing access?

6. Would you like to talk about **any initiatives, services or programs that are *working well* in terms of increasing access?** (or have worked well in the past). If so – would it be a useful case study for the project report, of interest to others? (NB: Arrange to obtain more detailed information; check if any written documentation is available).

7. What do you see as **the main *barriers* to access, or *gaps* in service provision?**

8. What do you think **needs to happen *in the future* to address these barriers to access**, and in what services or areas specifically?

9. Client confidentiality: How is ethical implementation of CHS- wide policy/practice about maintaining client confidentiality ensured? Are there particular issues in relation to Aboriginal people?

10. Effectiveness: Is there any CHS-wide approach to monitoring or evaluating the *effectiveness* of services, interventions or programs? If so, can we discuss?

ABORIGINAL COMMUNITY CONTROLLED HEALTH SERVICES

CEO, Board members, elders

1. What is your experience or knowledge of Aboriginal people at risk of diseases like HIV/AIDS and Hepatitis, or who already have these conditions?

2. How big a issue do you feel it is in Aboriginal communities in this locality?

3. What do you think about what is being done for these people now? Is it enough? Is it working?

4. What is the AMS able to do to help?

5. Are there things the AMS would like to be able to do but can't at the moment? Why? What needs to happen for the AMS to do more?

6. What would be your advice to services that are trying to make contact with these people to encourage them to come to the services? Is it different for people at risk, compared with those already sick? How?

7. What about getting information to people at risk – what is the best way to do this?

ABORIGINAL COMMUNITY CONTROLLED HEALTH SERVICES

Staff involved in service provision

PLEASE BRING EXAMPLES OF ANY INFORMATION OR EDUCATIONAL MATERIALS DEVELOPED FOR USERS OF YOUR SERVICE.

Clarify the roles of participants and how they are involved in this issue.

Access

1. What do you think about the *extent* to which the risk of BBIs, or BBI infection, is affecting Aboriginal people in this locality? What is the basis for those views (eg data, other information)?

2. What are your views about the extent to which people in the target group are *accessing* services now? What *specific services* are being accessed? Any idea what *factors* might be important in increasing access?

3. Would you like to talk about any initiatives, services or programs that are *working well* in terms of increasing access? (If so – would it be a useful case study for the project report, of interest to others? NB: Arrange to obtain more detailed information; check if any written documentation is available).

4. What do you see as the main *barriers* to access, or *gaps* in service provision?

5. To what extent are these barriers and/or gaps being *addressed*, and in what services or areas specifically?

Client confidentiality and data

6. What arrangements are in place to maintain *client confidentiality*, in the your service(s)?

7. What *data collection activities* do your services participate in that would contribute to understanding the incidence of BBI in the client target group? How accurate is the data, in your view?

8. Are there any examples of data collection to *monitor Aboriginal access* to programs or services, or to evaluate their effectiveness? If so, would this example be useful for case study purposes? (NB arrange to obtain detailed information; check if documentation is available).

Other issues

9. Are there any other issues you would like to raise?

PROJECT ON INCREASING ACCESS TO SERVICES FOR ABORIGINAL PEOPLE AT RISK OF OR WHO HAVE BBIs.
NSW Health Department staff with statewide responsibilities which impinge on Aboriginal people at risk of or who have blood borne infections.

FRAMEWORK FOR DISCUSSION

Throughout the meeting it will be important to differentiate between Hepatitis B and C, and HIV/AIDS.

SCOPE AND APPROACH

Broadly, we are interested in finding out –

- What is happening now?
- What are the gaps and issues?
- What needs to happen in the future?

… in relation to access for Aboriginal people at risk of contracting or who have contracted BBI.

Key areas to be explored include:

- ethical data collection, storage and dissemination relevant to the client group;
- protocols involving client confidentiality;
- services in education, prevention and treatment;
- resources and support provided to Aboriginal Sexual Health Workers to improve client access to services;
- ways of working (such as partnerships); and
- assessment of the effectiveness of interventions.

AGENDA

At the opening of the meeting, *each participant* will be invited to briefly explain:

- how their responsibilities impinge on the project's target group;
- how that relates to any overall statewide strategy, and
- whether there are any special initiatives of interest to the project team. (Refer to the areas to be explored, above, and topics below).

The meeting will then become *a focus group type discussion* around the following issues:

1. **Epidemiology and data collection:** the *extent* to which the risk of BBIs, or BBI infection, is affecting Aboriginal people in NSW; the availability of accurate data; any issues or gaps in relation to data; suggestions for action to address the issues.

2. **Access by Aboriginal people to education, prevention and treatment services**:
   (a)The current situation.
   (b)The main barriers to access, or gaps.
   (c) What needs to happen *in the future* to address these barriers to access, and in what services or areas specifically?

3. **Aboriginal Sexual Health Workers.**
    (a) How the Department sees the role and purpose of ASHWs, now and as it might evolve in the future.
    (b) Key elements in the Department's strategy to support ASHWs.
    (c) Gaps, issues and suggestions for the future.

4. **Partnerships (internal/external), and linkages between Infectious Diseases and other branches of the Department.**
    (a) Current situation and aims.
    (b) Areas for future activity/initiatives.

5. **Developing an evidence base to determine the effectiveness of interventions.**
    (a) Key initiatives relevant to this project.
    (b) Suggestions, or plans for the future.

6. **Resources or documents (eg policy, strategy, research, evaluation) of relevance to the project.**

Please give some thought as to whether you can assist the consultants with references, links or copies of relevant materials. Thank you!

CONTACT DETAILS

If at any time you need information about the project or to contact the consultants, they are available as follows:

James Ward	Tel. 02 9698 1099 Email jward@ahmrc.org.au.
Ruth Cotton	Tel. 02 9929 3770 Email rcotton@mandalaconsulting.com.au.

PROJECT ON INCREASING ACCESS TO SERVICES FOR ABORIGINAL PEOPLE AT RISK OF OR WHO HAVE BBIs.

Organisations with statewide or national responsibilities which impinge on Aboriginal people at risk of or who have blood borne infections.

FRAMEWORK FOR DISCUSSION

<u>Throughout the meeting it will be important to differentiate between Hepatitis B and C, and HIV/AIDS.</u>

SCOPE AND APPROACH

Broadly, we are interested in finding out –

- What is happening now?
- What are the gaps and issues?
- What needs to happen in the future?

… in relation to access for Aboriginal people at risk of contracting or who have contracted BBI.

Key areas to be explored include:

- ethical data collection, storage and dissemination relevant to the client group;
- protocols involving client confidentiality;
- services in education, prevention and treatment;
- resources and support provided to Aboriginal Sexual Health Workers to improve client access to services;
- ways of working (such as partnerships); and
- assessment of the effectiveness of interventions.

AGENDA

At the opening of the meeting, interviewees will be invited to briefly explain:

- how their organisation's work and priorities are relevant to the project's target group;
- whether there are any special initiatives being conducted by the organisation that will be of interest to the project team. (Refer to the areas to be explored, above, and topics below). If so, a brief outline of the initiative would be appreciated, together with any available supporting documents.

The meeting will then explore the following issues, differentiating between Hepatitis B and C, and HIV/AIDS.

Epidemiology and data collection

1. **T**he *extent* to which the risk of BBIs, or BBI infection, is affecting Aboriginal people in NSW; the availability of accurate data; any issues or gaps in relation to data; suggestions for action to address the data issues/gaps.

Access

2. Views **about the extent to which people in the target group are *accessing* services now.** What *specific services* are being accessed? Are some being accessed more than others – if so, which ones? Any ideas about what *factors* might be important in increasing access?

3. **Any initiatives, services or programs that are *working well* in terms of increasing access?** (or have worked well in the past).

4. **The main *barriers* to access, or *gaps* in service provision.**

5. What **needs to happen *in the future* to address these barriers to access**, and in what services or areas specifically.

6. Any other issues.

CONTACT DETAILS

If at any time you need information about the project or to contact the consultants, they are available as follows:

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11 APPENDIX 3: ORGANISATIONS CONSULTED

Statewide organisations and services

NSW Aboriginal Health and Medical Research Council
NSW Health Department
NSW Department of Corrective Services
AIDS Council of NSW
Hepatitis C Council of NSW
NSW Users and AIDS Association
NSW Association of Adolescent Health
Alliance of NSW Divisions of General Practice
Australian Society for HIV Medicine Inc
Albion Street Clinic
AIDS Dementia AND HIV Psychiatry Service

NSW Area Health Services

Metropolitan services
Central Coast AHS
Central Sydney AHS
Hunter AHS
Illawarra AHS
Northern Sydney AHS
South Eastern Sydney AHS
South Western Sydney AHS
Wentworth AHS
Western Sydney AHS

Rural services
Far West AHS
Greater Murray AHS
Macquarie AHS
Mid North Coast AHS
Mid Western AHS
New England AHS
Northern Rivers AHS
Southern AHS

State wide Area Health Service
Corrections Health Service

Aboriginal Community Controlled Health and Health Related Services
Armidale & District Services Inc.
Armajun Aboriginal Health (Inverell)
Awabakal Newcastle Aboriginal Co-operative Ltd.
Balranald Aboriginal Health Service Inc.
Biripi Aboriginal Corporation Medical Centre (Taree)
Bourke Aboriginal Health Service Ltd.
Bulgarr Ngaru Medical Aboriginal Corporation (Grafton)
Condobolin Aboriginal Health Service Inc.
Coomealla Health Aboriginal Corp. (Dareton)
Dharah Gibinj Aboriginal Medial Service Corp (Casino)
Durri Aboriginal Corporation Medical Service (Kempsey)
Griffith Aboriginal Medical Service Inc.
Illawarra Aboriginal Medical Service Aboriginal Corp. (Wollongong)
Katungul Aboriginal Corporation Community and Medical Services (Narooma)
Maari Ma Aboriginal Corporation (Broken Hill)
Menindee Aboriginal Health Service Inc
Murrin Bridge Aboriginal Health Service Inc.
Oolong House (Nowra)
Orana Haven (Brewarrina)
Peak Hill Aboriginal Medical Service Inc
Pius X Aboriginal Corporation (Moree)
Riverina Medical and Dental Aboriginal Corporation (Wagga Wagga)
South Coast Medical Service Aboriginal Corp (Nowra)
Tamworth Aboriginal Medical Service Inc.
Tharawal Aboriginal Corp (Campbelltown)
Thubbo Aboriginal Medical Co-op (Dubbo)
Wellington Aboriginal Corp Health Service

Others
Australian Federation of AIDS Organisations
Individual clinicians with specific expertise in BBIs.

12 APPENDIX 4: REFERENCES

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APPENDIX 5: SNAPSHOT OF SERVICES

APPENDIX 5: SNAPSHOT OF NSW SERVICES DECEMBER 2003 FOR ABORIGINAL PEOPLE AT RISK OF CONTRACTING OR WHO HAVE CONTRACTED BLOOD BORNE INFECTIONS (BBIs)

AHS	AHS strategic documents	Core educ/prev services & programs	Core treatment services	Specific action to increase access & cultural appropriateness	ASHW	Specifically targeted programs of services	Relevant short term projects or services	Further plans to increase access
South Eastern Sydney	SESAHS *Communicable Diseases Plan 1999-2002* SESAHS Hepatitis C Strategy 2000-2003 SESAHS Sexual Health Strategy 2000-2003 Healthy People 2005	Health Promotion Team, HIV/AIDS & Related Diseases Unit Sydney Sexual Health Centre Kirketon Rd Centre (KRC) includes NSP Albion St Centre St George D&A Services Hep C Project Officer, IDU, homeless 2 Health Promotion Officers for 3 localities – including youth & BBV	St Vincent's Hospital, Level 5/6 HIV & Hep C St Vincent's Community Health Service Prince of Wales (POW) Hospital, Level 5/6 HIV & Hep C POW Community Health Service St George Hospital, Level 5/6 HIV & Hep C Sexual Health Services: Sydney & St George Albion St Centre (ASC) ADAPHT: Statewide assessment & case management for complex cases	*Cultural awareness training* Culturally appropriate resources Partnerships & linkages eg ADAHPT with AMSs across the state *Cross referrals to AMS, ACON & Sex Workers Outreach Program (SWOP) Aboriginal workers* Needs assessment with AH&MRC approval Outreach to La Perouse, KRC, Langton Centre & Woolloomooloo	Aboriginal HEO at KRC AHW new position	Partnership with Redfern AMS Negotiation to appoint 1 worker through Partnership Needs assessment by new ASHW Aboriginal Sexual Health Advisory Committee to co-ordinate Area initiatives Access project to locate IDU not using services Assessment & co-case management for Aboriginal people with HIV & complex needs KRC AHEO runs weekly get togethers for clients. Nightly outreach in Kings Cross area Resource development by KRC	*Screening at ASC & sexual health services* Opportunistic NSP to community nurses to target homeless people including Aborigines Funding for Hep B vaccination of homeless people including Aborigines Outreach work in parlours in partnership with SWOP 6 month PHO project on methadone service model at KRC as KRC has high numbers of Aboriginal clients	Seek partnership agreement to expand number of Aboriginal workers, reach of services, program development Implement Needs Assessment Evaluate existing resources & develop new ones. Improve linkage with ACON Aboriginal Team and KRC Aboriginal HEO. Cultural awareness training for BBI-sector staff

AHS	AHS strategic documents	Core educ/prev services & programs	Core treatment services	Specific action to increase access & cultural appropriateness	ASHW	Specifically targeted programs of services	Relevant short term projects or services	Further plans to increase access
Central Sydney	Aboriginal Sexual Health Strategy 2003-2008 Hep C Strategic Plan 2003-2006 in draft	Sexual Health Service – screening, health promotion, immunisation REPIDU: (Resource, Education Program for IDU, Redfern) Outreach NSP, education, referral, outreach overdose management for Redfern locality	Sexual Health Service Royal Prince Alfred level 5/6 HIV & Hep C	Aboriginal Sexual Health Strategy AHEOs – community education, capacity building, support groups, partnerships including with councils Cultural awareness training for all staff Male & female doctors Resource development No Medicare card needed for clinic consultation & walk-in clinics	AHEOs: 1 male, 1 female	Direct client management with Aboriginal men & women with HIV &/or Hep C Resource development for men on Hep B & Hep C Monthly outreach to Aboriginal IDU in one locally Education for Aboriginal clients for Newtown Probation & Parole	Direct client management with Aboriginal men & women with HIV &/or Hep C Resource development for men on Hep B & Hep C Monthly outreach to Aboriginal IDU in one locality Education for Aboriginal clients of Newtown Probation & Parole	REPIDU: health bus to provide advice referral, information to street users. In 1 locality. Will move to others if effective. Planned project to mentor & train Aboriginal RNs & Ens in sexual health Proposal for separate walk-in Aboriginal men's & women's clinics in partnership with AMS Redfern

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South Western Sydney	Aboriginal Health Plan 2001-2008 Aboriginal Health: A Partnership between Thurawal Aboriginal Corporation & SWSAHS HIV/Sexual Health Action Plan 2002-2003	NSP HIV/Sexual Health team: community education & develops health service capacity	Sexual Health Service Hep B & C liver clinics in 3 sectors	ASHEO works with other Aboriginal Health Workers Community discussion groups Action research	AHEOs: at Sexual Health Centre	ASHEO develops resources for Area 7 AHEOs in 6 sectors Aboriginal D&A workers: 1 sector Aboriginal Men's Health group: 1 sector Project: Urine screening chlamydia, gonorrhoea at Aboriginal women's clinics in 2 sectors GP for Aboriginal community in 1 sector – many Hep C cases	Playing your cards right 3yr HIV Demonstration project – sexual health literacy for Aboriginal youth Community education forum on SH & IDU for Aboriginal women in Bonnyrigg STI & BBI training for AHWs	

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Western Sydney	Aboriginal Sexual Health Project Advisory Group (ASHPAG) Action Plans 2000-2003 Aboriginal Health Plan: but no specific emphasis on BBIs	NSP HIV/Sexual Health Promotion Unit	Sexual Health Service At Parramatta (level 5) & Mt Druitt Westmead services level 5/6 HIV & Hep C Storr Liver Unit – Hep B&C tertiary level	Needs analysis: Assessing the Sexual Health Needs of Aboriginal Communities in Western Sydney Aboriginal Cultural Awareness Training course for sexual health workers in WAHS & WSAHS Aboriginal Sexual Health Project Advisory Group (ASHPAG) Action Plans 2000 - 2003	ASHW originally funded across both WSAHS & WAHS. Recent review has acknowledged difficulties of this arrangement Funding has been sought to create an ASHW position in each Area. To date this application has not been successful. Existing position to be located in WSAHS.	ASHPAG partnership WSAHS, Daruk AMS & Wentworth	2 year projects: Young Gay Men's HIV Testing Project with WSAHS, SWSAHS, NGOs & GP/Sexual Health Liaison with WSAHS With SWSAHA & WSAHS, Play your cards right. 3 year HIV Demo project sexual health literacy for Aboriginal youth Statewide chlamydia campaign: Aboriginal young person's resources in partnership with Daruk AMS & WSAHS Literature review of Health Promotion programs for Aboriginal communities ASHPAG project	

AHS	AHS strategic documents	Core educ/prev services & programs	Core treatment services	Specific action to increase access & cultural appropriateness	ASHW	Specifically targeted programs of services	Relevant short term projects or services	Further plans to increase access
Wentworth	Aboriginal Sexual Health Project Advisory Group (ASHPAG) Action Plans 2000-2003	NSP HIV/Sexual Health Promotion Unit Health Care Worker Training – mandatory training for all AHS staff in Hep C and HIV	Sexual Health Clinics – Blue Mountains Hawkesbury & Nepean Outpatients Liver Clinic Hepatitis B & C services	Needs analysis: Assessing the Sexual Health Needs of Aboriginal Communities in Western Sydney Aboriginal Cultural Awareness Training course for sexual health workers in WAHS & WSAHS Aboriginal Sexual Health Project Advisory Group (ASHPAG) Action Plans 2000 - 2003	ASHW originally funded across both WSAHS & WAHS. Recent review has acknowledged difficulties of this arrangement Funding has been sought to create an ASHW position in each Area. To date this application has not been successful. Existing position to be located in WSAHS.	ASHPAG partnership WSAHS, Daruk AMS & Wentworth	2 year projects: Young Gay Men's HIV Testing Project with WSAHS, SWSAHS, NGOs & GP/Sexual Health Liaison with WSAHS With SWSAHA & WSAHS, Play your cards right. 3 year HIV Demo project sexual health literacy for Aboriginal youth Statewide chlamydia campaign: Aboriginal young person's resources in partnership with Daruk AMS & WSAHS Literature review of Health Promotion programs for Aboriginal communities ASHPAG project	South Court Primary Care Clinic Plans to initiate a Hep B immunisation clinic & start work on a Peer Network Hepatitis C Project

AHS	AHS strategic documents	Core educ/prev services & programs	Core treatment services	Specific action to increase access & cultural appropriateness	ASHW	Specifically targeted programs of services	Relevant short term projects or services	Further plans to increase access
Northern Sydney	Very small Aboriginal population No specific policy or planning documents re Aboriginal people and BBIs	NSP	Level5/6 HIV & Sexual Health Service Hepatology Unit	Program AIDS does not specifically target Aboriginal people for access Average of 3 to 5 occasions of service per quarter for people who identify as Indigenous	No	No targeted programs or services	Projects to target PLWHA, gay/MSM, queer youth, people who inject drugs, some CALD communities	

AHS	AHS strategic documents	Core educ/prev services & programs	Core treatment services	Specific action to increase access & cultural appropriateness	ASHW	Specifically targeted programs of services	Relevant short term projects or services	Further plans to increase access
Central Coast	CCH HIV and Sexual Health Business Plan 2003-2004 CCH Hepatitis C Strategic Plan 2002-2005 CCH Aboriginal Health Strategic Plan CCH HIV and Sexual Health Strategic Plan 2003-2007	Harm Minimisation Team, (NSP) HIV and Sexual Health Service Sexual Health Promotion Team, HIV and Sexual Health Service	Sexual Health Clinic Liver Clinic	Cultural Awareness Training ASHW involved in community education, capacity building, partnerships AHEO works in NSP and Sexual Health Clinic to increase access All Aboriginal health promotion projects are conducted in partnership with Aboriginal health service and other Aboriginal organisations AHEO has strong links with Aboriginal Health Service	ASHW based in HIV and Sexual Health Service	ASHW works within NSP to engage Aboriginal client group Aboriginal people are a key target population for HIV & Sexual Health Service. Not all projects recurrently funded but each year at least 1 project specifically target Aboriginal people	Getting it on safe sex awareness, one target group is Aboriginal people Pass the message stick: peer education on Hep C Koori Sports Day: resource distribution Partanna Purro: Aboriginal Health Screening Day	Increased role of ASHW within Sexual Health Clinic to enhance access

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Southern	Area Health Plan Public Health Plan in draft Sexual Health Strategy planning in progress Aboriginal Health Strategic Plan (draft)	NSP Sexual Health Clinics Didgeridoo project with Aboriginal/vulnerable youth in Goulburn Hep B immunisation	Sexual Health Clinic	Cultural Awareness training by all staff (some staff pending) Support for Rossy Smith memorial AIDS Day Increasing communication with local AMS (Katungal)	1FTE area wide position 1 part time AMS	ASHW attends all Sexual Health Medical Clinics (4 clinics across area each month) Hep B immunisation	Didgeridoo project (Aboriginal/vulnerable youth project) completed	No plans that have been authorised by CEO

AHS	AHS strategic documents	Core educ/prev services & programs	Core treatment services	Specific action to increase access & cultural appropriateness	ASHW	Specifically targeted programs of services	Relevant short term projects or services	Further plans to increase access
Greater Murray*	Hepatitis C Strategy 2000-2003 Sexual Health Strategy 2000-2003 Sexual Health Promotion Strategy 2002 Healthy People 2005	NSP STI/BBV & NSP education Youth/sexual health program Sexual Health Service: outreach & education Education programs in schools, Juvenile Justice & with "at risk" groups and clients HCW training	Sexual health clinical services: VMO, CNC, RNs, and Educators	Aboriginal specific outreach clinics Cultural awareness training Cultural appropriate resources- fliers, videos, 1800 phone number Partnerships & linkages eg Juvenile Justice, AMS Strong links with AHEOs in the Area Health Service and across the state Facilitates statewide education for ASHW Strong partnerships with local community run Aboriginal organisations	CNC: Aboriginal Sexual Health 1FTE 0.5FTE Aboriginal Sexual Health nurse position advertised (not recruited)	Hep B immunisation Clinical services in sexual health & HIV are integrated for Aboriginal clients with Diabetes screen ect Youth/ sexual health program	Youth camp Aboriginal men's health/sexual health video	Seek partnership agreement with Corrections Health to access Juvenile Justice and prison populations Actively recruit 2nd RN Aboriginal Sexual Health position

* The information for Greater Murray was provided by staff from the Sexual Health Service. They did not have the opportunity to consult other Aboriginal Health Workers or services in the area, so there may be other current services that are not represented here.

AHS	AHS strategic documents	Core educ/prev services & programs	Core treatment services	Specific action to increase access & cultural appropriateness	ASHW	Specifically targeted programs of services	Relevant short term projects or services	Further plans to increase access
Macquarie	Public Health Plan in draft Sexual Health planning in progress	Sexual Health Service: outreach & education Education programs in schools, Juvenile Justice & with "at risk" groups and clients HCV training	Sexual Health Service clinical team: doctor and nurse with BBV expertise	Aboriginal specific outreach clinics Sexual health flyer in development by AHEO	2 AHEOs 1 male and 1 female	Outreach services in Cobar, Mudgee, and Gulargambone and soon in Coonabarabran, Warren. All are in partnership with CDEP (Community Development Employment Program) or Land Council Will respond to need with one-off clinic 1800 phone number		

AHS	AHS strategic documents	Core educ/prev services & programs	Core treatment services	Specific action to increase access & cultural appropriateness	ASHW	Specifically targeted programs of services	Relevant short term projects or services	Further plans to increase access
Mid North Coast	HIV, Hep C & Sexual Health Plan 1999-2003 Service Plan for HIV, Hep C, Sexual Health & Harm Prevention 2003-2006 Aboriginal Health Strategic Plan 2000-2005 Clinical Services Plan 2001-2005	NSP Sexual Health Services: education & prevention programs GUYA 2002: partnership workshops for HCWs & others working with Indigenous youth Education programs for Aboriginal students in schools, colleges etc	NSP Sexual Health Services HIV Specialist Clinic Hep C Clinic	Regular community consultation Strong collaboration between AMS and AHS staff in planning, resources, cross referral and case management Current discussion re satellite sexual health clinic for outlying Aboriginal health post	ASHW: provides education in 1 sector and consultancy Area-wide	Access & disposal program in identified communities re safe disposal of injecting equipment Upper NSW Aboriginal Sexual Health Network Development Project with NRAHS, HAHS, NEAHS, MWAHS, FWAHS: provides support, advice, assistance & training for all ASHWs in STIs, BBIs & harm prevention		

AHS	AHS strategic documents	Core educ/prev services & programs	Core treatment services	Specific action to increase access & cultural appropriateness	ASHW	Specifically targeted programs of services	Relevant short term projects or services	Further plans to increase access
New England	Sexual Health Strategic Plan 2000-2005	Education, referral, support, capacity building for Aboriginal people, men who have sex with men (MSM), gay & lesbian, people with HIV, Hep B & C provided by MSM workers, Senior HEO in sexual health & CNC HIV, Hep C Cultural sharing is not always cultural caring: IDU education program for Aboriginal people NSP Rain Coats for Rainy Days: support for rural MSM, safe sex injecting	Sexual Health Clinics 2 local CNCs in sexual health & BBV 1 visiting Hep C CNC 1 FTE HIV specialist (s100 prescriber) 1 visiting Interferon prescriber		ASHWs: 2 with Area roles in Tamworth & Armidale, 1 at AMS in Moree	Education & promotion Area wide on STI & BBV by Aboriginal workers NSP Pre & post test counselling Hep B immunisation	Short term funding to initiate Cultural Sharing is not always cultural caring NSP access for Aboriginal people in Moree	Further harm minimisation projects as funding permits

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Northern Rivers	Sexual Health Strategic Plan 2000-2005 Health Promotion Plan 2003-2005 Aboriginal Health Strategic Plan	NSP Sexual Health Service: Tweed, Murwillumbah SHAIDS (Sexual Health & Infectious Diseases Service) Lismore, Ballina, Byron Grafton: sexual health educator BBV IDU project (Aboriginal target group) STI project (Aboriginal target group)	Sexual Health Service: Tweed, Murwillumbah SHAIDS Lismore (15% of clients in 02/03 were Aboriginal) Grafton: referral to AMS for clinical service Hepatitis C Clinic opening in 2004	Community consultation, information, resource development Links with Aboriginal services in Tweed Links with ACON in STI project: education, health promotion, peer support Cultural awareness training for all staff Youth clinic- no appointments or Medicare cards required	AHEO in Tweed: education & case management of HIV clients AHEO (0.5 FTE) in Lismore: vacant awaiting secondment	Partnership with ACON re Lismore AHEO Clinical services in sexual health & HIV are integrated for Aboriginal clients	NSW HIV/AIDS Demonstration Project: development of Aboriginal & Torres Strait Islander NSP Education Package	

AHS	AHS strategic documents	Core educ/prev services & programs	Core treatment services	Specific action to increase access & cultural appropriateness	ASHW	Specifically targeted programs of services	Relevant short term projects or services	Further plans to increase access
Far West	Area Sexual Health Strategy	NSP NSP Education for HCWs & Aboriginal Boards Hep C education for HCWs & AMSs BBI & STI Health promotion Hep B vaccination	Sexual Health Services: screening, treatment, care, support Sydney Sexual Health specialists	Partnership AMS & Sexual Health: planning & staff education MOU-FWAHS cross cultural training for Sydney sexual health staff	ASHWs in AMSs	ASHWs in AMSs & APHCWs plan/consult on all programs		Currently 3.5 sexual health nurses, sexual health Co-ordinator & Sydney Sexual Health Centre support Regular program review No budget to expand