

**REVIEW OF SERVICES FOR
PEOPLE LIVING WITH HIV
IN NEW ZEALAND**

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ACRONYMS

AEG	AIDS Epidemiology Group
AMTAC	AIDS Medical and Technical Advisory Committee
ANC	Antenatal care
APP	Absolutely Positively Positive
ARV	Anti-retroviral
BP	Body Positive
CBO	Community-based organisation
CSW	Commercial sex worker
DHB	District Health Board ADHB – Auckland District Health Board CCDHB – Capital and Coast District Health Board CDHB – Canterbury District Health Board WDHB – Waikato District Health Board
ESR	Institute of Environmental Science and Research
FP	Family Planning
FTE	Full-time equivalent
GAPSS	Gay Auckland Periodic Sex Survey
HAART	Highly active anti-retroviral therapy
HCW	Health care worker
ID	Infectious diseases
IDU	Injecting drug user
INA	INA Foundation
MARP	Most at-risk populations
MH	Mental health
MOU	Memorandum of Understanding
MPI	Māori and Pacific Islands
MSM	Men having sex with men
NGO	Non-government organisation
NZAF	New Zealand AIDS Foundation
PC	Prostitutes Collective
PLHA	People living with HIV/AIDS
PW	Positive Women
SH	Sexual health
SHC	Sexual health clinic
SHP	Sexual health physician
STI	Sexually transmitted infection
T&C	(HIV) testing and counselling
TOP	Termination of pregnancy
UNAIDS	United Nations Joint Programme on HIV/AIDS
UNGASS	United Nations General Assembly Special Session on AIDS
WHO	World Health Organization

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About the author

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Dr Miller is a New Zealander with in-depth experience at the international professional level as a clinical psychologist, as a public health specialist and as a designer and implementer of corporate governance. He has worked in clinical, public health, policy and governance settings in London, Geneva and New Delhi and conducted training and interventions in over 50 countries (mainly Africa and Asia) across government, NGO, bilateral and multi-lateral sectors. Dr Miller has also developed clinical protocols for psychosocial management in HIV/AIDS that have been adopted and adapted globally by ministries of health, bi-lateral and United Nations agencies and NGOs.

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EXECUTIVE SUMMARY

This review has identified that **services for people living with HIV/AIDS (PLHA) in New Zealand are reaching and being appreciated by those for whom they are designed**. PLHA in New Zealand contacted and interviewed in this review spoke unanimously and extremely enthusiastically about the quality of care they receive from District Health Board (DHB) services providing HIV-related diagnostic, treatment and support services. There appears to be excellent collaboration and peer support between physicians providing diagnostic and treatment services for PLHA in New Zealand and moreover, close and fruitful collaborations between departments of infectious diseases and sexual health services in each of the DHBs reviewed.

Additionally, there was overwhelming appreciation for the community-based NGO support services being provided for PLHA in the main centres where such services exist.

In addressing current service provision for PLHA in New Zealand, we might usefully ask whether it is both necessary and sufficient to fully address the needs of PLHA. The general answer appears to be: Necessary, yes; sufficient, not yet.

In terms of community-based support services, Auckland is something of a city-state – three of the major HIV support NGOs are there; two have no physical infrastructure outside Auckland beyond telephone and internet links. NGO groups and PLHA outside that city expressed significant disenchantment with the weighting of support services in Auckland, despite recognition of the epidemiological basis for it.

A main and consistently cited gap in service provision for PLHA identified by DHB and NGO staff and service users relates to **mental health (MH) coverage**, particularly for those with longer-term psychiatric and psychological issues. A review of benchmarks for minimum MH service coverage in infectious diseases (ID) and sexual health (SH) services would be timely, as would an exploration of potential alternatives for MH service access for PLHA outpatients with chronic conditions, including dual diagnoses and pre-existing conditions.

Additionally, many health workers and NGO staff and service users identified **primary care service fees as a major obstacle to PLHA making use of primary care services** for HIV-related management not necessitating specialist secondary or tertiary services. In practice, PLHA are using DHB and NGO services as a proxy for primary health care services, as a way of receiving free treatment.

A national review of **guidelines and standards for HIV testing and counselling (T&C)** appears to be necessary, in the light of developments in HIV testing technology and the recent availability of testing outside of routine clinical settings. The newly defined standards would need to be initiated in all settings without diminishing the efficacy of current efforts. This review could include standards as to the degree of training and competency necessary prior to administering and interpreting HIV tests, the level of pre- and post-test counselling and service backup required wherever rapid testing is provided, and compatibility with established national and international benchmarks for HIV T&C.

Stigma was repeatedly mentioned as a major issue in the context of HIV in New Zealand. It is evident that stigma is the elephant in the waiting room of HIV public health responses – often invoked as the cause of sub-optimal population responses to prevention and support activities, yet hard to quantify or isolate by region or population. Operationally, it is of major concern particularly among both African and Māori communities. Given the reported ubiquity of stigma as a public health issue associated with HIV, it would seem a useful exercise to explore its parameters and the means of its maintenance in HIV management. A national conversation on stigma in health would enable a broad understanding of what it is, how it works and how it can be addressed. An action agenda can then be

initiated to systematically take evidence-based experimental approaches with populations concerned. Unless stigma is addressed in a mature manner in the management of HIV, diagnostic, preventive, treatment and care initiatives and interventions will always be playing ‘catch-up’ as stigma effects are subsequently revealed.

New Zealand has no coordinated or comprehensive research agenda linked to HIV/AIDS or sexually transmitted infections (STIs). This means that there is a continual and pressing absence of data for policy and programme refinement, for example in relation to the almost mythic issue of the impact of stigma on HIV service engagement, and in relation to the impact of geography and demographics on the availability, structure, and functioning of HIV services in New Zealand. Development of such an agenda with Ministry of Health backing would strengthen service delivery and the evidence base for service development. In addition, as part of the development of a national research agenda, **a framework for external quality audits of PLHA services is needed – for both DHB and NGO PLHA services.** Reviews of the quality of service processes and impacts are well overdue.

Finally, smaller NGOs with demonstrated records of service provision and defined constituencies are having difficulty coping. Even though their constituencies may be well defined and relatively small, the demands of those constituencies are significant and growing, in terms of both practical and emotional needs. These NGOs need and deserve help. The Ministry of Health should consider core funding in each case to support sustainable, outcomes-based activities so these NGOs are not constantly distracted from their primary missions by the need to find funding for survival. Possible benchmarks could be implemented for providing funds to smaller community-based HIV support services.

SUMMARY OF RECOMMENDED RESPONSES TO ISSUES IDENTIFIED

ISSUE	RECOMMENDED RESPONSE
Ministry of Health <i>HIV/AIDS Action Plan</i> (2003) is out of date and needs revision; there is no Sexual and Reproductive Health Strategy action plan	Review and update the <i>HIV/AIDS Action Plan</i> ; develop a Sexual and Reproductive Health Strategy action plan
There is no national HIV research strategy; evaluation of quality of service delivery across sectors is absent	Develop a national HIV research agenda; develop a framework for external evaluation of HIV service quality
Mental health coverage for PLHA – particularly longer-term mental health support – is difficult to access in most areas	Establish benchmarks for MH coverage for PLHA; explore new pathways for access to qualified MH services
Cost is an obstacle to accessing primary care for many PLHA; DHB and NGO HIV services are a proxy for primary care services	Review primary care fee costs for PLHA; review core primary care staff training in HIV
There are variations in T&C for HIV according to sector and service	Initiate a national conversation on standards and guidance for T&C provision, training and monitoring
Stigma, particularly in minority populations, creates obstacles to HIV service engagement	Initiate a national conversation on stigma in health – examining experiences to date from a variety of perspectives; develop an action agenda
NGOs are experiencing difficulties in coping with demand	Identify possibilities for core funding of sustainable, outcomes-based activities to enable NGOs to survive without being distracted from their primary mission; explore implementation of benchmarks for funding smaller support services

INTRODUCTION

The national clinical and policy response to HIV is a New Zealand success story. Being a small country with an extremely mobile commercial and recreational population, and a South Pacific hub for tourism, New Zealand's spread of HIV might have been considerably greater. HIV infections have remained at a low level annually, and despite well-founded concerns about the need for prevention and education, there has been no cross-over of HIV from communities most at risk to the wider New Zealand population. Legislation to decriminalise homosexuality and prostitution; coordinated epidemiological surveillance coupled with advanced medical diagnostic and treatment services; continual funding of creative, targeted prevention campaigns; reliance on evidence-based action; and a flexible and committed DHB and NGO workforce in the management of HIV/AIDS have all contributed to New Zealand's continuing low incidence of HIV.

The structure and functioning of HIV support services in New Zealand are very much determined by the physical characteristics of the country and its people – its small population size, its geography, its disparate demographics, its restricted institutional capacity, and the concentration of men having sex with men (MSM) in Auckland. New Zealand's whole population is less than that of cities in other developed countries, where HIV has become a major health burden.

There are estimated to be up to 2000 people living with HIV/AIDS in New Zealand. In 2009, 151 people were diagnosed with HIV through HIV antibody testing, and 28 people were notified with AIDS. A further 48 people with HIV infection who had not been tested in NZ had a first viral load test in 2009 – the majority had previously been diagnosed overseas. Of those diagnosed with HIV here, 73 were men infected through sex with other men, 50 through heterosexual sexual contact (24 men, 26 women), 5 (all men) through injecting drug use, three through mother-to-child transmission and two through possible nosocomial transmission overseas. For 18, the means of infection was unknown.

There is a network of linked HIV treatment professionals in DHB services providing care and support for this population. It has, in the context of this review, won universal praise from PLHA. Operational collaboration between these services and community-based support services appears very successful; DHB and NGO services meet regularly in what appears to be a constructive forum for a discussion of policy and operational responses to emerging crises and issues.

The policy structure upon which national responses to HIV/AIDS are exercised is the *HIV/AIDS Action Plan*. Published by the Ministry of Health in 2003, this plan identifies recommended action points under objectives deriving from the following:

1. societal attitudes, values and behaviour
2. personal knowledge, skills and behaviour
3. programmes and services
4. information.

Many of the actions and their operational interpretations are what would be expected of an evidence-based plan for HIV management within a nation signatory to the United Nations General Assembly Special Session on AIDS (UNGASS) and other international agreements. The action interpretations in the Plan tend to be reflective of the then current levels of activity; they are frequently non-directive and aspirational.

Table 1: Exposure category by time of diagnosis for those found to be infected with HIV by antibody test and first viral load test

Sex	Exposure category	HIV infection*							
		1985–2003		2004–2008		2009		Total	
		No.	%	No.	%	No.	%	No.	%
Male	Homosexual contact	1162	56.1	487	47.7	89	44.7	1738	52.8
	Homosexual and injecting drug use (IDU)	26	1.3	15	1.5	1	0.5	42	1.3
	Heterosexual contact	212	10.2	198	19.4	27	13.6	437	13.3
	IDU	53	2.6	7	0.7	5	2.5	65	2.0
	Blood product recipient	34	1.6	0	0.0	0	0.0	34	1.0
	Transfusion recipient [§]	9	0.4	4	0.4	0	0.0	13	0.4
	Perinatal	13	0.6	17	1.7	5	2.5	35	1.1
	Other	4	0.2	5	0.5	0	0.0	9	0.3
	Unknown	239	11.5	65	6.4	28	14.1	332	10.1
Female	Heterosexual contact	234	11.3	187	18.3	33	16.6	454	13.8
	IDU	11	0.5	0	0.0	0	0.0	11	0.3
	Transfusion recipient [§]	8	0.4	2	0.2	0	0.0	10	0.3
	Perinatal	11	0.5	9	0.9	0	0.0	20	0.6
	Other	7	0.3	5	0.5	1	0.5	13	0.4
	Unknown	24	1.2	20	2.0	9	4.5	53	1.6
Transgender	Total	8	0.4	1	0.1	1	0.5	10	0.3
Not stated	Transfusion recipient	5	0.2	0	0.0	0	0.0	5	0.2
	Unknown	13	0.6	0	0.0	0	0.0	13	0.4
TOTAL		2073	100.0	1022	100.0	199	100.0	3294	100.0

* Includes people who have developed AIDS. HIV numbers are recorded by time of diagnosis for those reported through antibody testing and by time of first viral load for those reported through viral load testing. The latter include many who have initially been diagnosed overseas and not had an antibody test here. The date of initial diagnosis may have preceded the viral load date by months or years.

§ Among all people in this category diagnosed since 1996, infection was acquired overseas.

The evidence base for policy and clinical service development in New Zealand comprises clinical and operational research conducted by clinicians and by university departments linked to epidemiological and service groups (see Appendix 4: 'Documentation reviewed'). The epidemiology of HIV in New Zealand is published quarterly by the AIDS Epidemiology Group (AEG), Department of Preventive and Social Medicine, University of Otago, Dunedin. Additionally, the New Zealand AIDS foundation (NZAF) has either commissioned or published studies concerning MSM (for example the *Gay Auckland Periodic Sex Survey (GAPSS 2002)* and some analyses of sub-sets of the GAPSS data (for example Saxton et al 2004). Other important studies in which NZAF participated closely have been published in the *HIV Futures New Zealand* series (for example Grierson et al 2008). NZAF also publish the *HIV Prevention Plan 2009–2014*, which constitutes the basis for prevention planning and activity for the Foundation.

The available data show that in the past 10 years, among those who have acquired HIV in New Zealand, Māori have had the same rate of HIV diagnosis as New Zealand Europeans. In 2008, the 10 Māori identifying as takatāpui represented 16 percent of all MSM diagnosed in New Zealand. GAPSS and Gay men’s Online Sex Survey/Te Rangahau Tane ai Tane (2006) data show that the rate of MSM having anal sex with a casual partner and not using a condom at least once in the previous six months was roughly the same for Māori (40.9 percent) and New Zealand European (39.5 percent) MSM. These data also show that 69.9 percent of MSM had tested for HIV at least once in their life: the figure was higher among Māori (72.8 percent) and New Zealand European (72.1 percent) MSM than it was among Pacific (40.9 percent) and Asian (51.6 percent) men.

Table 2: Ethnicity[‡] by time of diagnosis in New Zealand for those found to be infected with HIV by antibody test and first viral load test

Sex	Ethnicity	HIV infection*							
		1996–2003		2004–2008		2009		Total	
		No.	%	No.	%	No.	%	No.	%
Male	European/Pākehā	513	50.0	430	42.1	70	35.2	1013	45.1
	Māori†	60	5.8	75	7.3	9	4.5	144	6.4
	Pacific Island	18	1.8	25	2.4	5	2.5	48	2.1
	African	96	9.3	127	12.4	10	5.0	233	10.4
	Asian	91	8.9	81	7.9	18	9.0	190	8.5
	Other	19	1.9	35	3.4	18	9.0	72	3.2
	Unknown	22	2.1	25	2.4	25	12.6	72	3.2
Female	European/Pākehā	53	5.2	30	2.9	5	2.5	88	3.9
	Māori†	7	0.7	8	0.8	3	1.5	18	0.8
	Pacific Island	13	1.3	11	1.1	1	0.5	25	1.1
	African	88	8.6	130	12.7	17	8.5	235	10.5
	Asian	44	4.3	28	2.7	6	3.0	78	3.5
	Other	1	0.1	8	0.8	5	2.5	14	0.6
	Unknown	1	0.1	8	0.8	0	0.0	9	0.4
Transgender	Total	1	0.1	1	0.1	7	3.5	9	0.4
TOTAL		1027	100.0	1022	100.0	199	100.0	2248	100.0

‡ Information on ethnicity of people diagnosed with HIV has only been collected since 1996.

* Includes people who have developed AIDS. HIV numbers are recorded by time of diagnosis for those reported through antibody testing and by time of first viral load for those reported through viral load testing. The latter include many who have initially been diagnosed overseas and not had an antibody test here. The date of initial diagnosis may have preceded the viral load date by months or years.

† Includes people who belong to Māori and another ethnic group.

New Zealand has a sexual and reproductive health strategy (Ministry of Health 2001) that describes an overall vision for achieving satisfactory sexual and reproductive health for the New Zealand population and outlines principles, international obligations, strategic context and strategic directions. Among other things, it highlights the need to increase knowledge about safer sex and to provide information on sexual and reproductive health; the risks of STIs (including HIV); and prevention, early diagnosis and treatment. However, it does not include an action plan for sexual health, in a form such as that of the operationalised plan for HIV/AIDS (Ministry of Health 2003). National surveillance is by voluntary data provision from sexual health clinics (SHCs), Family Planning

(FP) clinics, student and youth health clinics and laboratories. Improvements to the reporting of laboratory surveillance data were made in 2009, enabling comprehensive regional and national population estimates of STI incidence. The Institute of Environmental Science and Research (ESR) produces an Annual Surveillance Report (which quotes the AEG data on HIV/AIDS). Chlamydia was the most commonly reported STI in 2009. From 2005 to 2009, SHCs reported an increase in the number of cases and clinic visit rate of chlamydia (from 3.3 to 7.1 percent). These trends were supported by laboratory data, which reported an 11.3 percent increase in the chlamydia restricted national rate (based on nine DHBs) between 2006 and 2009. In SHCs, over 50 percent of cases were from non-European ethnic groups (Māori, Pacific Peoples and Other).

From 2005 to 2009, SHCs also reported an increase in the number of cases and clinic visit rate for gonorrhoea (from 17.5 to 21.7 percent). These trends were not reflected by laboratory data, which reported a 22.0 percent decrease in the gonorrhoea restricted national rate (based on 10 DHBs) between 2006 and 2009. A national gonorrhoea rate (based on 18 DHBs) of 66 per 100,000 population was reported from laboratory surveillance data. Over 60 percent of cases reported by SHCs and laboratories were in people aged less than 25 years.

Syphilis statistics appear alarming, although case numbers are relatively low. Between 2008 and 2009, the number of cases of syphilis reported by SHCs increased by 50.0 percent (from 92 to 138 cases). SHCs reported higher numbers for individuals aged over 40 years and those of European ethnicity (44.9 percent and 55.8 percent respectively). Over the last five years the number of cases reported by SHCs has increased by 193.7 percent. These figures point to the need for a continual strengthening of sexual health surveillance, not least because syphilis, for example, is mainly occurring in MSM and being transmitted within New Zealand: the links between ulcerative genital conditions and HIV transmission are well accepted.

As stated in the recent New Zealand *UNGASS Country Progress Report* (Ministry of Health 2010), the Ottawa Charter for Health Promotion has formed the basis for operationalising approaches to HIV health promotion in this country, ensuring that responses are led by communities most at risk. Accordingly:

- the New Zealand AIDS Foundation (NZAF) delivers HIV prevention programmes that target the most at risk populations – MSM (predominately New Zealanders) and heterosexual African migrants in New Zealand. It also provides community based HIV rapid testing services, sexual health clinics for men and care and support services for anyone affected by HIV. NZAF leads on national advocacy and Pacific Region partnerships (including an NZAF International Development Unit), policy advice and coordination of the National HIV and AIDS Forum. Within the NZAF's prevention programmes is a specific social marketing team that uses new technologies and social networking sites to build a pro-condom social movement. Community Engagement programmes that work with community volunteers include work stream teams led by gay non-Māori, gay and fa'afafine Pacific People and African heterosexual migrants to New Zealand.
- Peer support organisations (Body Positive Inc, the Māori, Indigenous & South Pacific HIV/AIDS Foundation (known as INA), Positive Women Inc, Absolutely Positively Positive) provide support and advocacy for people living with HIV and AIDS (and their families). Body Positive Inc also provides rapid HIV testing and other clinical services. Positive Women Inc promotes awareness of HIV and AIDS in the community through educational programmes with a focus on prevention and de-stigmatisation. INA organised an HIV positive Māori, Indigenous and Pasifika Conference, held from 28 January to 1 February 2009 where participants were encouraged to discuss the impact of HIV and AIDS on Māori, Indigenous and Pasifika people. Despite presently not receiving any financial assistance from Government, these organisations are involved in HIV awareness, self esteem development, and challenging stigma and discrimination at a number of levels.
- ...

- Family Planning is a not-for-profit organisation which provides quality sexual and reproductive health services for all New Zealanders. Family Planning seeks to expand access and reduce the barriers to achieving improved sexual and reproductive health and reproductive rights. There are 30 clinics with 180,000 visits per annum, nationally. HIV is integrated into all areas of health promotion, education, clinical and professional development work. Family Planning acts as a strong advocate and lobby group for the empowerment of women and girls, particularly with respect to sexual and reproductive health issues such as HIV.
- Other programmes and clinical services are delivered via District Health Boards, in sexual health clinics and sexual health promotion services. The services offer free, confidential, specialist sexual health care services including diagnosis and treatment of sexually transmitted infections, telephone information and advice, testing and treatment of HIV/AIDS, sexual health counselling and free condoms. District Health Boards also fund Primary Care Organisations which are a first point of contact for people with sexual health concerns and offer testing and treatment of common STIs.
- There is access to a range of sites for HIV testing. The greatest proportion of people diagnosed with HIV infection is in primary care (pp. 4–5).

This report goes on to state:

Testing, treatment and care are provided in a number of health settings, including general practice, sexual health centres, community based centres, specialist units based in major hospitals, and hospices. Patient centred integrated care is a particular feature of HIV and AIDS services, for example, enabling patients to care for themselves at home (p. 5).

Data from the extensive survey of PLHA in New Zealand *HIV Futures New Zealand 2* (Grierson et al 2008) indicates good use of available services by PLHA. For HIV-specific treatment, most respondents to this survey (80 percent; n=209) went to HIV specialists as their primary provider; 7 percent saw sexual health centre physicians for this purpose. For general health care, 52 percent saw primary care staff, 21 percent saw primary care staff with a high HIV caseload and 18 percent saw an HIV specialist at an outpatient clinic. In the six months prior to the survey, 79 percent had seen an HIV specialist in an outpatient clinic, 56 percent had seen a primary care physician, 22 percent had seen a dentist and 20 percent had seen a primary care physician with a high HIV caseload. NGO services also provided vital services for PLHA responding to the survey – 34 percent had received treatment advice from an NGO, 31 percent had received counselling, 20 percent had received social contact and peer support, 12 percent had received complementary therapies and 15 percent had received treatment information. The *Futures 2* survey showed that a little less than two-thirds (62 percent) of those surveyed had some contact with HIV/AIDS organisations, the majority receiving a newsletter or some of the services they provided.

Against this background, the author of the present document was competitively selected to undertake a review of selected services for people with HIV infection, with the expressed aim of identifying possible gaps in services and areas for potential future investment. The Ministry of Health specified services to be included in the review, although the discussions against which information was received and analyses undertaken included other organisations' representatives as well. The review was commissioned by the Public Health Group of the Health and Disability National Services Directorate of the Ministry of Health (the Terms of Reference are in Appendix 1).

Structure of this report

The Introduction to this review has presented its background. Subsequent sections describe the review's methodology and the results of the review process: first the results of discussions with DHB staff in the main centres, and then the results of discussions with the NGOs recommended as

participants by the Ministry of Health. For reasons of brevity, NGO self-reported information relating to governance, reporting and impact (DHBs did not supply this in written form) is presented as an appendix at the rear of this report. Content analyses of discussions with PLHA are presented at the end of the 'Results' section. Final sections include a synthesis ('Discussion') and concluding remarks.

Appendices at the rear include the terms of reference for the review, key issues raised with key informants, persons interviewed, documents received, HIV NGO website information and NGO self-reported data.

METHODOLOGY

This review effectively presents a stock-taking of services for people living with HIV. It is important to stress that it is not a qualitative review or an audit of service processes or functioning.

The review involved the following steps.

1. SITE SELECTION AND REPORT DESK REVIEWS

- a. Organisations identified by the Ministry of Health as appropriate for inclusion in the review were approached by letter, and identified staff were later contacted by telephone. In DHBs, those approached included the managers of SH services and ID heads of departments.
- b. Organisation reports and relevant documentation, requested in the preliminary correspondence, were received and reviewed.
- c. Appointments were made for site visits and discussions with key staff and service users.

2. SITE VISITS AND KEY STAKEHOLDER DISCUSSIONS

- a. Structured discussions were undertaken with relevant senior staff and service providers using the Key Issue list (see Appendix 2). These discussions were supplemented by information provided by NGOs completing the service data tables (see Appendix 6).
- b. Focus group discussions were undertaken with service users, where the service determined this was feasible.

3. REPORT PREPARATION

- a. Data gathered from steps 1 and 2 were collated.
- b. Summary reports on each service were prepared and then reviewed by the relevant services.
- c. All findings were synthesised.
- d. Preliminary recommendations were made.
- e. A draft was submitted to the Ministry for review and feedback.

4. FINAL DRAFT PREPARATION AND SUBMISSION

- a. Feedback from the Ministry was reviewed.
- b. The final report was drafted and submitted.

The author maintained open channels with the Ministry and services participating at all stages, establishing a collaborative, supportive working relationship. At every stage the services involved in the review were engaged for fact-checking and verification where appropriate. At all times the review was conducted as a form of appreciative enquiry.

The review initially involved approaches to the following community-based NGOs:

- New Zealand AIDS Foundation (Te Tūāpapa Mate Āraikore o Aotearoa) in Auckland, Wellington and Christchurch
- New Zealand Family Planning, Wellington

- INA Foundation, Tirau
- Positive Women Inc, Auckland
- Body Positive Inc, Auckland.

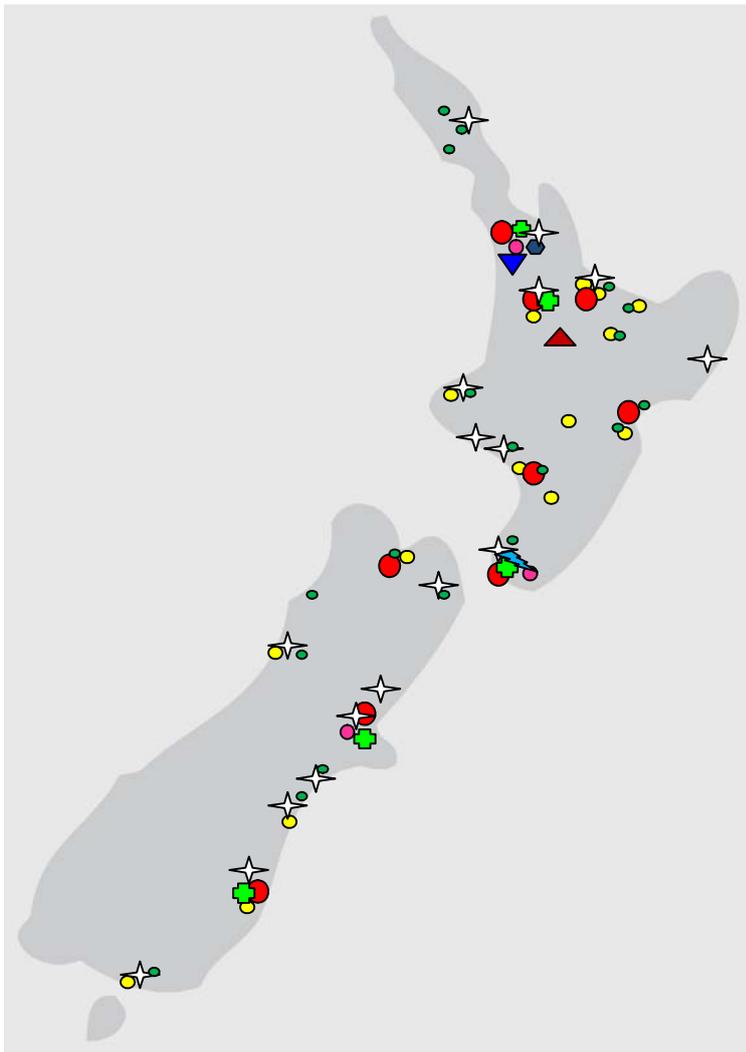
During the course of the review, input was also received from the following:

- the convenor of a regular peer-support group for PLHA (formerly Poz Plus) in Christchurch
- Absolutely Positively Positive, Wellington
- the New Zealand Prostitutes' Collective, Wellington
- focus groups of people living with HIV in Christchurch, Wellington and Auckland
- individual PLHA
- colleagues with historical and experiential associations with HIV developments in New Zealand since the mid-1980s.

Senior staff from DHBs providing sexual health and infectious diseases services in Christchurch, Wellington, Hamilton and Auckland were also interviewed.

Appendix 3 provides a full list of colleagues who provided input to this review.

Figure 1: Locations of HIV services in New Zealand*



* This does not include all DHB services providing for PLHA: only those in major centres.

- | | | | |
|---|--------------------------------|---|-----------------------------|
|  | Positive Women |  | INA Foundation |
|  | NZAF office (and counsellors) |  | Body Positive |
|  | NZAF contract counsellors |  | FP clinic |
|  | DHB ID department |  | DHB SH services (full-time) |
|  | Absolutely Positively Positive |  | DHB SH services (part-time) |

RESULTS

1. DISTRICT HEALTH BOARD SERVICES FOR PLHA

A. AUCKLAND DISTRICT HEALTH BOARD (www.adhb.govt.nz)

Infectious diseases

ADHB's Adult ID service has the largest HIV cohort in New Zealand, currently providing care for approximately 750 PLHA. Referrals to ID come from primary care staff, other ADHB services, NZAF's Burnett Centre, Body Positive (BP) rapid testing, antenatal care (ANC) and the refugee centre. The Adult ID service covers Northland to Bombay (including Waitemata and Counties, who pay for services on a pro rata scale). The service makes a conscious effort to link with SH services in the same region.

Adult ID runs five HIV clinics on Wednesday mornings and Thursday afternoons. For outpatient clinics there are six ID physicians, three clinical nurse specialists and one registrar. They are supported by the Community HIV team, and liaise with primary care staff, although, as appears commonplace in DHB services for PLHA, ID can almost become a default primary care service – especially for immigrant populations. This issue is raised frequently in this report.

Adult ID, together with two paediatric ID physicians and a paediatric clinical nurse specialist, run a family clinic for children and parents affected by HIV. At the time of the review, the establishment of a paediatric/young person clinic was under discussion. Adult ID liaises closely with the Maternal-Foetal Medicine service, which provides for the care of women with HIV infection who are pregnant.

Usually up to four patients receive inpatient ward care at any one time, although more inpatients can be accommodated as required. Follow-up care for outpatients is provided according to their clinical status – appointments can vary in frequency from monthly to yearly.

Adult ID staffs the Community HIV team, comprising four part-time nurse specialists and one full-time social worker, housed in the Adult ID department. As well as its work with inpatients and the outpatient clinic, the team has a significant role in the community, addressing issues such as medication, treatment monitoring, treatment adherence and primary care liaison. The majority of patients that the Community HIV team deals with are cared for by the Adult ID service. However, small numbers of patients are cared for by the Paediatric ID service and by SH.

Sexual health

SH services currently have 70 PLHA under their care, some of whom are seen in conjunction with ID.

Patients are generated internally: some are referrals from Body Positive (who have their own rapid testing programme), and a few come following rapid testing at the NZAF Burnett Clinic. SH doesn't have dedicated HIV clinics. They see PLHA on average every three to six months, and the majority of patients are gay men (they currently see fewer than 10 women with HIV, and very few heterosexual men). SH services provide outpatient care only: any hospital admissions are made through ID.

There is no direct nursing input in SH – staff noted the general lack of nurse education on HIV in SH.

SH provides the following services and clinical interventions:

- STI screening, diagnosis and management
- an outreach programme to the New Zealand Prostitutes Collective

- an adult sexual assault unit – SH runs this five days per week, and administers the out-of-hours roster
- an outreach clinic at the NZAF Burnett Centre – nurse-led STI screening
- cervical screening on an opportunistic basis where appropriate, including to HIV
- patients
- genital dermatology
- management of sexual dysfunction/genital pain syndromes (combined)
- pre and post-HIV test counselling
- ongoing management of ambulatory HIV positive patients.
- emergency contraception, pregnancy testing and termination of pregnancy (TOP) referral.
- education for medical students and related services (such as midwives, nurses and specialty registrars)
- advice for general practitioners and other health workers
- partner notification
- surveillance of STIs, including collation and provision of information to ESR
- participation in Ministry of Health advisory groups.

In terms of staffing, Auckland SH has the following full-time equivalents (FTEs): four in the education unit, 1.85 medical officers, 0.65 counsellors, two registrars, 3.75 sexual health physicians, 10 staff nurses and two team administrators. One physician noted,

‘SH in Auckland do not have public health nurses or health advisors and we have no access to the Regional Public health Service resources as we are not formally linked with them and they are not funded to provide any service to SH’.

As commonly seen in this review, regular case-work collaboration between ID and SH is a feature in ADHB. SH run voluntary peer review sessions every two months, along with a combined journal club five times yearly, with ID. The close working relationship is valued, although being on different geographical sites is a practical challenge.

Those tested for HIV in SH all get the combined HIV antigen/antibody screening test and Western Blot confirmation of initial positive results (Western Blot confirmation is also given for specimens identified with HIV in the Burnett Centre and the K Road Clinic). SH can obtain HIV antigen/antibody screening test results in two hours if required urgently.

Like all DHB services reviewed, those in Auckland are fully committed to multi-culturalism. For example, interpreters are widely used where necessary. Adult ID has recently started using telephone interpreters for some clinic visits – this is an ADHB policy.

All SH services and NGOs participating in this review were asked about attempts to monitor patient or service-user satisfaction. SH in Auckland noted that patient satisfaction surveys should be undertaken every six months, but are actually more typically done every 12 months. In this context, it was noted that many PLHA are not necessarily aware of which services are HIV-related and which are not.

Prevention

This review discovered a subjective impression of sub-optimal engagement in SH assessment and treatment among Maori and Pacific Islands (MPI) men. Correspondingly, rates of gonorrhoea and chlamydia are described as ‘high’ in South Auckland, in which a large proportion of MPI men reside.

(It is noteworthy that data specific to the Counties Manukau district is not separately reported to or by ESR – only Auckland SH data as a whole is reported.) A recent survey in South Auckland revealed that many MPI are electing not to have tests for HIV or other STIs (McAllister et al 2008).

While SH services participating in the review from other regions noted as a continual obstacle to prevention the unquantified though reportedly significant population of MSM who do not self-identify as gay or bisexual, this is reportedly much less of a problem in Auckland. However, peer-group coherence does not appear to necessarily correlate to behavioural prevention: One physician in ADHB noted that:

Of those who are aware [of HIV as a risk], many are more blasé. Traditional approaches to prevention aren't working. There is a sense that the amount of risk [behaviour] is going up.

It should be noted that HIV is now a chronic disease, rather than the 'death sentence' it once was, thanks to extraordinary developments in highly active anti-retroviral therapy (HAART). This may be contributing towards 'blasé' attitudes, along with a further potential spanner in the spokes of prevention: the availability of non-occupational post-exposure prophylaxis (nPEP). In some countries, this has come to be perceived by some as a 'morning-after pill' following high-risk sexual episodes. At the time of this review, the issue of having nPEP funded by Pharmac (with tight eligibility criteria was under discussion. nPEP carries significant costs – expected to be about \$1500 for a full course.

SH identified the following issues in current service provision:

- the need for greatly strengthened STI surveillance nationally – data is only collected voluntarily by specific clinical sites at present, although 40 laboratories report on chlamydia and 35 report on gonorrhoea nationally (importantly, there is no laboratory data collection on syphilis)
- the lack of sexual health behavioural data – the available MSM data comes from NZAF only. SH are currently making a submission to be included in the national health survey, so regular information can be collected to inform future control strategies for STIs and HIV.

Future investment

Catchments of concern in many developed and developing countries, such as injecting drug users and prisoners, only rarely came up in discussion during the course of this brief review. With respect to the former, SH and ID services reported little active interaction with methadone programmes and other drug treatment services (reflecting the current epidemiology showing a low rate of HIV infection in the IDU population). Prisons were described as 'an unknown area', although some patients do come from this context, having reportedly acquired HIV through tattoos, for example. Unfortunately, the review did not have the opportunity to discuss aspects of HIV service need with ADHB IDU services.

As in other DHBs, liaison psychiatry coverage was seen to be an issue in ADHB. Despite close liaison with the ID team, psychiatrists and mental health colleagues were perceived as working in very defined catchments, making acute engagement or referral more trouble than it is worth in terms of clinical requirement. SH cannot access liaison psychiatry because SH is an outpatient-only service; SH physicians therefore sometimes find themselves clinically managing mood disorders in HIV outpatients. SH noted that they prefer to enable referrals through primary care services, or liaise with community psychiatric services.

B. WAIKATO DISTRICT HEALTH BOARD (www.waikatodhb.govt.nz)

Infectious diseases

HIV service provision in Waikato DHB, which covers geographical areas from Turangi to Bombay, including Gisborne and the Bay of Plenty, sees a reportedly seamless collaboration between the Infectious Diseases and Sexual Health services, and other services relevant to HIV management. ID recorded 360 separate clinical contacts (clinic visits) for the approximately 160 HIV patients under their care during the 2009/2010 year. They report less than five inpatient events among the HIV-infected population in any year, causes for which would be made up of new AIDS diagnoses, treatment side effects and events in which HIV is incidental to presentation (for example microvascular angina or coronary artery events).

It was noted that an ID consultant was appointed in Tauranga in 2007 – 45 patients from Waikato transferred there following that appointment.

Waikato DHB moved its HIV services to a chronic disease model in 1996, and worked very closely with the NZAF office in Hamilton until its closure at the end of 2009. The process of closure of this office was described by Waikato clinicians as having begun five years earlier, when the NZAF sought to instil more formal working processes than had been the norm in the collaboration with Waikato DHB services – clinicians said that NZAF centrally did not endorse the flexible, multi-tasking, multi-service and multi-sector Waikato model.

This model had meant that patients in WDHB did not have to explain the story of their HIV status multiple times, because at the time of diagnosis there were often a number of health care workers (HCWs) from different but closely related services/departments present. There had been a sharing of roles and responsibilities across departments and even sectors. NZAF were central in this, particularly in providing longer-term social work or counselling backup for DHB services. For these reasons, clinicians said that ‘the NZAF removal was a big jolt and shift for us’.

In discussion of gaps in current service provision, ID identified:

a major gap between knowledge and practice – condom use is down and going down further. Even highly educated and experienced gay men are saying ‘I don’t wear condoms’ – HIV is no longer a death sentence ...

It was also emphasised that the Waikato DHB was presently not adequately resourced to cover the needs of PLHA in the Waikato. This reported inadequacy rested on there being:

- no funding recognition that service users have grown in numbers from 10 to 160 since the mid-1990s
- no long-term support of PLHA in the absence of NZAF, in terms of social work, mental health and other services. Counselling services are now under private sector short-term contracts only, and those providing counselling had, at the time of the Review, reportedly yet to be orientated to the specific issues of HIV.

Patients now have less frequent contact with clinical services (sometimes as few as once a year if clinically stable, whereas previously three-monthly visits were more common). Additionally, many clients do not access primary health care – so specialist services are taking on this function by proxy.

It was alleged that services were not reaching those at risk in terms of HIV and STIs. The need to focus on links between HIV and STIs (in the provision of information, in discussion with service users and in service delivery) was emphasised.

Despite these reported shortfalls in services and personnel, Waikato staff affirmed that the high quality of intra- and inter-service relationships lessened the impact of operational gaps.

Nevertheless, they highlighted difficulties in securing community engagement with HIV/STI prevention. As one physician put it, 'Community ownership is very difficult where there is no *visible* consequence to high risk behaviour.' Community ownership is also next to impossible when the behaviours being discussed are not acknowledged by target populations. The same physician noted,

“How can Muslim communities, for example, be encouraged to discuss HIV risks when any such discussion is avoided on the basis of its associations with ‘shame’, to the extent that blanket denial is the inevitable result?”

Sexual health services

Sexual health services in Waikato reflect the full spectrum of service provision seen in other SH services in the context of this review. A strong emphasis on collaboration with ID and other services has meant that services are widely available for those who need them, with the caveat that providing services to WDHB's wide rural catchment area brings particular challenges. For example, it was reported that although the Waikato MSM population is substantial, it is not integrated or internally coherent, as MSM populations are in New Zealand urban centres, for example.

The following services are provided by SH services, through self-referral or referrals from other agencies:

- cervical screening
- genital dermatology
- sexual dysfunction interventions
- genital pain syndrome interventions
- pre- and post-HIV test counselling
- ongoing management of ambulatory HIV positive patients
- emergency contraception, pregnancy testing and TOP referral
- education for medical students and related services
- advice for general practitioners and other health workers
- contact tracing
- surveillance of STI incidence, including collation and provision of information to ESR
- participation in Ministry of Health advisory groups.

The office of the New Zealand Prostitutes Collective, which is in Tauranga, encourages Hamilton-based commercial sex workers (CSWs) to attend the SH clinic in Hamilton –there is no perceived or requested need for an outreach clinic in the Collective's office.

There is a high level of operational collaboration between SH services and Family Planning services within Hamilton. SH receive many referrals from the FP clinic for STI treatment, and likewise refer patients with low STI/HIV risk but ongoing contraceptive needs to FP.

Reaching minorities

The Ministry of Health funded NZAF to train and provide African HIV/STI educators to reach African populations. However, in Waikato this reportedly led to a disconnection between community education and clinical experience. Hamilton African populations are mainly Muslim. Major tensions reportedly emerged within these populations because the presence of the health workers was

perceived as formally (if implicitly) acknowledging a link between HIV and STIs and what might be thought of as 'shameful behaviour'. Concerns were also reported about disclosing HIV vulnerability to persons who are from the same small community. It was suggested that such perceptions would act as an obstacle to engagement with HIV testing in that population.

The question of how to engage African populations is especially challenging. It was reported that, among both Māori and African populations in Waikato, stigma is a pressing obstacle to service engagement. On a practical level, creative and service-user-acceptable solutions have been found in some areas, for example the use of Language Line in anonymous translation for African service users.

SH services' considerable emphasis on contact tracing, and testing, and routine ANC testing has been institutionalised in WDHB. SH sees a narrow spectrum of heterosexuals – ANC sees a much wider spectrum.

When individuals are identified as being infected with HIV, Waikato DHB staff may speak to a patient's significant others and family members (with client consent). Waikato DHB described its use of 'highly effective behavioural education' focussed around HIV positive people, and its willingness to extend such activities anywhere they were needed – for example prisons, rest homes (where major STI outbreaks have been reported) and employers.

Data for evidence-based programming is wanting in a number of areas – for example, there is a lack of good data on condom use among the broad population. (Although there has been some research carried out: one school-based study by the Adolescent Health Research Group (2008) found that, among adolescents, 64 percent used a condom the last time they had sexual intercourse.)

In terms of recommendations for future investment, Waikato SH staff appreciatively emphasised that the Ministry of Health has been responsive to clinicians' requests over the years, for example in the provision of nevirapine, in addressing the issue of Zimbabwean refugees not being routinely tested and in the formation of the AIDS Medical and Technical Advisory Committee (AMTAC). The latter was seen as a needed forum and a useful pathway for addressing issues.

Waikato staff requested that acknowledgement be given to the fact that many community-based organisations (CBOs) do not fit comfortably within business models. This observation was particularly made in reference to the closure of the NZAF office in Hamilton, which is still keenly felt in WDHB.

Waikato's wish-list for future development included a perceived urgent need for enhanced training of trainers, to ensure the adequacy of interventions in sexual health education (Education Review Office 2007).

Six children in Hamilton are infected with HIV, and they receive care from Auckland because there are no paediatricians with HIV expertise in Hamilton. Commenting on this, one interviewee noted:

'When the previous paediatrician left, we realised what it all meant for families – the wider impact. That's where [support provided by] NZAF was so important.'

Accordingly, locally available paediatric ID specialist services are also on the wish-list.

C. CAPITAL AND COAST DISTRICT HEALTH BOARD (www.ccdhb.org.nz)

Infectious diseases

ID in CCDHB currently sees 250 people with HIV. ID also prescribes anti-retroviral (ARV) medications for PLHA under the care of SH services, as there is no registered prescriber in that service at present. Services in ID have reportedly evolved from a nurse-led service with one physician interested in the science of HIV to the current substantially more comprehensive department. The service is not an HIV-only service – they follow a generalist model, the only full-time staff member in the management of HIV/AIDS being the HIV clinical nurse specialist. HIV treatment drugs cost CCDHB \$2–3 million yearly; HIV staff costs amount to \$250,000. The service approach to HIV makes use of a chronic disease model.

CCDHB HIV services do not produce formal outcome reports, although contract reporting is undertaken for the Ministry of Health (covering numbers of viral load tests, HIV tests and neonatal transmissions; clinical monitoring; and complaints). Services are funded by contract volumes for outpatient services – laboratories and drugs are the identified items. CCDHB interviewees considered that a capitation fee would be a more viable approach to HIV services funding.

The efficiency of reporting processes was a recurring theme in the course of this review. Many services are self-evaluating, and reporting is largely service-defined. In this regard, one CCDHB physician noted:

We excuse ourselves from responsibility by saying [the Ministry of Health] has the overview. But we are not good at monitoring our deficiencies and need more active leadership in this regard.

It was agreed that the key role in the orchestration of all services for PLHA was that of the HIV clinical nurse specialist, who acts as a lynch-pin for the facilitation and coordination of required services, and also as a vital bridge between DHB and NGO community services.

Of course, each geographical area also has its own demographic characteristics. Defining the most at-risk populations (MARPs) in each region can uncover specific challenges. In Wellington, one specific issue is the relatively significant cost of translators. One staff member asserted that another issue was the tendency in many services towards ‘selective attention’: focussing in a local manner on issues that might have national implications. With resources spread thinly across the board, selective attention might well be an important survival mechanism employed by cash-tight services.

HIV services in CCDHB, as in all DHBs, have a considered and functional peer support structure. Despite – or perhaps because of – recent dramatic advances in HIV treatment, HIV diagnostic, management, preventive and cultural processes remain highly emotionally charged. One interviewee suggested that counselling, psychologists and psychotherapists for both staff and patients should come from outside. In this respect, the role of community-based services becomes part of the discussion. If, as was the case in Hamilton, NZAF is moving away from an integrated community support model, hospital services will need to continue to adapt and evolve, for example by enhancing DHB-provided psychological support and social work services.

Another common theme raised by CCDHB ID staff was the role of personalities in service development and maintenance. While this review is not qualitative, it must be noted how consistently this issue was raised. Personality issues, while possibly an artefact of a historically relatively small population of HIV colleagues, are clearly still a feature of the situation today. It was reassuring to note that staff in most services maintained very close – even collegial – relations within their own sectors, and frequently across sectors, too. Personality issues need to be addressed, to the extent that they might affect the quality or even quantity of service delivery.

The discussions in Wellington also raised two other familiar points of discussion: adequacy of mental health and social work service coverage for PLHA, and the importance of streamlining referral processes.

With respect to mental health coverage in Wellington, the following points were made by Professor Ellis:

“There would certainly be scope to extend psychological support and mental health services to more people if resources were increased, so that consumers would have a greater choice of clinicians and also of disciplines. Ideally, there would be a psychologist specifically attached to the clinic as well as a psychiatrist, for instance. A regular commitment of 0.1 FTE psychiatrist and 0.1 psychologist to the ID team would allow significant engagement with the ID team and other HIV services to better integrate care. An experienced MH nurse with counselling expertise (not just generic MH nursing skills) could supplement or even replace some of that time, and further extend choice for clients. In addition, there would need to be the capacity to respond to crises and urgent referrals, including of inpatients, as needed. The service we provide at present is unfortunately more a consultation than a true liaison one, albeit longstanding collegial relationships assist considerably ... It would be of considerable benefit to include a specific recommendation on the quantum of provision of secondary mental health services to people with HIV, within the context of consultation liaison psychiatric services in particular, and within mental health services more broadly as well. While mental health consumers have not been as vulnerable to infection with HIV as they have been in the USA, they are at greater risk and services need to address this.”

In view of these remarks, which were entirely consistent with opinions up and down the country, it would seem that the time is ripe for a broad discussion on appropriate benchmarks for mental health service coverage in the context of HIV services. The same could be said of benchmarks for social work needs in HIV care. In CCDHB, the current allocation of 0.2 FTE social workers for HIV patients was described as being wholly insufficient to address the level of issues raised in relation to, for example, housing and employment. In CCDHB, as in all other centres covered in this review, social work tasks are being undertaken by health professionals without the training or capability for such work. The consistently reported clinical fact is that the work is needed, as is the professional skill to carry it out.

CCDHB staff saw a fundamental need for service delivery integration at DHB (hospital) level – additional referral processes which take extra time, add uncertainty for patients and reduce clinical seamlessness need to be eliminated. This observation may have been in reference to the contracting out of SH services in the Wellington region, which has inadvertently led to some unforeseen complications in designing seamless service delivery (see below).

Gaps in ID services were suggested as resulting from the fact that the service is not regional – at present it does not receive region-specific funding. This could rectify, for example, the fact that there are no clinics in Hutt or Masterton, which would benefit from having their own services. It was also suggested that outreach to specific communities – for example Māori and Pacific Islands populations – could best be effected by channelling it through DHB services. In other words, CCDHB staff suggested that there be a re-design of prevention initiatives, starting with a regional discussion on how to ensure maximum impact through current service mechanisms, and how these systems need to evolve. An additional focus for future investment is adherence support for those receiving ARVs and HAART (psychological services play a significant role in this respect in some countries).

Sexual health services

CCDHB SH services are funded by the DHB but managed (under contract) by Compass Health. Referral access to hospital-based services is therefore occasionally impacted – for example, some hospital departments reportedly had difficulties liaising with a public specialist service sited outside the hospital. There do not seem to be adverse patient impacts, however. Indeed, SH reported some service-users express a reluctance to attend hospital services – the reason being that they feel they are less visibly identified as having HIV-related issues in SH (unlike in the ID HIV clinic).

CCDHB SH is a regional service – it covers greater Wellington, Kapiti and Wairarapa. It currently has about 20 PLHA on its books. As mentioned earlier, there is a productive and collegial symbiosis between SH and ID services, with the HIV clinical nurse specialist acting as the mortar between the blocks in keeping the relationship strong and functional, particularly in the realm of social services. There is a regular monthly meeting between SH and ID to discuss HIV cases.

The staff complement is as follows:

- 1.0 FTE SH physician
- 0.4 FTE SH physician seeing patients for HIV T&C, with no active HIV positive caseload
- 0.7 FTE ‘medical officer special scale’ (0.2 full-time equivalents see patients for HIV T&C, with no active HIV positive caseload)
- 1.0 FTE nurse, carrying out MSM screening and SH checks, and maintaining a close working relationship with the ID clinical HIV nurse specialist; this nurse also works at the Awhina Centre outreach clinic at NZAF
- 1.5 FTE nurses
- 1.0 FTE clinic nurse manager (0.5 clinical; 0.5 managerial).

The HIV clinical nurse specialist facilitates active liaison with ID in patient management. The SH service always encourages service-user engagement with primary care providers, though some service-users require primary care-type cover.

Similarly to other SH services reviewed, the Wellington regional SH service provides the following services for PLHA:

- T&C
- SH screening and care
- contact tracing
- counselling
- routine testing for all patients attending SH (for, among other things, HIV, syphilis and hepatitis B), and ongoing testing in high-risk populations (for example MSM).

The SH service collaborates closely with key NGO community-based services for HIV, including NZAF and FP. It runs a weekly sexual health outreach clinic with NZAF in the Awhina Centre, and there is now a very effective referral process in place to and from this Centre. Additionally, the SH service gets a lot of referrals from nurses at FP for example for warts and skin treatments). Some FP clinicians do HIV testing and some do not. SH also runs a weekly outreach clinic at the offices of the Prostitutes Collective.

SH staff asserted that, perhaps because of the regional mandate, there are currently too few SH physicians (SHP) in Wellington. This means that at some times there is therefore insufficient cover for teaching, leave or sickness – as in smaller SH services, cover (such as phone support) has to be

informally arranged with SH colleagues in other DHBs. There is no formal remuneration arrangement between DHBs for this practice. The ability to provide inter-DHB support more ably to smaller centres would be a significant improvement. Staff reported often fielding clinical phone calls from areas outside the CCDHB region: for example from Nelson and other smaller centres. On a per head of population approach, CCDHB SH are under-resourced in terms of specialist SHPs, and report that this is reflected in their clinic waiting list times .

Peer support for SH management is achieved through a national online SH peer group, which was described as very helpful. However, it is still the case that the most recommended thrust in terms of future investment would be in the area of training – perhaps through strengthened workforce development for SH, and the institution of a full-time training registrar.

D. CANTERBURY DISTRICT HEALTH BOARD (www.cdhb.govt.nz)

For this review, interviews were undertaken with the CDHB Infectious Diseases and Sexual Health services in Christchurch, staff of the Christchurch office of the NZAF, a self-selecting group of PLHA based in Christchurch and a number of individuals providing HIV support services in the community in Christchurch and Dunedin.

The Department of Infectious Diseases

The Department of Infectious Diseases has, at time of writing, 230 patients under its care. Patients are monitored regularly – from three-monthly to yearly, depending on their health status. The Department employs three consultants and one registrar working with PLHA.

Like many DHB ID and SH facilities, the Department finds itself acting as a primary care service by proxy for many PLHA. The reasons for this include the following.

1. It helps patients avoid the consultation fee that primary care services charge.
2. Patients perceive that the relative anonymity of a hospital environment may dissuade the assumption – in the eyes of their community – that their visit is specifically HIV-related. Hospital visits are seen as enabling greater privacy and confidentiality than NGO HIV service visits.
3. The ID department acts as a nexus for facilitated referral to appropriate specialist and other services – additional and related health issues can be coordinated and addressed efficiently, saving money and time for patients and staff.
4. Among Christchurch PLHA interviewed, primary care staff have a mixed reputation for quality of HIV management (validation of this widely held perception was beyond the scope of this review).

As is the case around the country, efficient inter-departmental and cross-sector collaboration in patient care in Christchurch is, to a substantial degree, dependent upon interpersonal relationships between key DHB and NGO partners. In the case of ID and SH services, there appears to be close collaboration and mutual patient-centred support. There is also reportedly close collaboration between these services and NZAF counselling services.

It will be interesting to see how collaboration with the NZAF develops following the soon-to-be finalised appointment of an NZAF-funded clinical nurse specialist to be based in ID, working in ID and SH and with community support services. The parameters of management responsibility and accountability appeared to be still subject to some negotiation during the period of this review, though what is certain is the clear need for such an arrangement, given the lack of funding available within CDHB.

Gaps in services were identified as the current lack of:

- an HIV clinical nurse specialist
- dedicated social work support
- specialist pharmacy support
- time within ID patient clinics to discuss non-clinical matters, such as behavioural HIV prevention.

Future investment recommendations included that there be funding made available for a clinical nurse specialist (although as noted above, this is soon to be funded by an NGO), a clinical psychologist, specialist pharmacist services and support for families, children and adolescents affected by HIV.

A need for a national conversation on engaging effectively with African populations was noted – issues of stigma, cost and other factors currently render African community engagement more of an unmet aspiration than a reality in the Christchurch experience.

CDHB staff mentioned the need to demystify testing and pre-test counselling processes in all communities, especially those most at risk. In Christchurch, testing for HIV is undertaken mainly in the SH service and in primary care surgeries.

Sexual health services

The Christchurch Sexual Health Centre provides a free, confidential, specialised service for all those affected by STIs, including assessment, diagnosis, treatment, education, contact tracing and counselling. HIV management is integrated into SH services, and the Centre currently sees 30 PLHA patients.

The service is led by a clinical director, a service manager and a clinical charge nurse, and has 2.7 FTE medical staff, 3.9 FTE nursing and health advisors and 2.5 FTE administrators. Peer and clinical supervision is reportedly very good: an online, invitation-only group of SHPs meets regularly for HIV case discussion and review.

The following services are provided by the Centre through self-referral or referrals from other agencies:

- an outreach programme to the New Zealand Prostitutes Collective
- cervical screening
- genital dermatology
- sexual dysfunction interventions
- genital pain syndrome interventions
- pre- and post-HIV test counselling
- ongoing management of ambulatory HIV positive patients
- emergency contraception, pregnancy testing and TOP referral
- education for medical students and related services
- advice for general practitioners and other health workers
- contact tracing
- surveillance of STIs, including collation and provision of information to ESR
- participation in Ministry of Health advisory groups.

Ongoing close collaboration between SH and ID occurs in the form of shared clinical management (for example, ID sees pregnant women with complications arising from HIV), and the services are linked through a weekly journal club in which HIV patient management is regularly discussed.

CDHB staff reported that HIV impacts on the ability of SH services to fulfil their mandate, because it takes up a significant proportion of staff time and resources. No service stock-taking has been undertaken to quantify this (although individual patient audits are a regular feature). In addition to patients' clinical status being routinely monitored through assessment of clinical indicators and viral load assessments, the Centre also carries out regular patient satisfaction surveys, eliciting patients' views on whether they were seen in a timely fashion, ratings of service quality, recommendations and feedback, and suggestions for service development. The Centre employs standardised patient data capture processes (using MedTech).

On a clinical level, the added value of providing testing through outreach programmes was reportedly unclear.

The following issues were reported as gaps or obstacles in service provision:

- dedicated ancillary services, such as psychology and psychometric testing
- resources – clinics are currently running at maximum operating levels
- responsiveness to cultural issues – for example for African patients
- stigma at community level, especially among refugees and recent immigrant populations
- the physical distance of SH services from other hospital services, including ID.

In terms of reaching all available populations, particularly in terms of HIV prevention, testing and follow-up, CDHB stressed the importance of focusing on Māori and Pacific Islands populations. There is a relative absence of statistical data on SH in these populations, but the importance of engaging them on sexual health issues is borne out by the recent substantial, dramatic increase in STIs among those demographics. The SH Centre has one staff member dedicated to Māori sexual health. One clinical question is whether the role is having a beneficial impact, or whether – as is the case elsewhere – stigma acts as an obstacle to effective implementation. It was reported that presently there is no budget or staff dedicated to health promotion in the SH service.

The SH Centre identified current and future needs as including:

- ensuring easier access to condoms – a prescription is currently needed to pay for subsidised condoms (144 per person for three months – no free samples are available for health promotion)
- a budget for health promotion
- social work support
- a clinical nurse specialist for hospital and community liaison in case management.

E. SUMMARY OF ISSUES EMERGING FROM THE REVIEW OF DHB SERVICES FOR PLHA

Key issues emerging from discussions with DHB staff in this review included the following.

Stigma in specific populations may be acting as an obstacle to testing for HIV, particularly in some African populations, and also to having populations engage in clinic and even NGO-based sexual health discussion. Interviewees made repeated reference to the crippling effects of stigma in indigenous and immigrant populations, and to the broader argument of how best to engage minority populations (including deciding which service provider is best able to do this). This issue appears to directly challenge the tenets of the Ottawa Charter, and was raised with such consistency that it may

be appropriate to initiate a national discussion on the theme. The issue is explicated in greater detail below.

The cost of visits to primary care services acts as an obstacle to PLHA accessing them. It results in ID and SH departments finding themselves acting as proxy primary care surgeries.

Mental health service coverage for PLHA is often inadequate, unless an individual has recently been diagnosed, is an inpatient or is actively or aggressively suicidal or violent. The availability of social work services is also very patchy (see below for discussion of the fact that NGOs often find themselves in the position of proxy social workers).

Evaluation of the quality of service delivery is largely absent in DHB HIV service provision. Patient surveys are usually belatedly carried out, and current reporting requirements do not have quality or impact components. DHB staff noted that NGOs do not necessarily fit comfortably in business models; another way of saying this is that NGO support can be difficult to quantify, although doubtlessly vital and depended upon by DHBs.

One DHB has recently collaborated with an NGO to create, in a new experiment, a key clinical liaison role to facilitate collaboration between the two entities. The impact and benefit of this strategy will become clearer over time. The concept is discussed further in the section on NZAF's services for PLHA, below.

2. NON-GOVERNMENT ORGANISATION SERVICES FOR PLHA

Material volunteered by NGO services in response to the structured questions with which they were provided (the 'Key Issue list') is presented in tables in Appendix 6.

A. NEW ZEALAND AIDS FOUNDATION (www.nzaf.org.nz)¹

The NZAF is the major HIV/AIDS NGO in New Zealand. As noted in the Introduction, the activities of NZAF cover HIV prevention and testing; sexual health clinics coordinating psychosocial follow-up services; and policy coordination, development and advocacy, including online and community engagement activities. This review focuses mainly on NZAF's 'Positive Health' initiatives – HIV and sexual health testing and follow-up services for PLHA.

The NZAF has been celebrating 25 years as a legally structured charitable trust in 2010 – it started in March 1985, and currently operates its administrative headquarters in Auckland, alongside T&C services in Auckland, Wellington and Christchurch. In 2010, The Foundation has a total of 39 staff (not FTEs), excluding seven administrative, information technology and finance staff. It supports six community-based workers nationwide and six national roles in communications, campaigns and technology, and has contract counsellors (the equivalent of 12 FTEs) in 15 centres outside Auckland. Although the staff complement (excluding 10 regular volunteers) is substantial, administrative costs are kept to under 18 percent of annual turnover. The NZAF is funded primarily (91 percent in 2008–2009) by the Ministry of Health on a rolling annual grant of around \$4 million, with a further \$400,000 coming from grants, fundraising, donations, bequests and other sources. In 2008–2009, 28 percent of the NZAF's funds were spent on Positive Health activities, 49 percent on HIV prevention and communications, 17 percent on national administration and 6 percent on research, analysis and information (NZAF Annual Report 2009).

¹ Information on websites for all NGO services reviewed in this report is presented in Appendix 5.

The NZAF is the only national NGO receiving an operating grant from the Ministry of Health, other than FP. Its services for PLHA are closely linked operationally with DHB services in Auckland, Wellington and Christchurch (and Hamilton, until late 2009). As such, it can be characterised as a nationalised community-based HIV service, which also acts in a facilitative relationship with sister HIV NGOs such as Body Positive, Positive Women, the INA Foundation and others who do not receive Government contracts.

At the time of this review, the NZAF was expanding its network of contract counsellors – qualified counsellors providing T&C for HIV, and a limited number of follow-up sessions. They reported contracting ‘therapeutic staff’ in Rotorua, Wanganui, Tauranga, Napier, Palmerston North, Greymouth and Dunedin, with recruitment and training processes planned in order to create similar roles in Hamilton (two), Mount Maunganui (two), Tauranga, Whakatane, Nelson, Taranaki, Timaru, New Plymouth and Invercargill.

A cornerstone of NZAF service provision is its adherence to known data – it works from a peer-reviewed, scientific evidence base in its provision of services for PLHA, and in its design of initiatives for the prevention of HIV. It has extensive systems in place for reporting, has its finances audited regularly and operates according to tried, tested and successful systems for internal governance (see Appendix 6).

Positive Health services summary

Positive Health provides what it calls ‘professional’ – as opposed to ‘peer’ – services. According to the NZAF, its staff specialise in advice and support on the following topics: living with HIV or AIDS, sexual behaviours, sexual health and safe sex, adherence to medication, sexual identities, gender identities, sexuality and sex issues, stress and burnout, relationship issues for HIV positive and negative couples, anger management, grief and loss, and self-esteem and anxiety. NZAF Positive Health services also provide:

- education and training for health and allied professionals
- sexual health screening: community-based HIV and syphilis testing (including in ‘sex-on-site’ venues)
- community-based free STI clinics in Auckland and Wellington, and on-site testing at a ‘sex on site’ venue in Christchurch
- counselling and psychotherapy for those affected by HIV – site-based in the NZAF offices in Auckland, Wellington and Christchurch, and through the network of contract counsellors currently being expanded throughout New Zealand
- advocacy for work issues involving HIV
- career guidance
- social work
- group work
- publication of *Collective Thinking* – a magazine for those living with or affected by HIV
- the Positive Speakers Bureau – a list of speakers living with HIV/AIDS providing talks to schools, workplaces, etc, as an element of HIV de-stigmatising and awareness-raising.

The NZAF also facilitates health-related grants through the Wellness Fund – a PLHA grant scheme with a cap of \$500 per application for dentistry, podiatry and other health interventions. NZAF staff also provide support in the following areas:

- HIV information pertaining to immigration

- liaison with clinicians on hospital visits
- provision of information about anti-retroviral medication
- adherence support
- psychosocial interventions, for example following new diagnoses
- a 'buddy' service.

The NZAF's testing and counselling services are contextualised by its drive for HIV prevention – all pre- and post-test counselling is aimed at risk-reduction, and conforms to guidance on counselling content suggested by the Ministry of Health (2008) and the latest World Health Organization (WHO) documentation (WHO/WPRO 2009). Rapid tests used by NZAF are also WHO- and United States Food and Drug Administration (FDA)-approved.

Service users and DHB colleagues alike interviewed for this review conspicuously and spontaneously praised the quality of NZAF counselling staff and procedures in all centres. All NZAF counsellors are professionally qualified and registered with the appropriate professional organisations (for example the New Zealand Association of Counsellors or the New Zealand Association of Psychotherapists), and externally supervised to New Zealand national standards. The NZAF also implements a sophisticated programme of internal monitoring and review of case management and case notes. Alongside its 12 FTE counsellor staff, it maintains an evolving cadre of professional volunteers, including third-year Auckland University of Technology students and student social work placements, and is currently considering making use of student nursing placements also.

All staff are inducted into a programme of NZAF-facilitated professional development.

Data from NZAF centres in 2009 reveals the following testing results.

1. HIV tests (22 positive results confirmed)

January–December 2009	First test	Second test	Total	% of total
Awhina (Wellington)	289	126	415	27.5
Burnett (Auckland)	546	218	764	50
Te Puawaitanga o te ora (Hamilton)	30	8	38	2.5
Te Toka (Christchurch)	217	85	302	20
TOTAL			1509	100

2. Syphilis tests (18 positive results confirmed)

January–December 2009	First test	Second test	Total	% of total
Awhina (Wellington)	273	104	377	27.5
Burnett (Auckland)	524	209	733	53.5
Te Puawaitanga o te ora (Hamilton)	26	5	31	2.5
Te Toka (Christchurch)	156	70	226	16.5
TOTAL			1367	100

Of those tested in 2009, 83 percent were male and 16 percent female (1 percent were non-identifying). 44 percent self-identified as homosexual, 10 percent as bisexual, and 43 percent as heterosexual. 54 percent identified as European, 15 percent as Asian and 14 percent as Pākehā; Africans accounted for 3 percent and Māori for 5 percent.

Auckland – Burnett Centre

Auckland has the largest HIV positive population and the largest gay population in New Zealand. In the region in 2009, 194 individuals received a total of 1677 counselling sessions. Up to five counselling sessions are offered initially, and decisions on increasing this entitlement up to a maximum of 15 sessions are made as required on a case-by-case basis. In 2009, 490 episodes of HIV support services were recorded for 133 service-users, including hospital visits (45 percent of the total), participating in case conferences (16 percent), advocacy (7 percent) and home visits (3 percent).

The Burnett Centre – which is effectively the operational arm of the NZAF's Positive Health services in Auckland – houses the northern and midland regional manager (one FTE) and an administration assistant (one FTE) to deal with calls relating to the two regional areas. A 0.5 FTE therapeutic leader (psychotherapist) is also based at the Burnett Centre; although this is a national position, the role provides oversight of the Centre and assists in recruitment of staff and student placements.

Therapeutic staff include 1.8 FTE counselling staff (two people), 0.8 FTE psychotherapist staff (two people) and 0.4 FTE (one person) as a paediatric social worker. This latter position is Auckland-based, as Starship Hospital covers most paediatric HIV nationally.

In addition to the HIV and syphilis screening carried out at the Burnett Centre, as shown in the tables above, the NZAF also operates a full sexual health screening programme at the centre, in partnership with ADHB SH services (as agreed in a Memorandum of Understanding [MOU] between both organizations). A similar service now operates in the Awhina Centre in Wellington, as does a 'sex on site' testing service in Christchurch – all under MOUs with the relevant DHBs.

In addition to screening and testing services, and counselling and support activities, like all such centres NZAF in Auckland provides the following services and activities:

- training on HIV for health professionals, medical and nursing students and New Zealand Blood Services, among others, and also for employers (they have also recently provided training to the Department of Corrections)
- a group established in the last year for female partners of HIV positive men – more group work is being developed for the 2010/2011 operational year
- access to information about treatments and availability of funding (the head of Positive Health is a member of the treatment officer network)
- lobbying for new medicines both directly with Pharmac and as part of the 26-strong NGO collation for access to medicines (ATM)
- staff of the Burnett Centre are members of International Rectal Microbicide Advocacy, and act as coordinators for national and international (Australasia and East Asia) Candlelight Memorials for the Global Health Council (for which the Positive Health director sits on the international board).

Management of the Positive Speakers Bureau has recently gone to tender with peer NGOs, as has publication of *Collective Thinking*.

Christchurch – Te Toka Centre

The Christchurch office currently employs six staff, including the regional manager (currently also acting in that capacity in Wellington), a receptionist, an outreach worker for African populations, a prevention specialist and two counsellors.

It is to be expected that the nature of interventions varies to some degree region by region. In Christchurch, NZAF staff make hospital visits to provide information packs for the newly diagnosed. These packs include basic advice on a variety of issues (such as nutrition). In this region stand-alone HIV testing tends to be discouraged, because of the correlation of HIV with STIs, so HIV testing is generally done alongside a full STI screen.

At the time of this review there was no clinical nurse liaison role in Christchurch. Counselling work tended to overlap with social work functions – the NZAF would accompany clients to DHB services, for example.

In Christchurch the NZAF has two counsellors, seeing about 90 clients each annually. The NZAF does not provide a crisis service as such, but says that it is flexible in attempting to provide appropriate assistance. Its first stated priority is the newly diagnosed, for whom it facilitates confirmatory blood tests and induction into DHB services.

NZAF contract counsellors also provide rapid tests to clients on request. They receive training on doing so in a two-day NZAF course run in Hamilton, and there appears to be a substantial appreciation among counsellors of the requirements of the testing process. Pre-test counselling and discussion includes assessment of motivations, discussion of health behaviours, discussion of meanings associated with the test, ensuring 24-hour availability of counsellor backup if necessary, obtaining written consent to the test, result-giving, answering questions and, if the test has been carried out less than three weeks after a potentially risky behavioural episode, requesting return for a re-test. In the case of a positive result obtained outside of the three centres with NZAF offices, the NZAF makes a referral to the nearest ID physician, and the nearest main NZAF centre is contacted for counselling backup.

It appears that the NZAF's planned employment of a clinical nurse liaison specialist for PLHA will be an extremely positive step forward, although at the time of the review some clarification was still required as to the clinical authority and line management responsibilities of this role. Creation of the role is an important demonstration of the value placed on DHB/NGO collaboration in PLHA care in Canterbury.

Wellington – Awhina Centre

The Wellington office currently has five staff, including a regional manager, a counsellor, two prevention staff and a receptionist. The small size of the office was felt to be an asset (as it was in Christchurch), and staff reported cohesive working relationships. As one staff member stated, 'We get strength from each other.'

The Wellington region has a considerable population of immigrant Africans – it was estimated by the NZAF African community worker that there were 2000 Somali in their catchment, along with 60 Zimbabwean families, 50 Congolese families and 50 Ethiopian families.

The Wellington office opened 25 years ago. It was initially independent, then became part of a national network. It has recently seen significant down-sizing, from six staff working on prevention down to two at the time of this review. Wellington staff described support (including budget management) from Positive Health management in the NZAF as 'very good'. They noted, however, that the expansion of contract counselling support was haphazard (this was reliant upon counsellors applying for support themselves, so to a large extent coverage was out of the control of the NZAF).

As indicated above, there is a strong culture of evaluation in the NZAF, involving surveys of service-users, annual audits of counsellors' client plans (in a process separate to that of ongoing external professional supervision), evaluations of workshops and record-keeping (for example of client sessions, events and consumables dispersed). There was, at the time of this review, some discussion about developing client entry and exit surveys.

A number of issues regarding procedural, relational and operational aspects of the NZAF's work were raised in the context of this review, as follows.

1. **Inadequate mental health coverage:** As previously stated, the NZAF does not see itself providing a crisis or long-term psychological or psychosocial service, other than during the crisis of diagnosis, or in a small minority of exceptional cases, even when the reality might indicate the need for such intervention. There are always exceptions to the rule, determined by clinical need. This issue is not, of course, unique to the NZAF or even NGOs – it was a feature of discussions with all DHB providers also, as well as with PLHA in focus groups created for this review.
2. **Primary care services patients coming to the NZAF for rapid tests:** Like DHB services, the NZAF is seeing people who choose not to visit their primary caregiver for HIV (and even sexual health) testing.
3. **Links with sister NGOs:** The NZAF has convening and advocacy authority that many of its sister NGOs lack – it wields the authority of 25 years of front-line experience and advocacy, it has the funding, and it maintains the networks within and outside DHB services. Given the operational limits of NZAF SH services delivery, a degree of 'friendly territoriality' can be detected among NGOs outside of the NZAF when it comes to defining the scope of PLHA services. While the NZAF remains the only Government-funded HIV NGO, it inevitably retains a position of paternal authority over its companion NGO services, and this may be raising avoidable tensions.
4. **Excessive expectations among the NZAF's constituencies:** It could be argued that the NZAF is somewhat handicapped by its ubiquity in discussion about HIV services. It has a substantial and respected footprint, but many service-users want more service support than the NZAF is able to provide. Many PLHA perceive that the NZAF is not providing the longer-term services for psychosocial support or mental health that they want. This may generate a degree of defensiveness that is unwarranted, given the NZAF's primary role of HIV prevention. That primary role, and the others the NZAF fulfils alongside the SH initiatives that Positive Health services provide, is simply not understood – and is therefore sometimes apparently resented.
5. **The need for external quality audits of NZAF PLHA services:** The NZAF has been the subject of regular external audits, but not of its process quality. Although the NZAF is following accepted national and international protocols in the delivery of T&C, its processes are subject only to self-evaluations (for example through service-users' surveys) and self-reporting. The same can be said of all other NGOs (and DHB services) reviewed for this report. It would seem timely to consider this as a foundation for the next generation of PLHA service delivery.

B. FAMILY PLANNING (www.familyplanning.org.nz)

Family Planning has been operating for 73 years. It is a not-for-profit sexual and reproductive health organisation, which has at its core, the mission of 'preventing unintended pregnancies, working to reduce STI rates, providing and advocating for quality sexuality education and professional development' (New Zealand Family Planning 2009, p. 7).

The focus of FP is on general sexual health. It identifies itself internally as a mainstream sexual and reproductive health service mainly for women (although approximately 5 percent of attendees at its

clinics are men). It is a specialist service for addressing these issues, offering a viable alternative to DHB primary care services. HIV is integrated into all aspects of FP's work, for example by the provision of HIV testing in clinics, as well as in the organisation's education, health promotion, advocacy and professional development work. Emphasis is given to sexual and reproductive health rights, and empowerment of women and girls in relation to these, including through HIV education. 60 percent of FP's health promotion activities target young people – through direct campaigns in schools, youth groups and outreach events, together with consultancy work in schools and the provision of professional training, for example of teachers. FP's adult health promotion often engages parents, making significant use of media, events and expos. FP has recently applied to provide medical TOP services.

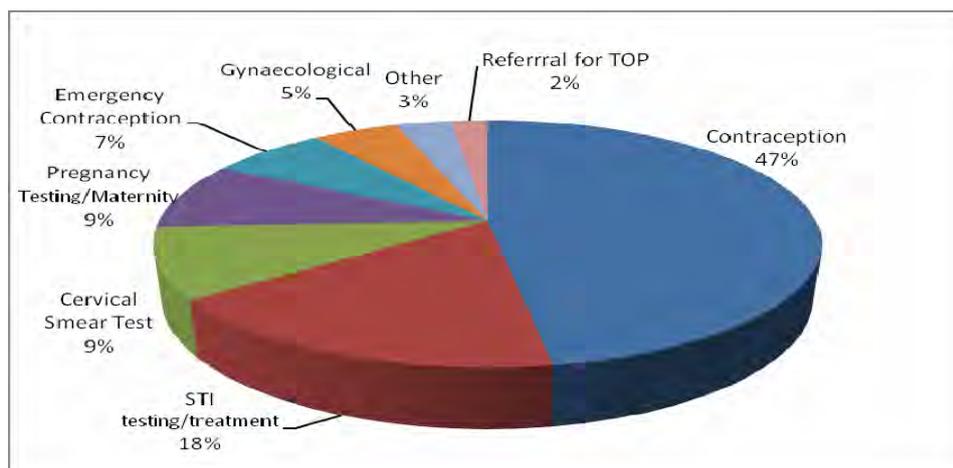
Nationally, FP has 33 clinics, with 280 staff, 22 of whom are full-time health promoters. 80 percent of FP funding (\$12–13 million) is from Government – approximately two-thirds is for clinical work, and one-third for health promotion. FP charges a co-payment for some service-users – services are free for those under 22 years, \$5 for Community Services Card holders and \$22.50 for all others.

Although FP offers diagnostic HIV testing as part of general STI screening in its clinics (and is participating in a pilot project on antenatal HIV screening in Hamilton), and promotes and distributes condoms as part of its general sexual health programme, it does not provide clinical care for PLHA; nor does it use rapid tests for HIV. When blood samples are taken for 'conventional' STI screening, clients are asked if they want to be tested for HIV also (the 'opt-in' model); if they do, they are sent to have their blood taken at the local laboratory. Occasionally, FP clinicians may refer a person to the local DHB SH service for T&C, though this is not the normal practice. Where people are found to have HIV infection, they are referred to the local hospital ID department for clinical follow-up.

During 2008–2009, FP recorded 180,000 client visits to its clinics, 95 percent of which were by females. Approximately 50 percent of those attending were under 22 years, and the most commonly cited reason for attendance was 'contraception'; STI testing/treatment was the second most-cited reason, accounting for 17.4 percent of visits (see Figure 2). In the same period, FP reported 60,000 health promotion contacts. According to FP data, 'Maori make up around 14 per cent of our total client numbers, Pacific Island people 5 per cent, and Asian people around 5.6 per cent.' The rest self-identified as European. FP uses the Office of Ethnic Affairs' Language Line translation service to assist clients who speak English as a second language: telephone translators protect client confidentiality (Family Planning 2009, p. 7). Given the pressure on services, clinic visits are much like those of primary medical care services – 10-minute encounters are the norm.

In discussing current gaps in services for PLHA in New Zealand, FP acknowledged that beyond the scope of services it provides, it could refer clients to further treatment and support services (albeit with limitations in some geographical areas). However, it expressed a clinically based concern about the lack of targeted and effective prevention for migrant communities, and for MSM.

Figure 2: Reasons for FP clinic attendance 2008–2009



C. POSITIVE WOMEN INC (www.positivewomen.co.nz)

Positive Women Inc (PW) is a community service for women and families living with HIV. It started in 1990, when a group of five women felt the need to assert a specifically female HIV identity rather than being subsumed under the umbrella of Body Positive, which, at the time, had a particularly gay male identity. Initially, it began as a series of peer-support unstructured coffee mornings, before eventually becoming an incorporated society in 2000. Currently, PW works with 140 HIV positive women, in addition to providing support to the children and families of women with HIV. It acknowledges that there is some membership overlap with Body Positive, and to a lesser extent with the NZAF, but it sees this as providing advantages from a service-users' perspective: 'We always recommend members to go to NZAF outside Auckland.' On the other hand, it is acknowledged that the relatively small number of PW's service users means they tend to struggle to obtain central funding support.

PW's aim is to provide support for women and families living with HIV, and 'to identify ways to empower women to go forward'. In fulfilling its mission, it has one full-time staff member, and is engaged in the following activities:

- support – psychosocial and informational, practical, accompanying, social work
- an annual women's retreat
- a biannual family retreat
- a regular newsletter
- a 24-hour 0800 number for information and advice
- a one-on-one support service –PW did not call this service 'counselling', but in a similar fashion to counselling it offers practical counsel and solidarity for women facing HIV-related concerns.

In effect, PW offers a broad range of individual and community support. The retreats were described by service-users as 'a huge thing' in the way that they enabled women with HIV to obtain immediate advice, mentoring, support and acceptance in an atmosphere of normalcy and confidentiality. Women interviewed saw this as especially significant because, in the context of a national epidemic with an overwhelmingly gay male face, 'Being a minority in a country of low prevalence is very isolating.' The downside of PW's operation as a small NGO with a national identity is that it can very quickly become consumed with day-to-day issues: capacity for crisis management or administrative response may become strained very quickly.

PW, like all the NGOs covered in this review, operates within the necessary architecture of an incorporated society or charity. It has a board of six members, each with a two-year tenure and a two-year renewal period. Board members act as contact points in Invercargill, Whangarei, Wellington, Rotorua and Christchurch. They are described as representing a diverse demographic mixture (youth, Māori and African), and have a wide range of qualifications, skills and experience. In this way, professional and effective representation is ensured, in keeping with the 'greater involvement of people living with or affected by HIV/AIDS' (GIPA) principle, as promoted by the Joint United Nations Programme on HIV/AIDS (UNAIDS).

Priorities for PW are set by the members and ratified by the board, and evaluations are a routine means of communication between the two. All meetings are evaluated, and full membership surveys were undertaken in 2007 and 2010 to help PW develop its directions and review the spectrum of activities it offers its members. The latest survey indicated a desire for greater emphasis on support of families. In response PW organised a family hui, which attracted 70 people and received enthusiastic reviews. Other feedback has indicated a desire to generate increased HIV behavioural awareness in the broader heterosexual community, in order to change perceptions of the infection, which is now in a chronic disease management era.

Bruning (2009) identified that reports of feeling isolated, unheard and marginalised among women with HIV were a surface expression of the deeper issue of these women living in an environment in which the focus on HIV continues to centre around MSM.

In this regard, PW undertook an HIV de-stigmatisation campaign in February 2008, featuring images on buses and in magazines of HIV positive New Zealand women, in-depth magazine and newspaper articles, and television and radio appearances. The campaign ran for six months, a follow-up television commercial running in September and October 2009. PW has also been very proactive in developing brand recognition in hospitals. It expressed a desire to develop such work in schools and in the context of youth HIV awareness (around the time of this review, PW published a document about curriculum-based education on HIV, adapted from a United Nations Educational, Scientific and Cultural Organization booklet developed in Australia (Positive Women Inc 2010)).

All PW's work fits with the HIV *Action Plan* (Ministry of Health 2003) – specific details are identified in Appendix 6. PW activities are also in line with the Millennium Development Goals, the United Nations' declaration of commitment to HIV and AIDS and to gender mainstreaming of HIV and AIDS (AIDS Accountability International, 2009).

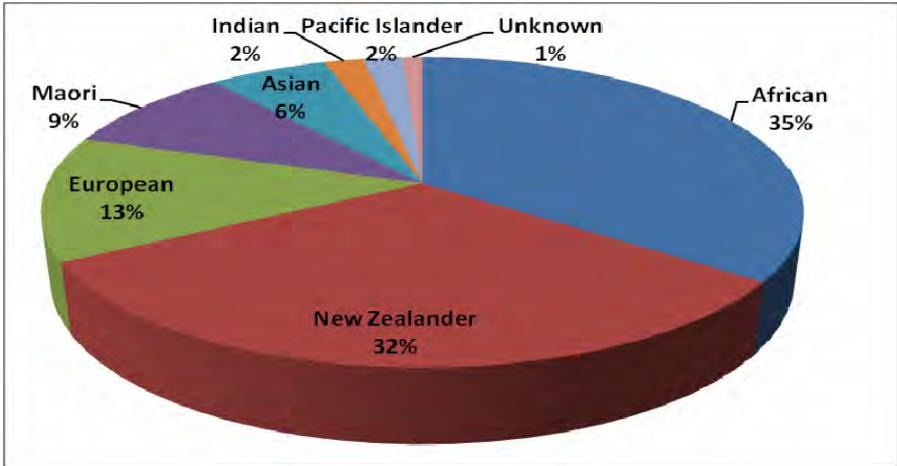
In terms of needs for future development, PW noted a number of issues, as follows.

- PW does not record a breakdown of the ethnicities it engages with on a daily basis, although it does record the ethnicity of members. However, anecdotally it reports increasing numbers of African service-users, which PW sees as an issue to be addressed.
- PW receives no funding directly from Government, and relies accordingly on grants from alternative sources. However, it maintains that it lacks the capacity for grant development.
- More funding is needed for PW's role in stigma reduction and awareness-raising among youth.
- Funding support is needed for day-to-day administrative issues, such as rent, costs of board meetings and audits (each costs \$3000 annually).
- Funds are needed to strengthen the capacity of the PW support network, and to maintain the national coordinator.
- PW would like to engage a social worker to assist with the increasing social needs of members.

As part of this review a focus group was held for PW service-users, and 12 women attended. These women identified support as the availability of ‘understanding, acceptance, recognition’. The group endorsed the sentiments of one member regarding peer support in particular: ‘Peer support is powerful because we know what it is like [to live with HIV]’. The group raised the following issues as cause for concern.

- Accessing HIV-related services through primary medical care surgeries – particularly for women with young families or those in a dependent benefit situation – is financially difficult (in Auckland, primary care costs \$42 per visit, not counting prescription charges).
- There is a need for greater availability of ‘social’ support facilities such as social workers and legal assistance, as well as mental health services. In-home outreach services would make life much easier for women with young families.
- Primary care practitioners vary widely in the extent of their knowledge of HIV: a free advisory service and hotline would save cost and time in this respect.
- Stigma and the fear of discrimination is a major concern, especially for Africans: one woman noted that ‘Africans get support from non-Africans [because of] ... fear of disclosure within African communities’. Life as an immigrant, having to self-fund treatment, offers specific additional challenges. PW was regarded extremely positively in this regard: one woman said ‘PWI is a listening ear when I need it. PWI are my family in New Zealand.’
- HIV positive women are reluctant to disclose their situation to employers, wary of fear-based dismissal. Occupational health and employment services need to be educated in this respect.
- Women are sometimes held to ransom by aggrieved or angry former partners threatening public disclosure of their status. The apparent lack – or ignorance – of a legal policy framework regarding confidentiality and manipulation of personal knowledge is seen as a significant problem.
- Mental health support at key times is currently inadequate – available only at diagnosis, or if women report feeling suicidal. Women interviewed characterised HIV as entailing a lifetime of consequence: the emotional burden of living – even healthily – with HIV was described as ‘really gruelling’. Without informed emotional and psychological support, one person stated, ‘All you can do is cry in your house.’
- Mothers with young children noted that information/education materials for children with HIV are very limited. Additionally, financial support for formula feed was identified as an important need.

Figure 3: Self-identified ethnicity of PW service-users, February 2010



D. BODY POSITIVE INC (www.bodypositive.org.nz)

Body Positive was incorporated in 1992, having evolved from the AIDS Support Network. The mission statement of BP is 'Peer support and advocacy for HIV positive people'. In fulfilling this mission, BP has three full-time staff, one part-timer and up to 12 volunteer staff at any one time. The board of BP ratifies the BP strategic plan and provides an internal governance function.

BP organises, facilitates and implements a wide variety of activities and services.

Clinics

- K Road Clinic – this is an HIV clinic within the Kiwi Health primary care medical practice, encompassing BP medical and other services, including the Aquamid facial filler clinic and HIV rapid testing.
- Aquamid facial filler clinic – this provides subdermal filling of facial areas to restore facial fullness (altogether, 78 people had been treated to the end of April 2010).
- HIV rapid testing – this occurs both at BP House and the K Road Clinic (statistics are discussed below).
- Kiwi Health primary health care practice – PLHA referred by BP receive free primary care consultations.
- Podiatrist – BP runs a monthly clinic offering 10 appointments at a discounted rate.
- Massage therapy – available two afternoons weekly at BP House.
- Psychiatric clinic – this is a monthly two-session clinic requiring medical referral, for which there is currently a waiting list of three months. BP provides follow-up dealing with any recommendations emerging from the clinical sessions, although counselling is provided only for those who are HIV positive.

Events

- Annual HIV+ Men's Retreat – a residential, three-day event featuring health and well-being workshops, and massage sessions. Over 70 people participate annually, and BP funds flights for men from all parts of New Zealand to attend.

Support

- 6 on 6 Peer Support Group – this group programme has run since 1995: newly diagnosed people meet weekly for six weeks to receive information, advice and support from visiting experts and trained facilitators.
- Community support officer and clinic coordinator – since 2008, the coordinator has overseen BP members' access to a wide variety of BP-mediated services, including those described here and other publicly funded agency services, such as those provided by Housing New Zealand and Immigration New Zealand.
- Staying Alive group – this is a health information and advice group raising awareness among BP members about correlative health concerns they may face.

Social activities/services

- Daily drop-in centre at BP House, 9–5 on weekdays.
- WINZ Satellite – a monthly satellite consultation service at BP House.

- Christmas dinner serving 100 or more.
- Free internet access at BP House.
- Vitamin bank – vitamins are sold at cost through BP.
- Food bank – this can be accessed at the City Mission through the BP services coordinator.
- Positively Living pot luck dinners – this is a monthly informal meal and discussion for up to 20 members.
- Straight Arrow Dinner – this is a monthly dinner for heterosexual PLHA, for up to 15 members.
- Naked Nutrition – this is an annual healthy-eating participative workshop.
- Budgeting service – this is a budget framework support service linked to WINZ benefits.

Publications

- In addition to its website, BP communicates with its members through the monthly *Positively Positive* newsletter (both in hard copy and electronically), providing up-to-date information and reminders of clinics and up-coming events; it also produces a regular insert in the *Express* newspaper.

In March 2010, BP recorded 375 visitors to the Body Positive Centre, along with 538 telephone calls and 71 calls for rapid testing.

BP is very much a peer support organisation, in that its administration, governance and direction are determined by those directly affected by HIV – all board members and staff are HIV positive. BP reports an ‘active’ membership of 419 persons: 92.6 percent are male, with an average age of 44 years and 7.4 percent are female, with an average age of 42 years. 16.5 percent self-identify as heterosexual and 83.5 percent as homosexual. Body Positive sees its function primarily in terms of care and support for PLHA, rather than prevention. It describes some complementarity with fellow HIV NGOs, for example through the Positive Speakers Bureau and the Wellness Fund (of which the NZAF are bursars).

BP receives no Government funding – all its funding comes from philanthropic organisations, making the organisation vulnerable to broader economic circumstances. The recent recession has led to three staff positions being disestablished.

Perhaps one of the most visible developments in BP’s recent history has been the provision of rapid HIV testing: on-site in BP House, at the K Road Clinic and in each of five ‘sex on site’ venues in Auckland. Between May 2008 and January 2010, BP conducted 496 rapid tests (93 percent of them for men, 7 percent in women), of which nine (1.8 percent) yielded positive results. BP’s data reveals spiking in numbers testing during specific campaigns and at times of national HIV-related controversy (for example the 2009 ‘HIV predator’ case in New Zealand).

The average age of those tested was 36 years among males and 30 among females. 69 percent of those BP tested self-identified as homosexual, 18 percent as heterosexual and 11 percent as bisexual. 61 percent self-identified as European, 16 percent as Asian, 9 percent as Māori and 5 percent as Pacific Islander. Eight of the nine positive test results were among homosexual men.

BP is of the clear view that the provision of rapid HIV tests is a necessary adjunct to the detailed pre- and post-test counselling that is the norm in rapid test provision in other settings, such as the Burnett Centre. By providing those who otherwise might never access formal HIV test services with the opportunity to be tested, BP sees itself having a vital role in developing HIV awareness and

supporting engagement with appropriate health and social services. BP reported identifying as many PLHA 'on-site' as NZAF has done nationally. It sees its accompanying/facilitative role for those found to be HIV positive through its own channels to be a crucial one – indeed, the spectrum of support services BP offers directly matches the needs that PLHA themselves express.

BP is a national service, but has a physical base only in Auckland. Its main national initiatives are the dissemination of information, the annual HIV+ Men's Retreat, the HIV Treatment Update (a day seminar) and its national 0800 helpline. There were no funds available for the establishment of branches elsewhere in New Zealand at the time of this review.

As a relatively small NGO with a very limited budget, BP reports being 'consumed with individual issues – it is difficult to take a step back to policy level'. Lack of resources impacts social work and counselling in particular.

All BP's activities and services are subject to internal evaluation and, in the case of the social worker currently employed, external professional supervision. Counsellors' protocols are peer-reviewed annually. All clinics and events offer evaluation forms.

Gaps

BP expressed the need for renewed support for the following:

1. outreach clinics for sex workers, immigration overstayers, Māori and others with HIV who will not engage with ID or SH, for whatever reason
2. treatment and funding support for treatment of lipodystrophy using Aquamid – BP report 200 of its members who need treatment (78 have been treated to date).

E. INA HIV/AIDS FOUNDATION CHARITABLE TRUST (www.ina.maori.nz)

INA was incorporated as a charitable trust in 2008, as a reaction to what the organisers saw as an lack of engagement of the NZAF with Māori men and women affected by HIV/AIDS. Based in Tirau, INA outlines its purpose in this way (INA 2009):

... to improve the quality of life for people living with HIV/AIDS Māori, indigenous and South Pacific and the quality of information about HIV/AIDS to the Māori, indigenous and South Pacific communities in Aotearoa. In particular, the [INA] Trust will:

1. ... establish programmes and prevention and intervention strategies specific to Māori, indigenous and South Pacific people;
2. ... establish effective support services for Māori, indigenous and South Pacific people living with HIV/AIDS, with culturally specific, culturally designed and sensitive programmes/projects.

INA is still in its development phase. There is one staff member paid on a part-time basis (but in practical terms working full-time) and a board that meets twice annually (and more frequently through Skype and the telephone). Experienced colleagues, volunteers and board members make themselves available when required by service-users. INA's capacity to develop has been dictated by available public funding and donations – lack of funding for national development remains its main operational obstacle. To date, INA has secured three grants totalling \$75,000 to fund its first years of operations, and has recently developed strategic performance indicators and operational documents (including a comprehensive business plan).

Despite INA's development constraints, it has already established a national presence, obtaining a place at the table at national forums and representation at national and international meetings. In its 2008–2009 Annual Report, INA reports having participated in the following consultation groups and conferences:

- Indigenous HIV/AIDS pre-Conference 2006
- International AIDS Conference 2006
- Indigenous HIV/AIDS pre-Conference 2008
- International AIDS Conference 2008
- International Indigenous HIV/AIDS Working Group
- International Indigenous HIV/AIDS dialogue advisory group to UNAIDS and Health Canada
- International Collaborative Indigenous Health Research Partnership advisory group Ngā Pae o te Māramatanga
- Pacific Alliance of NGOs and AIDS Ambassadors
- Healthcare Aotearoa
- National HIV/AIDS Forum
- Behavioural Blood Donor Review
- various research projects.

The Foundation has also been on the advisory committee of the NGO committee on the International Decade of the World's Indigenous Peoples.

INA hosted a training conference in 2009 – the first HIV Positive Māori, Indigenous and Pasifika Conference, which attracted 30 PLHA and whānau – and reported delivering HIV awareness wānanga to over 2000 whānau, hapū and iwi on 15 marae in the North Island in 2008–2009. It reports training 19 Māori PLHA as volunteers and providing support for over 80 PLHA and their whānau over the same time period. INA has worked to raise awareness through participation in documentaries, television and radio interviews and magazine and newspaper publications.

A core tenet of INA is its aim to change the prevention and support focus from 'those at risk' to 'the community'. In particular, it notes (INA 2009):

... the trend [in demographics of HIV/AIDS] is leaning towards a disproportionately higher rate of [HIV] infection [among indigenous populations than among] non-Indigenous people. The socio-economic cultural factors place these populations at increased risk of HIV/AIDS infection.

Accordingly, INA asserts the need for Māori and Pacific Island (MPI)-focussed services which MPI will relate to and attend, for MPI-focussed literature and, in particular, for a sustained approach to MPI that is whānau-based. The contention of INA is that as long as services are perceived as being 'gay', 'white' and 'in Auckland', most MPI will remain un-engaged. With STI rates among MPI currently causing serious concern, and with 'stigma keeping Māori away from health services', the INA asserts that the need for developing specific approaches for MPI is stronger than ever.

One key issue when considering the relevance and impact of various HIV services in New Zealand is whether a 'by Māori for Māori' approach to HIV will yield greater results than the status quo of determinedly bi-cultural services staffed with essentially non-Māori-speaking staff.

INA state that NZAF and other community-based services 'do not engage gay/bisexual Māori men and women, because the outreach and education programmes employed are not based on whānau'. The INA approach is a focus on Māori-speaking kaumātua. Emphasising the purpose of whakapapa protection from HIV and STIs, they assert, will foster whānau/community solidarity (including the

traditional whānau acceptance without shame of takatāpui). Additionally (M Pala, email communication, 21 April 2010):

INA believes that the medical care of HIV positive Māori must stay with the current Infectious Disease Specialist, maintaining confidentiality, health care etc. The whare tapa wha (Mason Durie) approach includes Whānau family, Hinengaro mind/mental, Tinana physical/medical and Wairua spiritual/sustenance. ID Specialists are key to the tinana physical/medical. Whereas whānau, wairua and hinengaro are not culturally catered for appropriately by non-Māori service providers. INA can help refer someone to mental/psychological support, and provide listening support, INA can help with providing information about HIV to whānau, hapū and iwi, as well as support the whānau affected by HIV and INA can help refer and direct PLWHA to where best suits their spiritual needs, i.e., tohunga, kaumātua, priest, pastor, rongoa māori ...

INA is developing a process called 'ohu mahi' – a cellular approach of training satellite educators who will engage with their targeted constituents nationally. At the time of this review, INA stated that they 'have people ready to go in the South Island, Wellington, Lower Hutt, Porirua, Tauranga, Taupo, Opotiki and Whanganui'. Within the network, HIV and STIs are addressed as a package: the topic of HIV is brought up as a means of getting 'a foot in the door'; INA educators then aim to normalise HIV as an issue for discussion by increasing understanding, providing testing and facilitating access to treatment among the constituent community.

This approach (which is currently lacking the testing and post-test components) is being employed within gangs, prison populations, and alcohol and drug users. Where necessary, ohumahi includes bringing in health staff from the Pacific Islands. INA wants to work with DHBs in partnership, 'as an equal partner in facilitating MPI HIV engagement'.

F. SUMMARY OF ISSUES EMERGING FROM THE REVIEW OF NON-GOVERNMENT ORGANISATION SERVICES FOR PLHA

Stigma and the Ottawa Charter

How can NGO services best engage with communities at risk to educate about prevention, when stigma and fear of disclosure seems so effective in keeping them away? Like DHBs, NGOs reported often observing great reluctance to engage with services, even when need was pressing. This issue is raised in detail in the conclusions below.

Varying approaches to HIV testing

It is interesting that rapid testing for HIV appears to be the province of NGOs in New Zealand (other than, occasionally, in ANC). Of course, in most settings, HIV is tested for in the context of broader SH screening, so a group of test samples is sent to a laboratory for assessment in the same package. Nevertheless, broad DHB/NGO division in the use of HIV test technologies; the differing nature of information and counselling available alongside testing; and the fact that contract counsellors may, in the future, be administering tests in areas distant from HIV experienced medical or social support facilities or personnel all point to the absence of a nationally coherent approach to HIV testing processes.

The *Futures 2* survey of 2008 indicated that of people who had tested positive in the prior two years, only 22 percent had received pre-test counselling, although 80 percent had received post-test counselling – 36 percent from a physician, 26 percent from NGO staff, 17 percent from a counsellor and 7 percent from a nurse.

Difficulties in maintaining quality responses to constituents' needs

Smaller HIV NGOs clearly struggle to deliver their core services in the face of limited capacity. The business of delivering PLHA support can often be interrupted by administrative, reporting or accounting tasks, or by the need to spend time raising funds, rather than doing what the funds enable! Organisations often stated that relatively small amounts of assistance would make a considerable difference – for example, obtaining funds to hire assistance in writing funding grants. Small but highly visible organisations may come under severe pressure to blur the boundaries of their service provision, with potentially very difficult consequences. Gaps in service coverage (for example in mental health or social work support) and limited resources tend to unhelpfully intensify case-work, and therefore stress.

NGOs being used as proxy services for primary health care, mental health and social work services

The fact that NGOs tend to be used as proxies for other health care providers is a result of the costs of those services. It is also a consequence of the high value clients place upon the services of current HIV NGOs, and the acceptance and trust those NGOs have built in their constituencies. The issue may also relate to a difficulty many PLHA have expressed in getting clear information about services and how to access them.

The need for a framework for external quality audits of PLHA services

Standardised reviews of service quality for PLHA are well overdue. All NGOs reviewed ensured they met auditing requirements and had evaluation procedures in place, but such surveys essentially produce only self-report outcome measures – they are not being held to externally agreed national or international standards for care and support, and consequently PLHA are not able to make informed choices about which services they access.

3. ADDITIONAL CONTRIBUTIONS FROM PEOPLE LIVING WITH HIV/AIDS

As part of its process, this review sought input from PLHA besides those incidentally running or working in services. Focus groups of 90–120 minutes were held in Christchurch, Wellington and Auckland, and a number of individual PLHA were also solicited for comments, or volunteered them.

Typically, comments pertained to themes that were generally echoed across venues, and were of a wide-sweeping nature, which disregarded expected regional differences (for example in the extent of services available).

The following consistent themes emerged.

1. **A lack of understanding about the multiple roles of the NZAF, and the limits that other NGO and DHB services may be subject to because of lack of funds or expertise, or for other reasons:** The main area of misunderstanding concerned perceptions of the NZAF's ability to facilitate longer-term mental health or social work support: confusion was also frequently expressed as to the logic and extent of prevention activities. This issue was clarified by one PLHA:

[NZAF's] emphasis on the Ottawa Charter means it thinks different communities should be supported in finding their own ways to deal with HIV, and the Prostitutes Collective and the Needle Exchange are both good examples of how that has worked successfully. Communities with smaller populations of HIV+ people don't have the resources to do this, and often blame NZAF for not doing enough for them. In fact the counselling and support services are open to everyone, but when it was established the Ministry of Health was clear that NZAF would use its expertise in

dealing with the MSM population, and Family Planning would undertake HIV prevention in the heterosexual world.

MSM make up by far the majority of all HIV infections, and most of them happen in Auckland. Which brings us back to the problem of a small population spread over a long narrow piece of land. How does one provide a full suite of services to HIV+ people in Temuka or Kaitaia? How do you deal with their expectations? Obviously it can't be done under current financial constraints, but people resent this, and blame NZAF for not being there for them.

Others bemoaned a supposed lack of understanding that appeared to diminish options for services focusing on their own constituencies: a typical view was that 'We need much more [practical] support, materials and information for women and for children.'

2. **A desire for a national PLHA forum, with paid staff coordinating activities for PLHA from all constituencies:** A forum of this nature would support PLHA meeting regionally, among other initiatives (possibly including administration of the Wellness Fund, led by and for PLHA). (The establishment of such a forum was announced during the preparation of this report.)
3. **The ubiquity of stigma about HIV:** Stigma has wide effects: in society in general, in groups most affected and at risk, and in groups of those infected. To provide one example, one interviewee commented that: 'It is very unsafe to say "I'm HIV+" in the gay community – you'll be ostracised and isolated [here] and outside.'

Many others mentioned the judgementalism of the communities they were a part of, making the perceived risks of disclosure too great, particularly if they were facing additional issues, such as decisions about their immigration status.

A large proportion of discussion about stigma concerned the challenge of disclosing HIV status to members of one's own community. African PLHA often said that they would not tell any fellow Africans their status, and would avoid being seen in any HIV-related group or services to which fellow Africans belonged or attended. According to interviewees, the impact of fundamentalist religion, the lack of integration of gay Māori within traditional gay frameworks, geographic specificity in prevention and support strategies and the pressure of social frameworks in small towns all also act as obstacles to overcoming stigma and effective engagement in community behavioural change. This prevented many people from regularly engaging with services they knew would be of benefit. One person commented: 'I don't tell anyone [about having HIV] in the rest of my life.' Another, by way of addressing the public, pleaded 'Make it okay for us to be visible!' Interviewees suggested HIV champions, HIV positive heterosexual characters on television soaps, and television advertisements, among other ideas, as ways of discouraging the association of HIV with MSM and ensuring a broad public awareness of behavioural risk.

4. **Praise for the quality of DHB-provided HIV treatment, care and support services:** Comments included 'brilliant', 'very impressed – absolutely fantastic, though administration is not always so good at maintaining appointment times' and '[in DHB services] we feel no stigma at all'.
5. **Praise and gratitude for NGO support services:** PLHA gave free and often emphatic praise to NGO services. In particular, they were enthusiastic about services that were able to address their issues quickly and facilitate ease of access. This appreciation was usually couched in the context of recognition that services cannot be 'all things to all people', and of the obvious geographic weighting given to PLHA in Auckland.

6. **The need for consistent targeted information for PLHA on available services, and for the general community on prevention strategies:** Comments included the following:
 - Knowledge of specific services needs to be increased – people don't necessarily know what's available. Primary care staff may have poor knowledge of services available for HIV and safe-sex information needs to be in more depth about the virus, its ease of transmission and consequences.
 - First communication [about HIV] has to be in plain language and simplified. We need greater information transparency and clearer definitions and terminologies.
 - I needed examples to help me contextualise information given.
7. **Rapid testing being seen as a licence for high-risk behaviour if not administered properly within a context of counselling and support:** One person said that 'Rapid testing is being used [in some venues] as a pre-risk licence, not a post-risk assessment.' Some also expressed concern that post-exposure prophylaxis could become the new 'morning-after pill', undermining initiatives to develop a condom culture.
8. **The need for training of primary care staff:** High primary care service fees and perceptions of low HIV competence among primary care staff were cited regularly as reasons why PLHA have been using DHB (and some NGO) HIV services as an alternative to primary health care. In some specific areas, such as management of treatment adherence, PLHA rarely if ever consult primary care staff.
9. **Insufficiency of mental health and social work services:** PLHA repeatedly stated that NZAF and SH counselling support was all that was available, and that this was usually short-term. DHB psychiatric and psychological support and primary care-facilitated assistance was too difficult to get unless people were 'suicidal or violent' or there were particular arrangements in place through NZAF contacts. PLHA noted that dual diagnoses and pre-existing conditions require more mental health intervention than is currently available.
10. **The need for targeted and continual prevention education across society:** Typical comments included the following: 'Safe sex is accepted but not practiced.' 'Current approaches are simply missing the target – there is so much unsafe sex in sex on site venues.' 'People forget everyone has a past.'

DISCUSSION

A review of this nature (and indeed, the terms of reference for this review) inevitably focuses on gaps, rather than successes. Nevertheless, this review has identified that services for PLHA in New Zealand are successfully reaching those for whom they are designed. It is acknowledged that the majority of PLHA services are in Auckland, the region hardest hit by HIV. However, there are gaps in the administration, monitoring and evaluation of PLHA services in Auckland, as there are elsewhere. One way to address current service provision for PLHA in New Zealand is to ask whether it is necessary and sufficient to address current needs. The answer, for now, is: Necessary, yes; sufficient, not yet. Aside from the obvious tensions associated with increases in STI rates in many parts of New Zealand, and with the reported current absence of a condom culture in those groups where HIV has hit hardest, this review has raised other issues.

Support means different things for different people. For PLHA, life with HIV is a continuum, and support needs vary according to the stage they have reached on that continuum. Absence of viral load or symptoms does not necessarily mean an absence of problems. It was evident that some PLHA groups had specific issues that they felt current service structures were unable to meet.

One of the main gaps in service provision for PLHA identified by DHB and NGO staff and service users relates to mental health coverage, particularly for those with longer-term psychiatric and psychological issues. A review of benchmarks for minimum MH service coverage in ID and SH services would be timely, as would an exploration of potential alternatives for MH service access for PLHA outpatients with chronic conditions, including dual diagnoses and pre-existing conditions.

Additionally, many health workers and NGO staff and service users identified primary care service fees as a major obstacle to PLHA making use of primary care services for HIV-related management not necessitating specialist secondary or tertiary services. In practice, PLHA are using DHB and NGO services as a proxy for primary care services, as a way of receiving free treatment. This could potentially cause a significant knock-on effect in clinic waiting times and resources. It would seem a significant and inexpensive solution to downsize primary health care fees for PLHA and perhaps their families, particularly those with young children.

All findings lead towards the suggestion that a national discussion about national guidelines and standards for HIV T&C is necessary, in the light of developments in HIV testing technology and the recent availability of testing outside of routine clinical settings. An aim of such a conversation would be to ensure that agreed standards are observed in all settings without diminishing the efficacy and outcomes of current efforts. Much discussion of rapid testing outside of New Zealand has been centred on concern over appropriate levels of training and capacity for administering tests, as well as pre- and post-test counselling and psychosocial support. This review could encompass such standards, alongside compatibility with established national and international benchmarks for HIV T&C.

Stigma was repeatedly mentioned as a major issue in the context of HIV in New Zealand. Stigma can be the cause of:

- reluctance to test for HIV among certain populations (including Māori in particular)
- reluctance of Africans to disclose their HIV status, particularly within their own communities
- reluctance of MSM to use community-based NGO services
- reluctance of PLHA to attend SH services
- reluctance to access primary care surgeries for HIV testing
- reluctance to use condoms
- reluctance to identify as gay or bisexual.

It is evident that stigma is the elephant in the waiting room of HIV public health responses – often invoked as the cause of sub-optimal population responses to prevention and support activities, yet hard to quantify or isolate by region or population.

There is some debate over how best to engage minority populations (and, correspondingly, who is the preferred service provider). One side of the argument is that a ‘by Māori for Māori’ (or a ‘by Africans for Africans’) approach is necessary to ensure the quality of engagement with those most at risk that would guarantee sustained, effective HIV/STI prevention and care. The other side suggests that the equal access guaranteed by current DHB and NGO services offers a greater degree of anonymity and confidentiality that is crucial. In other words, the impact of stigma differentiates health care delivery for HIV and SH from that of other conditions. One physician noted, ‘We are best placed to deliver [to minority ethnic populations] because of our place within the health service culture.’ Another noted that the presence of health providers outside traditional family and community networks encouraged engagement of some people with SH services citing the maxim, as has been quoted elsewhere, ‘you don’t know my auntie’.

The strength of the arguments on both sides is tempered by the limited data available for clarifying them. One example is the question over whether populations of Māori, or of Africans, and consequently their responses to HIV at an individual and community level, are homogenous. Many staff and PLHA asserted that they were not, and questioned public health responses relying on homogeneity as an assurance of expected ethnic responses. The experiences of Māori and African community personnel employed by the NZAF and DHBs have been difficult to accurately evaluate because of individuals’ often reported fear of disclosing their HIV status within their communities, either in or outside New Zealand. The power of this fear is doubtless compounded by the sense of vulnerability that is consistently reported among immigrant populations. It was also acknowledged that there was comparatively little literature focussed on Māori or African issues in SH.

Research into ‘conventional’ STIs offers a starting point for assessment of such issues. The recent chlamydia study undertaken in the Waikato (Morgan and Bell 2009), identified that equitable access to services was not an issue among Māori populations. In this study, Māori were as likely to be tested for chlamydia, but were twice as likely as non-Māori to test positive. Looking at patterns of testing in the various provider locations surveyed seems to suggest that equity of access had been achieved through initiatives to ensure access to free sexual and reproductive health services for all under-25s within the district. A Waikato DHB case management audit of 415 cases, 41 percent of which were Māori, found that time between diagnosis and treatment following a positive chlamydia result was equitable. However, a small number with untreated infections were more likely to be Māori than non-Māori.

The Hamilton SH clinic (who noted that ‘we only have data from people who come in to services’) reported that attendance is influenced by both perception of service staff competency and by whether such services are free or not. This study found that in general access was more affected by socioeconomic aspects than by ethnicity. This is consistent with the request from groups of service-users for HIV specialist services to provide essential primary care-type functions, because of the prohibitive costs of primary care.

While most adults are registered with a primary care practice, and at least 90 percent see their primary care physician at least once a year, data suggests this figure may be lower among those most at risk of STIs and HIV. For example, primary care data suggests that only 60 percent of 15–24 year-olds are engaged with a primary care physician. Also, recent data suggests that MSM often do not disclose sexuality to their general practitioners (Adams, McCreanor and Braun 2008).

Overall, then, given the reported ubiquity of stigma as a public health issue associated with HIV, it would seem a useful exercise to explore its parameters and the means of its maintenance in HIV management. A national conversation on stigma in health would enable a broad understanding of what it is, how it works and how it can be addressed. An action agenda can then be initiated to systematically take evidence-based experimental approaches with populations concerned. Unless stigma is addressed in a mature manner in the management of HIV, diagnostic, preventive, treatment and care initiatives and interventions will always be playing 'catch-up' as stigma effects are subsequently revealed.

In the course of this review, many comments were made regarding challenges for HIV prevention. This review was not asked to examine or assess the nature of HIV prevention services or activities in New Zealand, in terms of sexual, drug injecting or other potential risk behaviour. Nevertheless, because HIV prevention is inevitably linked to HIV care and support, and to stigma, education, gender, ethnicity, service provision and the Ottawa charter; because prevention was continuously raised in the context of this review; and because the contexts and outcomes of HIV prevention appear to be continually evolving, it would seem reasonable to consider a review of HIV prevention services in New Zealand in the future.

Although established research groups provide regular compilations of statistics and analysis relating to both HIV/AIDS and STIs (e.g., AEG, ESR, NZAF), New Zealand has no coordinated or comprehensive research agenda linked to HIV/AIDS or STIs. This means that there is a continual and pressing absence of data for policy and programme refinement, for example in relation to the almost mythic issue of the impact of stigma on HIV service engagement, or in relation to geographical and demographic differences in the availability, structure and effect of HIV services in New Zealand. Development of such an agenda with Ministry of Health backing would strengthen service delivery and the evidence base for service development. In addition, as part of the development of a national research agenda, a framework for external quality audits of PLHA services is needed – for both DHB and NGO PLHA services. Reviews of the quality of service processes and impacts are well overdue. It would seem timely to consider external standards as a foundation for the next generation of PLHA service delivery.

CONCLUSIONS

From the foregoing, some conclusions recommend themselves as a natural outcome of this brief review.

First, the Ministry of Health *HIV/AIDS Action Plan* (2003) is out of date and needs revision. The operational content of the plan needs to be strengthened and the activities it covers need greater definition, to enable greater specificity in benchmarking of performance against objectives.

In addition to this is the need for an action plan linked to the *Sexual and Reproductive Health Strategy*. Given the obvious and often-remarked link between STIs and HIV transmission, and the concerning increases in STI rates around the country, development of such a plan is a necessary component in terms of future HIV prevention and management. It would also provide an excellent opportunity for a coordinated process of reflection on prevention approaches and how they can be supported in this new decade, as a counter to the apparent behavioural complacency linked to community perception of HIV treatment successes.

Second, there is currently no coordinated strategy in place for research for policy and programme refinement in HIV/AIDS in New Zealand – this means that any research undertaken is opportunistic and incidental. The development of a national agenda for operational research for policy and programmatic strengthening should be a priority. Furthermore, evaluation of service delivery quality is absent across sectors. A framework for external audits is needed as a complement to existing financial and governance auditing mechanisms and self-report measures, and should be developed as part of a broader research agenda for HIV in New Zealand.

Third, repeatedly expressed concerns over levels of mental health coverage for outpatient PLHA highlight the need to establish benchmarks in this area linked to ID and SH services in particular, and to explore and identify options for increasing access to quality MH services and personnel among PLHA.

PLHA (particularly those with young families) often cited cost as an obstacle to accessing primary care services for many PLHA. In this regard, a review of primary care fee costs for PLHA is advisable. A review could have a significant effect on resources within outpatient ID and SH services for PLHA, since many PLHA currently use such services as a proxy for expensive primary care services. PLHA also made adverse comments about the quality of some primary care services: it is timely to review the reach and depth of core primary care staff training in HIV.

There are significant variations in HIV testing processes within and across sectors in New Zealand. Although New Zealand has its own national protocols for HIV T&C, these are not well known (at least to the majority of participants in this review). New Zealand is also a national participant in development and ratification of the standards and rights-based guidance published by WHO and UNAIDS. WHO and the Regional Office for the Western Pacific published updated guidance on HIV T&C last year, but the existence and content of this guidance was unknown to the majority of those interviewed for this review. A national discussion on standards in HIV T&C appears necessary. Such a discussion could also cover necessary training in administration of tests, protocols for pre- and post-test counselling and service backup, and compatibility with established national and international benchmarks for HIV T&C.

In view of consistent references to unquantified levels of stigma obstructing HIV-related prevention, diagnosis and care efforts, particularly within specific ethnic populations in New Zealand, the need for clarification of the impact of stigma on engagement with HIV services is urgent. A national conversation on stigma in health, examining experiences to date from a variety of perspectives and working towards development of an action agenda, would benefit operational responses to STIs and HIV/AIDS, and to other health issues also.

Finally, smaller NGOs with demonstrated records of service provision and defined constituencies are having difficulty coping. Even though their constituencies may be well-defined and relatively small, the demands of those constituencies are significant and growing, in terms of both practical and emotional needs. These NGOs need and deserve help. The Ministry of Health should consider core funding in each case to support sustainable, outcomes-based activities so these NGOs are not constantly distracted from their primary missions by the need to find funding for survival. Possible benchmarks could be implemented for providing funds to smaller community-based HIV support services.

APPENDIX 1: TERMS OF REFERENCE

REVIEW OF HIV POSITIVE SERVICE COVERAGE IN NEW ZEALAND

- Develop an HIV positive services review project plan and submit to the Ministry of Health for review and approval.
- Develop review methods (for example questionnaires/surveys) and submit to the Ministry of Health for review and approval.
- Undertake a review of identified key stakeholder organisations using the approved review methods and in accordance with the approved project plan.
- Submit a draft document and submit to the Ministry of Health for review and approval.
- Submit final HIV positive service coverage review document to the Ministry of Health.

APPENDIX 2: KEY ISSUES FOR ORGANISATIONS UNDER REVIEW

To be discussed with relevant senior staff and service providers:

1. IS THERE A CLEAR STATEMENT OF PURPOSE FOR THE SERVICE AND, IF SO, HOW WAS THAT DETERMINED?

- What type of service is it?
- Who is it designed to serve primarily?
- How was this determined?
- How long has it been in operation?
- Have the aims of the service altered during its history – and why?
- Is there a mission statement?

2. ARE THE AIMS AND ACTIVITIES OF THE SERVICE CONSONANT WITH APPLICABLE MINISTRY OF HEALTH POLICIES?

- Review alongside existing Ministry of Health statements about services for PLHA
- Does the service fill known gaps in public health service provision?

3. HOW IS THE SERVICE REGULATED INTERNALLY?

- Is there a board or similar oversight mechanism?
- Composition and how board members are appointed
- Involvement of PLHA
- Frequency and regularity of meetings
- Reported (and unreported) meeting outcomes

4. IS THE SERVICE STRUCTURALLY EQUIPPED TO MEET THE EXPRESSED NEEDS OF PEOPLE WHO ARE HIV POSITIVE?

- Are there sufficient trained and experienced staff?
- What do they do – what services are offered?
- How have they been trained / what are their qualifications?
- Is it conveniently located for service users and available at appropriate times?
- Is the service culturally appropriate and accessible?
- How is this determined?

5. BY WHAT CRITERIA ARE NEEDS OF PEOPLE WITH HIV PRIORITISED?

- How are these needs determined?
- How frequently are the needs reviewed?
- How is this done?

6. WHAT MAKES THE SERVICE EFFECTIVE AND RELEVANT FOR HIV POSITIVE PEOPLE?

- How many people use the service?
- For what reasons?

- Modes and frequency of communication with service users, members, constituents
- Processes of PLHA input to the design and operation of the service
- Challenges to service delivery

7. WHAT OBSTACLES – IF ANY – EXIST FOR POTENTIAL SERVICE USERS?

- Times, geography, culture, information, language, ideology

8. HOW IS THE SERVICE WORKING ON AN ADMINISTRATIVE LEVEL?

- Administrative capacity (staff numbers)
- Administrative needs
- Administrative strengths and weaknesses – how burdens affect outputs

9. HOW IS IMPACT, EFFECTIVENESS AND VALUE ASSESSED, AND WHAT HAVE THOSE ASSESSMENTS INDICATED TO DATE?

- Criteria employed
- Frequency and modes of assessments
- Evidence of data for policy

10. ARE THERE ANY GAPS IN SERVICE COVERAGE THAT NEED FUTURE INVESTMENT?

11. ARE THERE PLANS FOR SERVICE DEVELOPMENT OR EVOLUTION?

APPENDIX 3: CONTRIBUTORS

LOCATION	NAME	ORGANISATION
Dunedin	Nigel Dickson	AIDS Epidemiology Group, Department of Preventive and Social Medicine, University of Otago Medical School
	Sue McAllister	AIDS Epidemiology Group, Department of Preventive and Social Medicine, University of Otago Medical School
	Joan Greaves	Contract Counsellor, NZAF
Christchurch	Laura Jones	Regional Manager – Wellington and Christchurch, NZAF South Te Toka, Christchurch (and Awhina Centre, Wellington)
	Marian Hussein	Prevention specialist, NZAF South Te Toka, Christchurch
	Lisane Garbutt	Administrator, NZAF South Te Toka, Christchurch
	Hamish Milne	Prevention specialist, NZAF South Te Toka, Christchurch
	Victoria Riddiford	Counsellor, NZAF South Te Toka, Christchurch
	Brent Skerten	Counsellor, NZAF South Te Toka, Christchurch
	‘Michele’	PLHA, South Island
	Ray Taylor	Peer support organiser, Christchurch
	Richard Tankersley	Commissioner, Human Rights Commission, Christchurch
	A, B, G, M, N, N	NZAF Users’ Group, NZAF South Te Toka, Christchurch
	Edward Coughlan	Clinical director, Christchurch Sexual Health, Canterbury DHB
	William Pearce	Registered nurse, Christchurch Sexual Health, Canterbury DHB
	Alan Pithie	Chief medical officer, Infectious Diseases director, Canterbury DHB
	Maxine Wilkins	Clinical charge nurse manager, Christchurch Sexual Health, Canterbury DHB
Jane Chetwynd	Former chair, Public Health Research Committee, New Zealand Health Research Council	
Wellington	Ben Walter	Coordinator, Absolutely Positively Positive, Wellington
	Jackie Edmond	Chief executive, New Zealand Family Planning – Positive Sexual Health, Wellington
	Frances Bird	Director health promotion, New Zealand Family Planning – Positive Sexual Health, Wellington
	Grant Storey	Principal technical specialist (blood), Communicable Diseases, Population Health Directorate, Ministry of Health, Wellington
	Don Barclay	Administrator, NZAF Awhina Centre, Wellington
	Fungi Foto	Prevention specialist, NZAF Awhina Centre, Wellington
	Carl Greenwood	Prevention specialist, NZAF Awhina Centre, Wellington
	Debbie Langley	Counsellor, NZAF Awhina Centre, Wellington
	B, H, J	NZAF Users’ Group, NZAF Awhina Centre
	Timothy Blackmore	Professor of microbiology, Wellington Hospital, Capital and Coast DHB
	Peter Ellis	Professor of psychiatry, Wellington Hospital, Capital and Coast DHB
	Jane Kennedy	Clinical leader, Wellington Sexual Health Service, Compass Health
	Kylie Lahman	Clinical nurse specialist, HIV/AIDS, Wellington Regional Hospital, Capital and Coast DHB
	Jenni Masters	Service leader, Infectious Diseases, Wellington Hospital, Capital and Coast DHB
	Nigel Raymond	Infection Control and Infectious Diseases, Wellington Hospital, Capital and Coast DHB
	Richard Steele	Immunologist, Wellington Hospital, Capital and Coast DHB
	Catherine Healy	National coordinator, New Zealand Prostitutes Collective, Wellington

LOCATION	NAME	ORGANISATION
Hamilton	Kitty Flannery	Manager, Sexual Health Service, Waikato Hospital, Waikato DHB
	Graham Mills	General medicine and infectious diseases consultant, Waikato Hospital, Waikato DHB
	Jane Morgan	Clinical director, Sexual Health Service, Waikato Hospital, Waikato DHB
	Caroline Wharry	HIV clinical nurse specialist, Waikato Hospital, Waikato DHB
Tirau	Marama Pala	Executive director, INA (Maori Indigenous & South Pacific) HIV/AIDS Foundation
	Tony Pala	Board member, INA (Maori Indigenous & South Pacific) HIV/AIDS Foundation
	Apiaka Mack	Board member, INA (Maori Indigenous & South Pacific) HIV/AIDS Foundation
	Clive Aspin	Board member, INA (Maori Indigenous & South Pacific) HIV/AIDS Foundation (and at the Poche Centre for Indigenous Health, University of Sydney, Australia)
Auckland	Manaia King	Manager chronic disease, Health and Disability National Services Directorate, Ministry of Health, Auckland
	Warren Lindberg	Group manager, Public Health Group, Health and Disability National Services Directorate, Ministry of Health, Auckland
	Nohopuku Williams	Manager sexual health services, Health and Disability National Services Directorate, Ministry of Health, Auckland
	Linzi Jones	Portfolio manager, Family and Whānau Health, Public Health Group, Health and Disability National Services, National Health Board Business Unit, Ministry of Health
	Bruce Kilmister	Chief executive officer, Body Positive Inc
	Jane Bruning	National coordinator, Positive Women Inc
	C, D, E, J, J, J, K, L, M, N, R, W	Positive Women Users' Group, Auckland
	Ajit Arambalam	ADHB Fund and Planning, Auckland DHB
	Simon Briggs	Clinical director, Infectious Diseases, Auckland DHB
	Peter Church	Team leader, Ambulatory Health Services, Greenlane Clinical Centre, Auckland DHB
	Rick Franklin	Clinical leader, Greenlane Health Service, Auckland Regional Sexual Health Service, Auckland DHB
	Wendy Hoskin	Ambulatory services manager, Greenlane Clinical Centre, Auckland DHB
	Nicky Perkins	Clinical director, Auckland Sexual Health Service, Auckland DHB
	Murray Reid	Sexual health physician, Greenlane Clinical Centre, Auckland DHB
	Rachael Le Mesurier	Executive director, NZAF
	Simon Harger-Forde	Director HIV prevention and communications, NZAF
	Tony Hughes	Research director, NZAF
	Peter Saxton	Senior researcher, NZAF
	Eamonn Smythe	Director Positive Health, NZAF Burnett Centre
	Wayne Otter	Northern and Midland regional manager, NZAF Burnett Centre
A, J, J, J, M, M, P, P	NZAF Burnett Centre Service Users Group	
Michael Stevens	Former NZAF board chair	

APPENDIX 4: DOCUMENTATION REVIEWED

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APPENDIX 5: HIV NGO WEBSITE DATA

Organisation	Website	Total hits	Average hits per day	Total visitors	Average visitors per day	Comments
NZAF	www.nzaf.org.nz	53,850 from 10.09–05.10	254	19,794	93	Traffic: direct = 64%; search engines = 26%; referring sites = 10%. Content: fastest advertisement = 22%; administration access = 12%; general/free-condoms-lube = 3%; our services = 3%; about us = 2%. 35.5% are new visits.
Positive Women Inc	www.positivewomen.co.nz	25,206 from 02.10–03.10 inclusive	432	1,182	20	Average page views per visitor = 1.73
Body Positive	www.bodypositive.org.nz	Data unavailable	Data unavailable	Data unavailable	Data unavailable	Body Positive is moving to a new website where such information will be readily available
INA Foundation	www.ina.maori.nz	777 from mid-03.10–04.10 inclusive	17	105	2.4	Traffic: direct = 50%; search engines = 28%; referring sites = 22%. Content: about us = 15%; home page = 24%; services = 10%; links = 8%. 48.6% are new visits. NB: At the time of the review, the website had been operational for only 44 days.

APPENDIX 6: HIV NGO SERVICE REVIEW SELF-REPORTED DATA

A. NEW ZEALAND AIDS FOUNDATION

Inquiry	Response
<p>1. Is there a clear statement of purpose for the service and, if so, how was that determined:</p> <ul style="list-style-type: none"> • What type of service is it? • Who is it designed to serve primarily? • How was this determined? • How long has it been in operation? • Have the aims of the service altered during its history – and why? • Is there a mission statement? 	<p>Statement of purpose:</p> <p>Vision: A world without AIDS</p> <p>Mission: Preventing HIV and supporting people with HIV to maximise their health and wellbeing.</p> <p>NZAF’s vision and mission lead the overarching direction of NZAF services. These statements are reviewed and revised every five years by our members and stakeholders (including staff).</p> <p>Type of service: A community-based national ‘not for profit’ NGO, founded by a Trust Deed in 1985 and with charitable registration. The services are:</p> <ol style="list-style-type: none"> a) providing national, regional and local population based HIV prevention programmes targeted at the populations most at risk of HIV transmission. This includes social marketing campaigns through the use of social networking sites and locally based volunteer ambassador programmes to promote peer-based support to build a national condom culture b) community-based HIV and syphilis testing, professionally registered counsellor and psychotherapist services in Auckland, Wellington, Christchurch and through NZAF trained counsellors in Dunedin, Greymouth/West Coast, Palmerston North, Whanganui, Napier, Rotorua, Tauranga, Whangarei; further seven sites in development c) community-based free STI clinics in Auckland, Wellington and on site testing at a ‘sex on site’ venue in Christchurch d) research and analysis on the population with the highest risk of HIV transmission in New Zealand – MSM e) national library resource on HIV, sexuality and human rights f) policy guidance and support for policy makers in the public and private sector. <p>Who is it designed to serve primarily</p> <p><u>In HIV prevention activities:</u> In accordance with the Mission it is designed to maximise the limited financial funding (MoH contract and fundraising revenue) to have the greatest impact on HIV prevention by focusing on the evidence of the groups most at risk of HIV transmission in New Zealand – men who sex with men (MSM) and African communities (both migrants and refugees). The whanau, supporters, work colleagues and local communities of these populations are key targets in HIV prevention campaigns as evidence shows that those close to those most at risk can and do have a significant impact on their safe sex behaviour.</p> <p><u>Free HIV testing services:</u> This service is designed to be used by those most likely to be at risk of HIV transmission. This is primarily MSM and Africans but is utilised by a cross section of the public including heterosexuals from low risk populations. Evidence shows that for people who have an early diagnosis of HIV it is beneficial to their long term health and wellbeing. It is also advantageous for undiagnosed to learn of their diagnosis as it increases the probability of their not transmitting the virus to others.</p> <p><u>Free STI and syphilis testing service:</u> This is targeted at highly sexually active MSM as evidence shows that an STI can be both indicative of unsafe sexual practices and can increase the possibility of HIV transmission.</p> <p><u>Counselling and psychotherapy:</u> This service is available to anyone affected by HIV. Those living with HIV regardless of their profile, their whanau/family and supporters including children, women, transgender and heterosexual men.</p>

Inquiry	Response
	<p><u>Research, analysis, and library</u>: These services are designed to provide evidence of the HIV epidemic that can be used internally and externally to enhance the sector’s understanding of the HIV epidemic in New Zealand, ensure the services are evidence based and that our national response is based on sound analysis. The library is open to anyone interested in accessing the resource and is used by, among others, secondary and tertiary students, other researchers, media personnel and community leaders.</p> <p><u>Policy</u>: NZAF is able to utilise the research outputs, the analysis, the data and experience of the prevention programmes and the clinical services to gather evidence. The policy work provides evidence based submissions, comment and guidance to internal and external audiences to progress the HIV and AIDS Action Plan and in particular challenge HIV-based discrimination and stigma e.g., HIV and the work place, Immigration guidelines, access to treatments network.</p> <p>How was it determined?</p> <p>The Mission leads the core focus of the NZAF services.</p> <p><u>HIV prevention</u>: In 2009 a new HIV Prevention Plan was developed using a rigorous planning process, utilising the latest New Zealand and international evidence and incorporating the programme logic model.</p> <p><u>Positive health services</u>: 2010 is undergoing a similar new planning process investigating current evidence on HIV testing as a prevention intervention, counselling as an effective prevention mechanism and assessing evidence on New Zealand based PLWH needs to redesign the service to meet gaps identified and concerns of unmet need, i.e., African heterosexual HIV positive men.</p> <p>How long has it been in operation?</p> <p>Since March 1985 as a legally structured trust.</p> <p>Have the aims of the service altered during its history – and why?</p> <p>In the main <i>No</i> as the objectives of the Trust were drafted to ensure the focus was on HIV prevention and care and support for people living with HIV. However two areas of change in the 25 years have altered the understanding of the objectives of NZAF.</p> <p>a) In the early 1990s NZAF enabled and supported the growth of Body Positive. Initially providing a legal umbrella for the emerging group as well as funding, admin and infrastructure support through free offices etc. When BP became autonomous NZAF continued to provide support through rent free accommodation and admin assistance. The last grant provided to BP was of \$80,000 in 2007. Similarly with Positive Women – the seed grant of \$40,000 was provided by NZAF in 2004 to enable Positive Women to employ their first paid coordinator. The organisation has been supported with free/low accommodation and office support since the mid 1990s. The new role was then able to grow financial revenue to build a strong position of autonomy.</p> <p>b) NZAF has been supporting the Absolutely Positively Positive group and the group that emerged in Christchurch Poz Plus was supported.</p> <p>c) From the late 1990s NZAF had an unwritten understanding that in accordance with GIPA these support organisations would provide the lead on peer based support services for PLWHA through 12 on 12 support groups, annual retreats and advocacy by positive people for positive people. NZAF did not duplicate these services.</p> <p>Is there a mission statement?</p> <p>See above.</p>

Inquiry	Response
<p>2. Are the aims and activities of the service consonant with applicable MoH policies:</p> <ul style="list-style-type: none"> • Review alongside existing MoH statements about services for PLHA • Does the service fill known gaps in public health service provision? 	<p>Are the aims and activities of the Service consonant with applicable MoH policies?</p> <p>The MoH contracts our current services so have assumed the provider specifications are in accordance with their policies.</p> <p>The current NZAF Strategic Plan 2005–2010 was drafted with the HIV and AIDS Action Plan in view.</p> <p>Does the service fill known gaps in public health service provision?</p> <p>Yes.</p> <ul style="list-style-type: none"> • Yes NZAF is the only national community-based provider of HIV prevention programmes and free qualified professional based support services. • NZAF HIV prevention programmes are the only sexual behaviour population based programmes targeting most at risk populations – gay and bisexual men and Africans. • The only free service providing HIV experienced and trained, registered, professional counsellors offering experienced support for those diagnosed to assist with managing their HIV status including their ability to maintain safe sexual behaviour. • The only targeted HIV and STI testing/screening approach to the populations most at risk – men who have sex with men. • The only regular sexual behaviour surveillance research (GAPSS and GOSS) and a ‘centre of excellence’ in analysis of MSM and HIV essential to planning effective interventions. • The utilisation of the evidence and experience to propose policy changes to progress the HIV and AIDS Action Plan.
<p>3. How is the service regulated internally:</p> <ul style="list-style-type: none"> • Is there a Board or similar oversight mechanism? • Composition and how they are appointed • Involvement of PLHA • Frequency and regularity of meetings • Reported (and unreported) meeting outcomes 	<p>Is there a Board or similar oversight mechanism?</p> <p>Yes. The NZAF Trust Board monitors progress on the Strategic Plan, and receives reports on key performance indicators for operational activities. The Trust Board has sub committees that have governance oversight of:</p> <ul style="list-style-type: none"> • finance and administration • working with Maori • research and quality assurance • membership and fundraising • strategic plan and communications. <p>Composition and how they are appointed</p> <ul style="list-style-type: none"> • There are seven trustees. • Four are elected by the NZAF membership (300+ members) and three are appointed by the Trustees against a set of governance skills criteria. • The elections occur at the AGM. • There are two year terms to a maximum of three terms. <p>Involvement of PLWHA</p> <ul style="list-style-type: none"> • One of the skills based criteria for appointment is ‘an intimate understanding of people living with HIV’. Up until December 2009 there has always been at least one ‘out’ HIV positive trustee. • The Trust Board are working on developing advisory groups to the Trust Board. Current project is developing a roopu of advisers amongst Māori stakeholders. Next is to develop one for PLWHA.

Inquiry	Response
	<p>Frequency and regularity of meetings</p> <ul style="list-style-type: none"> • The Trustees set the meeting timetable each year. • For 2010 the full Board meets at five face-to-face meetings including at a meeting before the AGM as well as three Skype meetings. • The sub committees meet at least seven times a year by a mix of phone and face to face. • There is an AGM for members and trustees every November. • Special general meetings are called by members or the Trustees (two occurred in last four years). <p>Reported (and unreported) meeting outcomes</p> <ul style="list-style-type: none"> • The full Trust Board meetings and AGMs are formerly minuted and these are available for public access (though not yet on line). All members receive a copy of the AGM minutes. • Sub committee meetings are reported in the full Trust Board minutes. <p>Other means to regulate the service</p> <ul style="list-style-type: none"> • Ministry of Health reports. These are provided every six months and cover a wide range of reports against provider specifications. These reports are monitored by the contract manager. • MoH independent audit of service 2004 and 2006. • JRA work place Staff Satisfaction Survey – annual participants. • Strategic Pay Remuneration Survey – annual participants. • Charitable Registration and submission of audited accounts. • Annual external audit of financial accounts. • External HR consultant to review and update good practice in HR – annually. • Consultation on planning documents – always include key communities and partners including PLWHA organisations. • Planning and service review meetings of national directors and programme managers. <ul style="list-style-type: none"> – Monthly service review meetings of the national directors – Quarterly planning and review meetings for directors – Quarterly planning and policy review for managers and directors – Programme teams meetings for planning review six-monthly – Annual staff hui including annual operational review and planning. <p>Involvement of PLWHA</p> <ul style="list-style-type: none"> • Development of PLHIV advisory group for positive health services. On hold as work through concerns PLWHA groups have of individual PH service users being involved as considered a threat to PLWHA status • PLHIV staff throughout NZAF service. Their personal wish on the privacy of their status is respected and they are invited to contribute to service review and development in manner appropriate to their wishes. • Positive health services – consultation on service change/improvement – often results in non-consensus across PLWHA groups and individuals, i.e., Wellness Fund, Positive Speakers Bureau, Collective Thinking.

Inquiry	Response
<p>4. Is the service structurally equipped to meet the expressed needs of people who are HIV positive:</p> <ul style="list-style-type: none"> • Are there sufficient trained and experienced staff? • What do they do – what services are offered? • How have they been trained / what are their qualifications? • Is it conveniently located for service users and available at appropriate times? • Is the service culturally appropriate and accessible? • How is this determined? 	<p>Are there sufficient trained and experienced staff?</p> <ul style="list-style-type: none"> • Our positive health services are designed to deliver services by professional registered and qualified counsellors, psychotherapists, psychologists, social workers and clinical nurse specialists. Evidence of qualifications and registration is required. <p>What do they do – what services are offered?</p> <p>They provide:</p> <ul style="list-style-type: none"> • HIV and syphilis testing with pre and post test counselling as part of a prevention intervention to support safe sex behaviours • ‘new diagnosis’ support service through trained professional staff • support service for those with complex/multiple diagnoses • counselling and psychotherapy for anyone affected by HIV – gay, bisexual heterosexual, female male, transgender, children and adults • counselling and psychotherapy on issues such as sexual behaviours, sexual identity, transgender issues, relationship issues for sero-discordant couples • group work, i.e., partners of people with HIV • social work for children, families • training for health professionals, e.g., blood donor staff, midwives • advice on treatments, immigration, insurance, career development, access to financial assistance/grants. <p>How have they been trained / what are their qualifications?</p> <ul style="list-style-type: none"> • As above. NZAF provides training on HIV and key areas such as homophobia for new staff and annual updates through the programme hui. <p>Is it conveniently located for service users and available at appropriate times?</p> <ul style="list-style-type: none"> • In addition to three main centres in the three largest cities that are either within or near to the to the city areas where high risk populations have gathered there are eight small centres across both islands where subcontractors are available who are qualified, registered and trained by NZAF to deliver an HIV testing and counselling service. Further counsellors have been hired and trained in 2010 to eventually have up to 14 NZAF trained qualified and registered counsellors across all New Zealand regions. • New services are being developed to include sessions on urban marae, in churches and community centres. <p>Is the service culturally appropriate and accessible?</p> <ul style="list-style-type: none"> • Not extensively – close to the majority of service providers in a Tau Iwi primary care provider (i.e., GPs). • All recently qualified counsellors and psychotherapists study included a paper on cultural competency. • Small initiatives have been taken to improve biculturalism in respect to use of te reo and understanding of tikanga. • All positive health staff undertook a training session on cultural competency in 2009. • NZAF venues and office spaces have been reviewed and improved in respect to cultural competency. <p>How is this determined?</p> <ul style="list-style-type: none"> • There is a limited annual audit on skills and quality of counselling therapist service provided that touches on aspects of cultural competency. • This is under review and a draft Maori Responsiveness Strategy is about to be implemented.

Inquiry	Response
<p>5. By what criteria are needs of people with HIV prioritised?</p> <ul style="list-style-type: none"> • How are these needs determined? • How frequently are the needs reviewed? • How is this done? 	<p>By what criteria are needs of people with HIV prioritised?</p> <ul style="list-style-type: none"> • Primarily as defined by PLWH. • Also through feedback from HIV positive individuals who are NZAF clients, those who are not NZAF clients, PLWHA organisations and PLWHA key care and support providers such as ID clinicians and family members. • Research and published literature. <p>How are these needs determined?</p> <p>A number of sources of feedback on PLWH needs have been utilised:</p> <ul style="list-style-type: none"> • HIV Futures2 is an independent research that indicates PLWH service needs but was not specific to NZAF • NZAF undertook a client survey in 2008/09, whilst small the results closely matched HIV Futures2 • Wellness Fund 07/08 survey by PLWHA survey of criteria and process • Review of Collective Thinking audience needs 2006/07 • Review of Positive Health Services 2009/10 <p>How frequently are the needs reviewed?</p> <ul style="list-style-type: none"> • Every year on different aspects of the services. <p>How is this done?</p> <ul style="list-style-type: none"> • As above, surveys (including online), focus groups, consultations with PLWHA organisations, PLWHA staff, external contractors leading the project and others by NZAF staff.
<p>6. What makes the service effective and relevant for HIV positive persons?</p> <ul style="list-style-type: none"> • How many people use the service? • For what reasons? • Modes and frequency of communication with service users, members, constituents • Processes of PLHA input to the design and operation of the service • Challenges to service delivery 	<p>What makes the service effective and relevant for HIV positive persons?</p> <ul style="list-style-type: none"> • Varies greatly based on their specific need and how closely NZAF matches that need. <p>How many people use the service?</p> <ul style="list-style-type: none"> • See attached report for positive health services. <p>Modes and frequency of communication with service users, members, constituents</p> <ul style="list-style-type: none"> • Ongoing through the NZAF website – booking appointments, FAQs and emails re concerns etc. • Formal communication with individuals, health professionals, family members through the Collective Thinking magazine every four months. • Weekly informal phone and email communication with PLWHA organisations – some more than others. • Direct access for individuals to centres through 0800 freephone and direct emails. • Monthly communication asking for comment and input with PLWHA organisations and health professionals. • Weekly list server from NZAF library on articles and studies of interest to those registered. <p>Processes of PLWHA input to the design and operation of the service</p> <ul style="list-style-type: none"> • As described above and varies based on specific service/project. In some service development individuals with PLWHA are involved in initial service design before released for full consultation or a PLWHA is contracted to lead the review, or the PLWHA organisations are consulted on a proposal before it is formalised.

Inquiry	Response
	<p>Challenges to service delivery</p> <ul style="list-style-type: none"> • Most significant is the challenge in securing a coherent consensus on needs and service changes differing views of PLWHA organisations from each other as well as key PLWHA stakeholders who have disassociated from the PLWHA organisations. Purchasing a formal externally purchased research project such as HIV Futures2 is essential. Majority views do not ensure agreement for example Wellness Fund. Strong feedback to not devolve to a PLWHA organisation. • HIV is now a chronic condition with almost full life expectancy on treatments. A significant challenge exists in assessing what is reasonable for tax payer support when compared with other chronic conditions that have higher fatalities amongst specific populations groups yet may be less resourced. • Lack of MoH leadership in respect to chronic conditions and national public health direction.
<p>7. What obstacles – if any – exist for potential service users?</p> <ul style="list-style-type: none"> • Times, geography, culture, information, language, ideology 	<p>What obstacles – if any – exist for potential service users?</p> <ul style="list-style-type: none"> • Minority cultures and internalised HIV and homophobia/stigma in their communities for: African heterosexuals – particularly men; Asian homosexuals and heterosexuals. • The challenges of being a minority within a minority: sense of isolation through being small marginalised within HIV. Heterosexuals, children and families. • Young people who have grown up with HIV. • High need complex diagnosis gay and bisexual men – often high need existing before diagnosis. HIV complicating who is best placed to provide support and meet variety of needs. • Confusion on who is best placed as a service provider to meet the variety of needs. Uncertainty and competition. • Personal views of ID clinicians as who is best placed to serve and support PLWHA patients.
<p>8. How is the service working on an administrative level?</p> <ul style="list-style-type: none"> • Administrative capacity (staff numbers) • Administrative needs • Administrative strengths and weaknesses – how burdens affect outputs 	<p>Administrative capacity (staff numbers)</p> <ul style="list-style-type: none"> • 39 staff, not FTEs, excluding admin staff (10 regular volunteers – include student placements) • 7 administration, IT and finance staff • 1 Trust Board secretary (part-time). <p>Administrative needs</p> <ul style="list-style-type: none"> • Supporting three centres that have regular client visits (i.e., 2876 HIV and syphilis test clients in 2009). • Supporting six community-based workers across the country. • Supporting six national roles in communications, campaigns and technology. • Supporting one international development project. • Supporting finances processes for over \$300,000 accounts payable/receivable per month. • Supporting 300 membership and 400+ volunteers. <p>Administrative strengths and weaknesses – how burdens affect outputs</p> <ul style="list-style-type: none"> • Aim to keep administration costs to 18% or under. • Vulnerable at times of sickness or high demand. • IT and network time increased to full time.

Inquiry	Response
<p>9. How is impact, effectiveness and value assessed, and what have those assessments indicated to date?</p> <ul style="list-style-type: none"> • Criteria employed • Frequency and modes of assessments • Evidence of data for policy 	<p>How is impact, effectiveness and value assessed, and what have those assessments indicated to date?</p> <ul style="list-style-type: none"> • Assessing the impact, evaluating our effectiveness and valuing our services are a significant, complex and multi layered range of activities. It is an area of constant focus and improvement. • A major impediment to effective evaluation is the cost of external, expert, independent contractors not being budgeted/funded specifically by the MoH. • Another major impediment is the being very little benchmark data (i.e., no sexual behaviour survey of all New Zealanders since early 1990s, no funding for next HIV prevalence study, only pilot funding for a small sexual behaviour survey of African populations). <p>Criteria employed</p> <ul style="list-style-type: none"> • GAPSS and GOSS behavioural surveillance on sexual behaviour of MSM and attitudes to HIV with components surveying attitudes towards and recognition of NZAF interventions, e.g., maintenance of numbers reporting constant condom use between 2002–2008. • Early stages of cost/benefit analysis as data on tests and treatment costs become available. • Independent external research when able to purchase – i.e., Shore centre ‘Men Talk’ on non condom users. Included survey on attitudes towards NZAF’s effectiveness. • Client surveys, non-client surveys. • Close analysis of the New Zealand epidemiology where feasible and funded. • Dr Saxton’s PhD thesis including GAPSS and GOSS data. • External financial audit annually. • Charitable registration. • Ministry response to NZAF reporting against our Ministry of Health contract. • External MoH audits 2006 and 2010. • Whilst indicative only: <ul style="list-style-type: none"> – increase in client use of services especially HIV testing – increase in clinician referrals – increase in volunteers, members and supporter database – increase in visitors of new website – increase in ‘members’ for social networking sites – GiO, Bro on Line, facebook and beebo – increase in fundraising – increase in qualifications and appropriate skills sets of candidates for vacancies – increase in suitable candidates for election to Trust Board. <p>Frequency and modes of assessments</p> <ul style="list-style-type: none"> • GAPSS and GOSS data 2002, 2004, 2006 and 2008. • Ongoing analysis of research and published literature. • HIV Futures 2000 and HIV Futures2 in 2005/06 – no funding for future surveys. • HIV Prevalence study of sexual clinic attendees 2006 – no funding for future surveys. • External behaviour surveillance. <p>Evidence of data for policy</p> <ul style="list-style-type: none"> • GAPSS & GOSS Data 2002, 2004, 2006 and 2008 – informing and directing HIV prevention campaigns (Bullfighter 2007, Fuck buddies 2003, HIV prevention Plan 2009–2014). • Briefing papers provided by Research and Analysis Unit direct NZAF policy position – e.g., blood donor deferral policy. • Use of New Zealand and international literature and research studies accessed through NZAF library to inform policy – i.e., Public Health Bill submission.

Inquiry	Response
10. Are there any gaps in service coverage that need future investment?	<p>Yes.</p> <ul style="list-style-type: none"> • Funding for impact assessment, comprehensive independent evaluation of interventions, increased research investment. • Inadequate national leadership and strategic direction from governments – i.e., lack of support for Public Health Bill.
11. Are there plans for service development or evolution?	<p>Yes</p> <ul style="list-style-type: none"> • Evidence-based redesign of services for HIV positive people. • HIV testing to become part of prevention services. • Comprehensive evaluation of Get It On social marketing 2011–2014. • Maori Responsiveness Strategy for operational services (in draft after full consultation). • Ongoing development of advisory groups for operational and governance – Maori, PLHIV, African (already exists).

B. BODY POSITIVE INC.

Inquiry	Response
<p>1. Is there a clear statement of purpose for the service and, if so, how was that determined:</p> <ul style="list-style-type: none"> • What type of service is it? • Who is it designed to serve primarily? • How was this determined? • How long has it been in operation? • Have the aims of the service altered during its history – and why? • Is there a mission statement? 	<p>Our vision statement: “All HIV+ people living fully productive lives free from stigma and discrimination” Prepared by Board and endorsed by “members.”</p> <p>Body Positive offers a range of services all designed to assist PLWHA.</p> <p>All services are authorised by the Trust Board. BP Has been in operation since the late eighties (informally) and was incorporated in 1992. The aims and service have changed over times to respond to the changing impact AIDS has had on our community from funeral, bereavement to today’s planning for the future.</p> <p>Our mission statement is “Peer support and advocacy for HIV+ people.</p>
<p>2. Are the aims and activities of the service consonant with applicable MoH policies:</p> <ul style="list-style-type: none"> • Review alongside existing MoH statements about services for PLHA • Does the service fill known gaps in public health service provision? 	<p>All of the services we supply potentially reflect a failing on where MOH services are not delivered or not available (funded) or not able to reach.</p> <p>Our services are “peer” reviewed as well as consulted with relevant professionals in either “Sexual Health” or “Infectious Diseases” or other relevant professionals.</p>
<p>3. How is the service regulated internally:</p> <ul style="list-style-type: none"> • Is there a Board or similar oversight mechanism? • Composition and how they are appointed • Involvement of PLHA • Frequency and regularity of meetings • Reported (and unreported) meeting outcomes 	<p>The Membership of the organisation (all HIV+) elects the Trust Board annually. The Board employs the CEO. The Board develops policy.</p> <p>The CEO employs the staff and delivers programmes to meet policy.</p> <p>All programmes are evaluated and statistically reported to the Board.</p> <p>The Board meets on a bi-monthly basis.</p>
<p>4. Is the service structurally equipped to meet the expressed needs of people who are HIV positive:</p> <ul style="list-style-type: none"> • Are there sufficient trained and experienced staff? • What do they do – what services are offered? • How have they been trained / what are their qualifications? • Is it conveniently located for service users and available at appropriate times? • Is the service culturally appropriate and accessible? • How is this determined? 	<p>Yes</p> <p>No</p> <p>Please see the separate range of services available.</p> <p>Where external professional input is required we will seek consultancy arrangements and negotiate contracts.</p> <p>All services in Auckland are located to best position for our community.</p> <p>The Board seeks representation for Maori and currently two Board members are Maori.</p>
<p>5. By what criteria are needs of people with HIV prioritised?</p> <ul style="list-style-type: none"> • How are these needs determined? • How frequently are the needs reviewed? • How is this done? 	<p>Usually the need is identified by members and relayed to the management. A survey can be sent out and / or a paper prepared for the Board.</p>

Inquiry	Response
<p>6. What makes the service effective and relevant for HIV positive persons?</p> <ul style="list-style-type: none"> • How many people use the service? • For what reasons? • Modes and frequency of communication with service users, members, constituents • Processes of PLHA input to the design and operation of the service • Challenges to service delivery 	<p>It is determined for and by HIV people.</p> <p>Approximately 450 PLWHA use one or more of our services.</p> <p>We communicate with our members on a monthly basis with a newsletter. This is complimented with an electronic broadcast as well as a quarterly insert in “gay media”.</p> <p>Everything is designed and delivered by PLWHA.</p> <p>Challenges are financial.</p>
<p>7. What obstacles – if any – exist for potential service users?</p> <ul style="list-style-type: none"> • Times, geography, culture, information, language, ideology 	<p>Most services are only available from Auckland. There are limited national services. We find it difficult to reach out to “African” communities without sufficient resources to do so. When we have a service or project involving women we work with Positive Women Inc.</p>
<p>8. How is the service working on an administrative level?</p> <ul style="list-style-type: none"> • Administrative capacity (staff numbers) • Administrative needs • Administrative strengths and weaknesses – how burdens affect outputs 	<p>We are a small operation due to fiscal constraints.</p> <p>One person works on administration.</p>
<p>9. How is impact, effectiveness and value assessed, and what have those assessments indicated to date?</p> <ul style="list-style-type: none"> • Criteria employed • Frequency and modes of assessments • Evidence of data for policy 	<p>Statistical information helps provide an evaluation of the project coupled with members (consumers) feedback.</p>
<p>10. Are there any gaps in service coverage that need future investment?</p>	<p>Outreach clinic and testing in the community.</p>
<p>11. Are there plans for service development or evolution?</p>	<p>Yes we have developed a Strategic Plan and as funding is achieved we will implement plans.</p>

C. INA FOUNDATION CHARITABLE TRUST

Inquiry	Response
<p>1. Is there a clear statement of purpose for the service and, if so, how was that determined:</p> <ul style="list-style-type: none"> • What type of service is it? • Who is it designed to serve primarily? • How was this determined? • How long has it been in operation? • Have the aims of the service altered during its history – and why? • Is there a mission statement? 	<p>INA is a not for profit charitable trust with services and objectives of improving the quality of life for people living with HIV and the quality of information about HIV to our communities (mission statement). Providing, advocacy, education, representation, whānau support, and development training. Incorporating the whare tapa wha² approach to holistic wellbeing; physical, mental, spiritual and family.</p> <p>INA’s target communities are Māori, indigenous and Pacific Island, regardless of age, gender, sexuality. INA also invites all ethnicities to participate in our events, etc. INA was developed as an indigenous response to HIV and AIDS as what was expressed in Toronto 2006 by the ‘Toronto Charter’ placing Indigenous communities at the heart of the response to the epidemic. Officially, INA has been operating since February 2008. Unregistered, INA was a concept rejuvenated from members, of the Te Whānau Tautoko group that started in the late 1980’s. And has been operating without official capacity since that time. A change since that time was the Charitable Trust Act 2008 that provided avenue to a renaissance of Te Whānau Tautoko and a transition to the new name of INA.</p>
<p>2. Are the aims and activities of the service consonant with applicable MoH policies:</p> <ul style="list-style-type: none"> • Review alongside existing MoH statements about services for PLHA • Does the service fill known gaps in public health service provision? 	<p>INA resonates the principles portrayed by the Ministry of Health Policies of Whānau Ora and He Korowai Oranga by:</p> <ul style="list-style-type: none"> • working collaboratively with whānau, hapū and iwi with Māori to identify appropriate methods of encouraging safe sex practices and healthy sexual behaviours that leads to preventing and treating disease. By utilising traditional knowledge, experiences and historic references – Tikanga and Kawa – to build a base of knowledge that will increase health and wellbeing pertaining to sexual health for the protection of whakapapa against disease • having active participation by Māori living with HIV at all levels of the health and disability sector in decision-making, planning, development and delivery of sexual health services. By developing Māori providers and workforce capacity; as Māori educators, counsellors, therapists, leaders, and health professionals. Studies have shown internationally, that the inclusion of people living with and affected by HIV/AIDS has a significant impact on prevention and policy. INA focuses on developing Māori living with HIV as well as Māori affected and concerned about the HIV/AIDS epidemic • addressing the inequalities currently within the New Zealand HIV/AIDS health sector and improving services to whānau that are culturally appropriate, timely, of high quality and effective. Therefore reducing disparities for Māori and increasing wellbeing through the application of Rangatiratanga and Tikanga Māori • allowing Māori to take an active leadership role within the ‘Fight against AIDS’, Nationally and Internationally. Also within the government and its agencies; to achieve the aim of whānau ora within the broader determinants of health for Māori.

² Mason Durie.

Inquiry	Response
<p>3. How is the service regulated internally:</p> <ul style="list-style-type: none"> • Is there a Board or similar oversight mechanism? • Composition and how they are appointed • Involvement of PLHA • Frequency and regularity of meetings • Reported (and unreported) meeting outcomes 	<p>INA has a board of trustees/Rūnanga Whakahaere (eight members – no less than three, no more than 10), three Takatāpui/MSM, three PLWHA, five Māori, two Pacific Island, two non-Māori, one kaumātua. They are nominated and voted on to the board with criteria for skills specific to HIV and tikanga. Two meetings per year. With Skype and teleconferencing in between for anything that arises. Meetings are minuted and distributed to members with outcomes within the Kaiwhakahaere monthly report.</p>
<p>4. Is the service structurally equipped to meet the expressed needs of people who are HIV positive:</p> <ul style="list-style-type: none"> • Are there sufficient trained and experienced staff? • What do they do – what services are offered? • How have they been trained / what are their qualifications? • Is it conveniently located for service users and available at appropriate times? • Is the service culturally appropriate and accessible? • How is this determined? 	<p>Currently we have one staff member and 19 volunteers. The Kaiwhakahaere is experienced in NGO management, funding applications, education, development, administration, support and advocacy. She currently provides all the services for INA, over and above normal working hours. She has a National Certificate Reo Māori level 4, BML Administration, Adv Dip Business Systems, BML Māori laws and philosophy. She is also HIV positive for the last 17 years, a member and ex board member of Positive Women, and currently works with the International Indigenous Working Group on HIV and AIDS, supported by the Health Canada's International Affairs Directorate (Public Health Agency of Canada) and the Joint United Nations programme on HIV/AIDS (UNAIDS)</p> <p>The service is centralised in the South Waikato, close to Auckland, Hamilton, Te Awamutu, Bay of Plenty, Rotorua, Taupo, Taranaki. Is available for drop ins, and able to travel to people in the region.</p> <p>As a Māori service it operates within the auspices of Tikanga Māori. Acknowledging Te Tiriti, and principles derived from a Māori world view.</p>
<p>5. By what criteria are needs of people with HIV prioritised?</p> <ul style="list-style-type: none"> • How are these needs determined? • How frequently are the needs reviewed? • How is this done? 	<p>INA's services are determined by whakapapa and are inclusive of all Māori regardless of sexuality or gender. This innovation addresses the systemic changes that are needed to re-orientate and initiate a Māori response to HIV/AIDS.</p> <p>Both the care and prevention categories within the sector lack any whānau ora approach. There is no inclusion within the care category of complete mental health care, whānau/hapū support and/or education, or spiritual and/or rongoa Māori practices. There are no culturally approved or appropriate prevention messages for whānau, hapū or iwi. With complete a lack of emphasis on Rangatiratanga and the protection of whakapapa.</p> <p>This innovation supports a change of inclusion of whānau ora, through the integration of culturally appropriate services for care and prevention. The holistic methodology of including whānau, hapū and iwi in the design and implementation of prevention messages enhancing Rangatiratanga and encouraging the protection of whakapapa. With the reintegration of including whānau ora in the care of Māori living with HIV, This innovation encourages whānau, hapū and iwi within their own rohe to become active protectors of whakapapa.</p>

Inquiry	Response
<p>6. What makes the service effective and relevant for HIV positive persons?</p> <ul style="list-style-type: none"> • How many people use the service? • For what reasons? • Modes and frequency of communication with service users, members, constituents • Processes of PLHA input to the design and operation of the service • Challenges to service delivery 	<p>80+ people use INA’s whānau support services, with over 2800 people accessing the HIV education and training services since 2008. Modes of communication are telephone calls, internet services – facebook, yahoo groups, twitter, linkedin, emails, cell phone text messaging, mail outs, and our website.</p> <p>INA incorporates the greater involvement of people living with HIV. With PLWHA on our governance Board and as employees. The input on services and designing services comes directly from the PLWHA.</p> <p>The challenges to services delivery are:</p> <ul style="list-style-type: none"> • lack of available funds • the influence of larger organisations, drowning out the voice of Māori • constant struggle with data inaccurately captured • understanding a ‘Māori for Māori’ approach. Understanding the intrinsic values of being Māori and being empathic to Māori struggles • stigma and discrimination in communities • lack of HIV education to communities.
<p>7. What obstacles – if any – exist for potential service users?</p> <ul style="list-style-type: none"> • Times, geography, culture, information, language, ideology 	<ul style="list-style-type: none"> • As acknowledged in the literature, “the failure to routinely collect and analyse evidence about mortality and morbidity based on ethnic identity [...] is not just disappointing [...] it also potentially reflects institutional racism” (Graham, 1995). Although far from ideal, data from countries with more complete HIV/AIDS epidemiological programs may provide a foundation to research, prevention, treatment, care and support initiatives in other areas. • The AIDS Epidemiology Group began surveillance in New Zealand in 1996, ethnicity data was not initially collected until 2001. This data collected is flawed and inaccurate, has limitations therefore ethnicity is not recorded appropriately. Contributing to the lack of priority on the national and international agenda. • Marginalised communities are less likely to be counted because of; geographical isolation, and stigma and discrimination act as disincentives to disclose HIV status. • There are social and cultural taboos that prevent disclosure and safe sex education. • Māori women make up one-third of all women diagnosed with HIV in New Zealand since 1996. • Māori are over-represented in HIV prevalence – 11% of total HIV infections 2007. • Māori and Pacific Island people tend to present later within their HIV infection – with more AIDS-related illness and deaths reported. 68% of AIDS diagnosis are Māori and Pacific people. • Māori and Pacific children have borne a greater burden compared to the European child population, e.g., 1.0 – European ref, Māori – 4.5 and Pacific – 4.6.³ • Māori and Pasifika women are at a higher risk of infection in New Zealand compared to European women, e.g., 1.0 – European ref, Māori – 2.8 and Pacific – 3.3.

³ Updated ethnic analysis – 2/03/09 – AIDS Epidemiology Group.

Inquiry	Response
	<ul style="list-style-type: none"> • Lack of information, lack of access to culturally appropriate services, misinformation on HIV risks, no access to culturally tailored information. • lack of political or social power, low individual and community self-esteem. • Urbanisation/trans-Tasman migration, fragmentation of whānau, hapū and iwi. • Geographic isolation. • Poverty – Māori are disproportionately on low and very low incomes. • Poor general health – limited access to health care and resources, i.e., condoms. • Low literacy and numeracy – lack of education. • Māori have the highest STIs recorded population; 80% are Māori under 25. • Substance abuse – alcohol and drug addictions. • Discrimination within the community towards sexual diversity and stigma attached to that diversity. • Men that have sex with men are identified as <i>“the exact group most at risk of infection”</i> in Aotearoa, with national organisations stating <i>“HIV in New Zealand continues to be almost exclusively a disease of white men who have sex with white men”</i>.⁴ • Māori have lower rates of testing – test trials showed 3.9% tested identified as Māori. • The Treaty of Waitangi has been excluded or removed from national provider’s policies. • The Ministry of Health 2003 HIV Strategy acknowledges Māori as a vulnerable group, yet key national service providers bases all statements on the HIV epidemiology and claims that this shows that <i>“Māori are not adversely affected by the epidemic”</i>. National providers have stated <i>“Māori and other ethnic groups hardly feature on the radar ...”</i>.⁵ • Cultural determinants or whakapapa and the impact of HIV on whānau, hapū, and iwi are not considered.
<p>8. How is the service working on an administrative level?</p> <ul style="list-style-type: none"> • Administrative capacity (staff numbers) • Administrative needs • Administrative strengths and weaknesses – how burdens affect outputs 	<p>Administration is done by the Kaiwhakahaere. INA needs another staff member to do all the administrative duties. With only one employee, time gets consumed and priorities are given to support and education. Administration is done when all other duties are not as important. This burdens the organisation with less time to source appropriate funding. Volunteers help wherever possible.</p>

⁴ Quote from Gaynz.com 2/03/09 Racheal Le Mesurier(NZAF Exec Director) “Towards 2010: the NZAF’s progress”.

⁵ As above.

Inquiry	Response
<p>9. How is impact, effectiveness and value assessed, and what have those assessments indicated to date?</p> <ul style="list-style-type: none"> • Criteria employed • Frequency and modes of assessments • Evidence of data for policy 	<p>Outcomes are measured by short term, mid term and long term goals. Each programme that INA administers included a client evaluation and feedback form. When education seminars are conducted whether in partnership with other organisations or alone, INA is able to capture information relevant to results and performance, this is then collated and analysed for evidential reasons and funding. This data is then reported via minutes, reports and announcements.</p>
<p>10. Are there any gaps in service coverage that need future investment?</p>	<p>INA operates by donations and grants with \$75,000 received in our first year of operation. However, the following year, showed a significant decline in funding availability for our services. Issues facing funding for INA include; a small pool of funding available for HIV, other groups competing for same pool of funding, and the perceived ‘newness’ of our organisation. When speaking to funders, they appreciate the need for the service, but also voice concerns about lack of support from larger services that hold government contracts and MOH support.</p> <p>The identified gaps are the provision of culturally approved and appropriate services to Māori, indigenous and Pacific peoples. With emphasis on; Māori for Māori (PI for PI) education and awareness on HIV to the community – whānau, hapū and iwi.</p> <p>There are non-Māori specific services available to PLWHA; however INA recognised a gap for Māori for Māori support, whānau support, by being a member of the non-māori specific services. Regardless of where and when, the māori gravitated towards each other and grew in numbers, with the question of “Why don’t we have a Māori AIDS Foundation?”.⁶ This question was answered by Māori; women, men, Takatāpui/MSM, transgender, PLWHA, kaumātua, whānau, hapū and iwi – that the time has come to have a Māori AIDS Foundation. Hence the registration of INA (Māori, indigenous and HIV/AIDS) Foundation.</p> <p>INA is the gap and the need for future investment.</p>
<p>11. Are there plans for service development or evolution?</p>	<p>INA has a comprehensive business plan highlighting the capacity building and development of the services, including:</p> <ul style="list-style-type: none"> • continued training of PLWHA to be educators and advocates • HIV campaigns nationally for whānau, hapū and iwi using multimedia resources, and travelling road show • research projects • ohu mahi – development of key PLWHA graduates of previous wānanga to be satellite services throughout New Zealand; capacity building • develop communications strategy, to reach rural and remote areas, as well as urban. Incorporate Pacific Island AIDS ambassadors to educate their New Zealand resident Pacific peoples • source rapid testing, and provide voluntary testing and counselling • employ a whānau support coordinator to liaison and refer to other services, a Communications coordinator, an education coordinator, event coordinator and two HIV health promoters • employ a further mental health professional, HIV nurse specialist, administration team of three, and a research project manager.

⁶ 2005 Pan Pacific AIDS Conference, Māori Caucus meeting.

D. POSITIVE WOMEN INC.

Inquiry	Response
<p>1. Is there a clear statement of purpose for the service and, if so, how was that determined:</p> <ul style="list-style-type: none"> • What type of service is it? • Who is it designed to serve primarily? • How was this determined? • How long has it been in operation? • Have the aims of the service altered during its history – and why? • Is there a mission statement? 	<p>Positive Women Inc. has a clear statement of purpose for the service which was determined by its members (women living with HIV or AIDS).</p> <ul style="list-style-type: none"> • Positive Women Inc. is a support organisation for women and families in New Zealand living with HIV or AIDS. The organisation is also involved in HIV advocacy, awareness and destigmatisation. • It is designed primarily to serve women and families in New Zealand living with HIV or AIDS. Secondary purpose is to raise awareness of HIV through advocacy and destigmatisation to the general population of New Zealand but particularly to women and young people as we believe there is a gap in services here. • The organisation was first established in 1990 due to a lack of ‘women friendly’ services at that time. It became an incorporated society in 2000. The original constitution was produced by members at the time. • The principal aims of the service have not altered during its history however the mission/vision statement of purpose were reviewed by members at the AGM held in 2004 and the constitution was amended at that time to include families, limited liability clause and also included an increased focus on HIV advocacy, awareness and destigmatisation. • The organisation’s mission statement is: to provide a valued and proactive organisation for women and families in New Zealand living with or affected by HIV or AIDS. • Mission/vision and strategic direction is reviewed annually by members at the AGM.
<p>2. Are the aims and activities of the service consonant with applicable MoH policies:</p> <ul style="list-style-type: none"> • Review alongside existing MoH statements about services for PLHA • Does the service fill known gaps in public health service provision? 	<p>The aims and activities of Positive Women Inc. in-line with most relevant aspects of the HIV Action Plan 2003.</p> <p>1. Societal attitudes, values and behaviour</p> <p>Objective 1: Ensure HIV awareness and prevention training is a key component of sexual and reproductive health education and promotion programmes, particularly those targeting young people:</p> <ul style="list-style-type: none"> • talks in schools • HIV in Schools resource booklet for educators • Travellers Campaign 2006 • representation on HIV Forum and APA. <p>Objective 2: Decrease stigma and discrimination surrounding HIV and AIDS, page 24:</p> <ul style="list-style-type: none"> • destigmatisation campaign 2008 • media: TV, magazines etc which reach our primary target audience • presentations at schools, medical staff, conferences • workshops for PLHIV members at women’s retreat, family hui, digital story telling workshop, Positive Speakers Training, Australian Kidz Camps, WAD events (fashion show, MAC media), advocacy training. <p>Objective 3: Improve public health outcomes and ensure the protection of human rights and freedom from discrimination, page 25:</p> <ul style="list-style-type: none"> • representation on advisory groups, HIV National Forum, Medical Council, HIV Ante Natal Screening Programme, speak at conferences • destigmatisation campaign 2008. <p>Objective 4: Demonstrate leadership in, and commitment to, HIV and AIDS prevention and treatment nationally and internationally, page 26:</p> <ul style="list-style-type: none"> • member of HIV National Forum, APA, APN+, UNAIDS PCB NGO consultation group • other activities as listed above.

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	<p>2. Personal knowledge, skills and behaviour</p> <p>Objective: Ensure MSM, refugees and migrants from high prevalence countries, IDUs, sex workers, and PLHIV have the knowledge and skills to make safe choices and practise safer sex, page 27.</p> <ul style="list-style-type: none"> • PW's focus on women and families living with HIV as other communities covered by other networks. No need to duplicate services (don't have capacity anyway) ... • keen to work collaboratively with other networks (doesn't happen as much as we would like). <p>3. Programmes and services</p> <p>Objective 1: Improve access to and coverage of services, particularly for PLHIV, MSM, refugees and migrants from high prevalence countries, IDUs and sex workers, page 32:</p> <ul style="list-style-type: none"> • focus on women and families living with HIV as other communities covered by other networks. Services include Women's Retreat, Family Hui, Australian Kidz camp, Newsletter, 0800 number, website, Digital Story Telling Workshop, Positive Speakers Training, Straight Arrows, Resources (HIV and Pregnancy, Treat Yourself Right, HIV A New Diagnoses, HIV for Educators), Attendance to National and International conferences, one on one issues, i.e., immigration, court cases etc • PLHIV under-represented with no government funding at all. <p>Objective 2: Create pathways of care between preventative, primary and specialist health care, page 33:</p> <ul style="list-style-type: none"> • represent on advisory groups as mentioned previously • work with ID specialists and CHIV but with very little real effect. PLHIV networks not taken seriously and difficult to work with clinicians at times due to confidentiality issues. <p>Objective 3: Strengthen primary care services, page 34:</p> <ul style="list-style-type: none"> • Presentations with health care workers, midwives and at conferences but predominantly from a positive person's perspective to elevate stigma and discrimination and to help identify service needs for PLHIV. <p>Objective 4: Strengthen specialist and secondary care services, page 36:</p> <ul style="list-style-type: none"> • As per Objective 3. <p>4. Information</p> <p>Objective 1: Better understand the trends, page 38:</p> <ul style="list-style-type: none"> • falls predominantly under AIDS Epidemiology (whom we liaise with so as to keep up to date with trends). <p>Objective 2: Better understand the behaviours driving increase in HIV incidence and the trends in populations at highest risk of HIV infection:</p> <ul style="list-style-type: none"> • as per Objective 1. <p>Objective 3: Ensure surveillance is flexible enough to move with the needs and state of the epidemic, and can increase understanding of what works and inform planning for prevention and care:</p> <ul style="list-style-type: none"> • as per Objectives 1 and 2 • primary prevention strategies, page 4 • steady increase of number of people living with HIV who need care, page 4 • more recently women (heterosexual community) are making up a greater proportion of the annual numbers diagnosed, page 4. This has been repeatedly identified in AIDS New Zealand publications (1998 AIDS NZ (37): 2001 (48): 2006 (58), to list just a few) Yet New Zealand continues to maintain a primary prevention strategy which focuses on people at high risk (high risk individual strategy) (AEG website) as opposed to a Population Strategy.

Inquiry	Response
	<p>Positive Women Inc. also uphold and promote the Millennium Development Goals, the UN 2001 Declaration of Commitment on HIV and AIDS and the Greater Involvement of People living with HIV (GIPA), as well as aiming for a greater focus on women and gender mainstreaming in regards to HIV policy/strategy for HIV prevention, education and support.</p>
<p>3. How is the service regulated internally:</p> <ul style="list-style-type: none"> • Is there a Board or similar oversight mechanism? • Composition and how they are appointed • Involvement of PLHA • Frequency and regularity of meetings • Reported (and unreported) meeting outcomes 	<p>Positive Women Inc. is governed by six Board members elected by Positive Women Inc. membership at the AGM (see structure doc.)</p> <p>Current skill level of Board members are as follows:</p> <ul style="list-style-type: none"> • JM has been involved with Positive Women Inc. on and off since its very early days as a social support network. Her inclusion on the Board began in 06/2008. To this position she brings skills ranging from a nursing background, psychology degree and knowledge gained from attending courses on group facilitation and grief counselling. JM has travelled extensively both as an individual and as a flight attendant for a major New Zealand airline for many years which enabled her to interact with people from around the world and gain an understanding of different ethnicities and cultures. JM's background also includes four years as a volunteer counsellor for Youthline and working on health aligned research studies. • JW has worked as a registered nurse for the past 30 years from which she recently retired. Her time is now divided between talking to medical students and nurses on living with HIV, helping other women through Positive Women Inc. and volunteering as an ambulance officer. JW has been on the Board for three years and was one of the faces of the Positive Women Inc. destigmatisation campaign launched in 2008 and has been involved in a number of documentaries on HIV and women. She is also been involved with the BD group by doing a safety video for their safety in the work force training and is on the Antenatal HIV Screening Implementation Group in Oamaru and Nelson. • BR is of Māori ethnicity and has been a Board member for Positive Women Inc. for six years. Her background is in public awareness having worked for a number of government departments in this area and has been involved in volunteering, public awareness, Board support and community relations. BR is also actively involved with the community working with non-government organisations such as Trade Aid and community arts groups. As part of working for community organisations she has been a member on several boards so has had a lot of experience as a community board member. BR is currently a secondary school teacher. • PP, originally from Zimbabwe, has over 30 years' accounting, administration and supervisory experience. A mature and responsible person with a dedicated outlook, PP has been a board member for PWI for just over a year and is passionate about working with and making a difference in the lives of people living with HIV. • ED has a BSc (Hons) Psychology, MSc Occupational Psychology and is currently undertaking doctoral research in anthropology. Her skills include group facilitation, counselling, project management, report writing, recruitment, teaching, training/development, performance management/coaching, and computing (various software packages) were developed through a varied career in which the common threads are, working with people, communication, understanding different cultures, research and organisational development. In addition to her professional career culminating in the role of UK Human Resources Director for a multi-national organisation, she has worked as a volunteer in the UK, New Zealand and Africa with various charitable organisations, supporting youth/adults facing problems, orphans, bereaved children, children/ families of prisoners and disadvantaged communities.

Inquiry	Response
	<ul style="list-style-type: none"> • MF is 26 and has over two years' experience in human services as a caregiver, a support worker, and a teacher for people with children and adults with disabilities. MF has credits towards the National Certificate in Human Services, and holds a number of other certificates in this field of work. Other areas of experience include: <ul style="list-style-type: none"> – teaching ESL for 2½ years in Bali and Java, both online and in a classroom after attaining her TESOL Certificate and speaks fluent Indonesian – advocacy training on sexual health and reproduction and HIV – positive speakers training followed by a number of public speaking engagements on HIV awareness and prevention since completing the training – digital story telling workshop where she produced a digital story on living with HIV which has been posted on the Positive Women Inc. website and Youtube. – attendance at the ICAAP9 Conference in Bali – worked as a volunteer for Positive Women Inc. to writing a number of issues of the Positive Women Inc. newsletters and assisting with various administration duties. <p>MF has a particular interest in youth education around HIV and reducing discrimination and stigma for people living with or affected by HIV, particularly women.</p> <ul style="list-style-type: none"> • The current Board has a youth, Maori and African representative to ensure representation of diverse membership. • There is one Board member each in Auckland, Rotorua, Wellington, Christchurch and Invercargill to enable contact with members in regions. • Board meetings are held four times a year, every three months, plus AGM members identify needs (end) Board formalises overall governance structure/policies which is a combination of Carver's policy governance and Nyland's community model (means and end). • National Coordinator implements 'means ' to achieve 'end'. • National Coordinator writes monthly accountability report to Board. • National Coordinator performance review by Chairperson. • Minutes are made of all Board meetings and all members are permitted to attend Board meetings, although attendance of members is not funded by Positive Women Inc. • Annual audit by auditor. • Board member review. • Training as required when gap identified. • Governance training. • Treaty training. • MoU training. • Trust/working as an effective team workshop. • Annual report. • Funder accountability reports.

Inquiry	Response
<p>4. Is the service structurally equipped to meet the expressed needs of people who are HIV positive:</p> <ul style="list-style-type: none"> • Are there sufficient trained and experienced staff? • What do they do – what services are offered? • How have they been trained / what are their qualifications? • Is it conveniently located for service users and available at appropriate times? • Is the service culturally appropriate and accessible? • How is this determined? 	<p>Considering the current staffing situation, it is actually incredible just how much Positive Women Inc. are and have been able to achieve; however with the increase in women now living in New Zealand and particularly the diverse cultural mix, it is becoming increasingly difficult to keep up with the needs of our members.</p> <p>The National Coordinator is trained and experienced but not able to keep up with demand of service requirement as only one person. Need at least three staff. National Coordinators' qualifications include:</p> <ul style="list-style-type: none"> • Masters in Social Practice (1st Class Hons) • Graduate Diploma in Not for Profit Management • Advance Certificate in Adult Teaching • National Certificates 3&4 in Travel and Tourism. <p>Experience includes:</p> <ul style="list-style-type: none"> • six years as National Coordinator of Positive Women Inc. • eight years teaching students towards gaining national certificates in travel and tourism at tertiary level • 20 years' experience working in travel and tourism and management • the National Coordinator is a woman openly living with HIV. <p>Other areas where the organisation gains assistance are through:</p> <ul style="list-style-type: none"> • third year nursing students from Auckland University who do two projects a year • this year we are to have social work students from Unitec • volunteers not sufficiently utilised – too busy to stand back and do strategic managerial overview and time for training up volunteers.
<p>5. By what criteria are needs of people with HIV prioritised?</p> <ul style="list-style-type: none"> • How are these needs determined? • How frequently are the needs reviewed? • How is this done? 	<p>The primary aim of Positive Women Inc. is to provide support/services for women and families living with HIV ... <u>member needs are always number 1</u>. Secondary to that we look towards HIV advocacy, awareness and destigmatisation to the wider community but these also inevitable assist those living with HIV.</p> <ul style="list-style-type: none"> • Maintaining core services such as the Women's Retreat and Newsletter as these are the key communication/contacts for members with the organisation and each other. • Strategic direction/planning session at AGM each year. • Evaluations from Women's Retreat and Family Hui. • Service Questioner 2007 and 2010. • HIV Futures and 1-1 feedback.
<p>6. What makes the service effective and relevant for HIV positive persons?</p> <ul style="list-style-type: none"> • How many people use the service? • For what reasons? • Modes and frequency of communication with service users, members, constituents • Processes of PLHA input to the design and operation of the service • Challenges to service delivery 	<p>The service is effective because it is managed and run by women living with HIV (GIPA) ... and members are fully involved in all major decisions/strategic direction of the organisation.</p> <ul style="list-style-type: none"> • We listen to members ... everything stems from our members and is for and on behalf of our members ... i.e., women living with HIV. However can't please all of the people all of the time and don't always have the capacity to do what members want. • Sense of ownership for members ... although there will always be some people who do not feel fully represented and being a member of such an organisation is not for everyone. • Safe and confidential ... and nothing else available which is relevant for the needs of women and families. • A genuine understanding ... only those living with HIV are able to truly understand what it is like to be living with a stigmatising virus such as HIV. • Challenges to service delivery include limited capacity and insufficient funding as well as involvement and recognition from other HIV sectors.

Inquiry	Response
<p>7. What obstacles – if any – exist for potential service users?</p> <ul style="list-style-type: none"> • Times, geography, culture, information, language, ideology 	<ul style="list-style-type: none"> • Not enough staff resulting in members not always able to get hold of someone when calling the office (currently looking to employ a member support and administration assistant). A social worker would be ideal. • Not able to offer as wide a range of services as needed and not always able to assist as don't have the staffing or expertise but do. • Don't promote drop-in as staff too busy. • Only one office in Auckland, insufficient support for members in other regions. • Voluntary membership. Often scary for women to make that initial call. • Service not widely known / service not always recommended (by GP's ID specialist). • Perception [that PWI is] part of NZAF. • Not having own office or at least own entrance into office. Women not always comfortable having to walk through BP House ... can be a bit intimidating and not 'woman/family' friendly. • Support networks not social norm for some migrant communities. Need to increase ways of reaching these communities. • Migrant communities fearful of stigma and meeting others from their community who may also be members. Don't trust each other to maintain confidentiality. Migrants prefer/need practical help ... i.e., lift to hospital, food, baby milk formula, etc. • Some people don't like to be part of a peer support network as a result of their own perceptions and fears of being associated with such an organisation (peer support is also not for everyone).
<p>8. How is the service working on an administrative level?</p> <ul style="list-style-type: none"> • Administrative capacity (staff numbers) • Administrative needs • Administrative strengths and weaknesses – how burdens affect outputs 	<ul style="list-style-type: none"> • Under-resourced both from a personnel and funding perspective. • Systems and procedures derive from policies ... policy manual and procedures manual ... • Systems/procedures/policies not up to date, i.e., accounting and member registration systems outdated (currently being updated) and lack regular review of policies/procedures. • Lack capacity to engage in monitoring and evaluation. • Shortage of skills (accounts, strategy). • Systems fall behind, unable to offer the variety of services members need. • Need to increase networking/collaboration with other networks, unable to do as under-resourced.
<p>9. How is impact, effectiveness and value assessed, and what have those assessments indicated to date?</p> <ul style="list-style-type: none"> • Criteria employed • Frequency and modes of assessments • Evidence of data for policy 	<ul style="list-style-type: none"> • While some evaluations are undertaken, overall this is an area we need to increase our focus. • Research (Bruning 2009) identified women feel unheard, marginalised and that there is a lack of support. However not convinced that is what they truly mean as there are a number of support networks ... PW, BP, INA, APP, NZAF ... the real issue as was identified in research was that women feel isolated and unrecognised/unaccepted living in an environment where the focus on HIV continues to remain on MSM, and women continue to feel invisible. • Members would like more services, i.e. workshops for youth, networking for families with children living with HIV, Couples Seminar, Hetro Male Retreat/Seminar, Greater advocacy for women (family rights).
<p>10. Are there any gaps in service coverage that need future investment?</p>	<ul style="list-style-type: none"> • We need to look for ways to increase reach to Asian and Pacific Island women. • Focused support network for Hetro men living with HIV. • Sexual and reproductive health and HIV education in schools for both prevention and reduction of stigma which would assist PLHIV.

Inquiry	Response
<p>11. Are there plans for service development or evolution? YES.</p>	<ul style="list-style-type: none"> • About to employ member support and administration assistant. • Positive Women Inc. would like to have their own 'women and family' friendly space as we currently share space with Body Positive which is not a conducive environment to encourage drop in for women and families. • Looking to further utilise volunteers (once have more staff). • Looking to increase collaboration and partnerships with other networks working in similar sector. • Would like to have staffed outreach offices in Hamilton, Wellington and Christchurch. • Youth Road Show, destigmatisation project for WAD 2010 (community poster exhibition).