

NAPWA CARE+SUPPORT AUDIT

# literature review

Scott Lockhart, National Portfolio Coordinator

November 2007

# WHAT ARE THE CONSIDERATIONS OF THE SOCIAL DETERMINANTS OF HEALTH FOR THE HEALTH AND WELL-BEING FOR PEOPLE LIVING WITH HIV/AIDS IN AUSTRALIA TODAY?

## INTRODUCTION

The NAPWA HIV Living Unit has, for the last two years, been conducting an audit of the changing care and support needs of people living with HIV/AIDS. This literature review was commissioned as part of the audit to examine relevant research centring on the social determinants of health and the consideration of these for the health and well being of people living with HIV/AIDS.

Literature reviews generally identify a topic for review, across a nominated timeline, within a selected jurisdiction (i.e. regional, national or universal coverage), reviewing the literature and relevant documentation collected from a wide variety of sources. As the purpose of this review is to provide supportive information to the NAPWA care and support audit, distinctive parameters were set to define and focus the scope of the review. These parameters were defined by the review question commissioned by the NAPWA Care and Support Audit Critical Reference Group (CRG membership, see appendix a): "*What are the considerations of the social determinants of health for the health and well being of people living with HIV/AIDS in Australia today.*"

The review will provide a contemporary analysis of the Australian literature and what it suggests for the changing care and support needs of people living with HIV/AIDS. The review also provides support to the NAPWA HIV Living Unit and a national response that incorporates full consideration of the relationship that the social determinants of health play, within the context of the changing care and support needs, upon the health and wellbeing outcomes of people living with HIV/AIDS.

The purpose of this literature review is to:

- Draw together HIV/AIDS specific data from the literature as it relates to the social determinants of health namely: employment, income inequality and access to services in Australia today.
- Identify and compile an extensive bibliography of the literature and information materials that have informed the NAPWA Care and Support Audit.

## METHODOLOGY

The literature review was commissioned in the first half of 2005 under the guidance of the NAPWA HIV Living Unit and the NAPWA CRG.

To ensure that a contemporary Australian analysis is provided, the literature under review spans publications and relevant materials dated 2002-2007. No literature published prior to 2002 has been included in the final review however, earlier publications have informed the discussions.

It should be noted, "*published articles reflect a time 2 years or more before the actual publication date.*" (Wilkes, 1998 cited in J Cochrane 2003) Consequently, the literature under review here can be seen to reflect a time span ranging approximately 2000-2005. All literature analysed is of Australian origin.

The brief of the NAPWA Care and Support Audit is to reflect the needs and experiences of the Australian HIV/AIDS community broadly however, where specific data was available on HIV positive sub populations, and that data sufficiently provides an additional dimension to the review discussions, that data has been included.

This literature review comprises:

- A listing of databases accessed for this review – see appendix b.
- A listing of Internet sites visited and referenced – see appendix c.
- A reference listing of research documents analysed in this literature review.
- A bibliography of the literature that has informed this review and the broader work of the NAPWA Care and Support Audit principle papers, namely, *Pressure Points*, *Transitions* and *Forced to the margins . . . again*.

It is not the intention of this review to reproduce the quantitative data in every detail as it appears in the literature, but rather, the review has selected minimal data for reproduction, sufficient to identify consistencies or anomalies, readers are directed to the reference list to gain access to comprehensive data sets.

Finally, this review will reflect upon the extent to which the social determinants of health; employment, income inequality and access to services, have been considered in relation to the research findings. The review does not provide a critique of the theoretical underpinnings of the literature or provide extensive information on the methodological aspects of research.

## KEY WORDS

HIV/AIDS, Australia, employment, social determinants of health, socio-demographic, health and well-being, care and support, HIV/AIDS services.

## HIV/AIDS AND EMPLOYMENT: THE LITERATURE

### *HIV Futures 2, Aboriginal and Torres Strait Islander people living with HIV*

Willis J, McDonald K, Saunders M and Grierson J, The Living With HIV Program, Australian Research Centre in Sex, Health and Society, La Trobe University. 2002 Monograph series number 30

### *Futures 3, Positive Australians on services, health and wellbeing*

Grierson J, Misson S, McDonald K, Pitts M, The Living With HIV Program, Australian Research Centre in Sex, Health and Society, La Trobe University. May 2002 Monograph series number 37

### *Juggling with HIV: The intricacies of positive women's lives in Australia today*

K McDonald, S Misson, J Grierson, The Living With HIV Program, Australian Research Centre in Sex, Health and Society, La Trobe University. 2002 Monograph series number 38

### *Positive Health, Then and Now . . . Following HIV-positive lives over time*

Fogarty A, Rawstorne P, Prestage G, Grierson J, Grulich A, Kippax S, Worth H, Murphy D, Monograph 9/2003. National Centre in HIV Social Research, Faculty of Arts and Social Sciences, University of NSW

### *HIV Futures 4, State of the [positive] nation*

J Greirson, R Thorpe, M Saunders, M Pitts, The Living with HIV Program, Australian Research Centre in Sex, Health and Society, La Trobe University. 2004 Monograph series number 48

### *The Journey Continues: Women Living with HIV/AIDS in Australia, HIV Futures 4*

K McDonald, R Thorpe, J Grierson, The Living With HIV Program, Australian Research Centre in Sex, Health and Society, La Trobe University. 2005 Monograph series number 51

### *Health and wellbeing of HIV-positive Australians: findings from the third national HIV Futures Survey*

JW Grierson, MK Pitts and S Misson, International Journal of STD and AIDS 2005; 16: 802-806

### *Growing Older with HIV: A Study of Health, Social and Economic Circumstances for People Living with HIV in Australia over the Age of 50 Years*

Pitts M, Grierson J, Misson S, Australian Research Centre in Sex, Health and Society, La Trobe University, AIDS Patient Care and STDs Volume 19, Number 7, 2005

### *HIV Futures 5, Life as we know it*

J Greirson, R Thorpe, M Pitts, The Living with HIV Program, Australian Research Centre in Sex, Health and Society, La Trobe University, 2006 Monograph series number 60

### *Men and women living heterosexually with HIV. The Straightpoz study, Volume 1*

Persson A, Barton D, Richards W, National Centre in HIV Social Research, Faculty of Arts and Social Sciences, University of New South Wales Monograph 2/2006

*Factors distinguishing employed from unemployed people in the Positive Health Study.* Andrea S. Fogarty, Iryna Zablotska, Patrick Rawstorne, Garrett Prestage and Susan C Kippax. AIDS 2007, 21 (supl 1):S37-S42

## HIV/AIDS AND EMPLOYMENT: RESEARCH FINDINGS

Here we examine the 'crude' employment (*or unemployment*) data to establish what the data indicates for HIV positive people and employment in Australia – across the review time span.

### *HIV Futures 2, Aboriginal and Torres Strait Islander people living with HIV*

Willis J, McDonald K, Saunders M et.al (2002)

The data for this research was drawn from the *HIV Futures 2: The health and Well-being of People with HIV/AIDS in Australia* survey (1999). The *Futures 2* survey comprised 924 HIV positive respondents from all States and Territories in Australia – representing over 8% of the HIV positive population, of whom 23 identified as Aboriginal or Torres Strait Islander people. Willis J, McDonald K et.al (1999, p2) warn that at the time of publication "no available statistics of how many Aboriginal and Torres Strait Islander people overall are living with HIV and so . . . are unable to say what proportion of these is represented by [the] sample" and that the survey presents a "unique snapshot of the experience of living with HIV for . . . the respondents, but they should be read with some caution" – providing four key reasons for this caveat (p2). Bearing this in mind the research found that:

- Around one quarter (6) of the respondents were in paid employment, of whom most (5) worked full-time.

### *Futures 3, Positive Australians on services, health and well-being*

Grierson J, Misson S et.al 2002

A cross-sectional study completed by 898 HIV positive people, at the time representing approximately 6% of the HIV positive population in Australia. Grierson J, Misson S et.al suggests that caution must be taken in the application of the findings due to sample representativeness "in reference to individuals who are less likely to be included in the sample." The *HIV Futures 3* survey found that:

- Slightly less than one half of respondents are currently in paid employment, with more than half of this number being in full-time work. The majority of the remainder described themselves as either not working or retired."

### *Juggling with HIV: The intricacies of positive women's lives in Australia today*

K McDonald, S Misson et.al 2002

The data for this research was drawn from the *HIV Futures 3* survey (2002), with 894 HIV positive respondents from all states and territories of Australia – of whom 75, or 8.3% were women – the findings indicated that:

- 50.5% of the women were in paid employment – averaging 41.6 hours (per week)
- 63.5% of the working women were employed on a part-time basis – contrasted with 41.5% of the total Futures 3 survey

### *Positive Health, Then and Now . . . Following HIV-positive lives over time*

Fogarty A, Rawstorne P, et.al 2002

A longitudinal study with a cohort of 307 respondents interviewed across two time zones September 1998-April 1999 and again between September 2000-April 2001 and published 2003, it was found that:

- "Less than half of the participants were in some form of paid employment. [And] only 30% of the cohort was in full-time employment."

JW Grierson, MK Pitts and S Misson, characterised the health and wellbeing of people living with HIV/AIDS in Australia in *Health and wellbeing of HIV-positive Australians: findings from the third national HIV Futures Survey* and found that in relation to employment:

- Overall 27% of respondents were in fulltime employment
- 15% of respondents were unemployed.

### ***Growing Older with HIV: A Study of Health, Social and Economic Circumstances for People Living with HIV in Australia over the Age of 50 Years***

The results for this research were drawn from the *HIV Futures 3* survey. "Older PLWHA were defined as those aged 50 years or more; this being 22% of the total sample comprising 98% males and 2% female – a significantly greater proportion of males than in the rest of the [*Futures 3*] sample (90%)." The research found that:

- "Older PLWHA were less likely to be in paid employment of any kind: 14.9% of older PLWHA were in full-time employment, compared to 29.2% of younger PLWHA."
- 47.9% of older PLWHA were not working or were retired.

### ***HIV Futures 4: State of the [positive] nation***

A cross sectional study of 1059 HIV positive respondents from all states and territories – representing 8.1% of the HIV positive population in Australia – the research found that:

- 43% of respondents were employed
- 25.7% of respondents were employed full-time – average hours of work 41.2 (per week)
- 14.4% of respondents were employed part-time – average hours of work 21.9 (per week)

### ***The Journey Continues: Women Living with HIV/AIDS in Australia, HIV Futures 4***

The data for this research was drawn from the *HIV Futures 4* survey (as above) in which, 96 women participated, representing approximately 8.0% of the HIV positive women in Australia. The findings indicated that:

- 56.1% of the women were in paid employment with 27.9% in part-time and 22.6 were in full-time employment.

The remaining respondents are described as either unemployed or occupied with home duties. Women were significantly more likely than men to be working part-time, occupied with home duties or not working or retired.

***HIV Futures 5, Life as we know it.*** The *HIV Futures 5* survey comprised 973 respondents, representing approximately 6.4% of the HIV positive population. Grierson J, Thorpe R and Pitts M do not presume to have obtained an entirely representative sample but suggest "broad sector involvement in both promotion and recruitment . . . has given us one of the most comprehensive pictures of life with HIV in Australia." The survey found that:

- "Just over half of the respondents were currently in paid employment (51.2%) the majority of these being in full-time work (34.1% of the total sample)" with 17.1% in part-time work.
- "The remainder tended to describe themselves as either unemployed (10.7%) or retired (19.8%)."

### ***Men and women living heterosexually with HIV. The Straightpoz study, Volume 1***

The survey recruited 31 respondents, comprising 14 positive males, 9 positive females, six negative female partners and 2 negative male partners with most aged 40-50 years and living across and beyond Sydney with a concentration in the inner and outer western suburbs. The research found that for the HIV positive respondents:

- 5 were in full-time, paid employment
- 1 respondent was self employed
- 4 respondents were employed on a casual or part-time basis
- 9 respondents received the Disability Support Pension
- 3 respondents received the aged pension
- 1 respondent was studying
- 5 of the 9 females worked, mainly full-time
- 5 of the 14 males worked, either full-time or part-time

For Fogarty, Zablotska et.al in *Factors distinguishing employed from unemployed people in the Positive Health Study* (accepted 2006), the objective was "to identify predictors of unemployment among Australian people living with HIV/AIDS." This research provides an advantage to other research, as "this study is longitudinal data analysis in an area that has often relied upon cross-sectional findings." The 704 respondents were recruited using convenience sampling, with all respondents being male. This necessarily cannot be viewed as a representative sample of the HIV/AIDS body positive in Australia. Interestingly, Fogarty, Zablotska et.al 2005 assert that their findings "did not greatly differ from a national sample of Australian PLWHA," citing the research of Ezzy D, de Visser R et.al 1997. The findings indicated that:

- In relation to the socio-demographic predictors of education level, children and age, univariate associations with unemployment indicated that "unemployment rates were lower among those who had a tertiary education [37.0%] compared with those with high school education [53.8%] and among those earning more than AU\$22,000 per annum [13.0] compared with those who earned up to AU\$22,000 [52.7%]. Unemployment rates were lower among people without children [42.5% compared to 50.8% among people with children] and increased with age [36.4% among people younger than 40, 42.9% among people aged between 40-49 years of age, and 54.8% among people aged older than 50 years of age].
- "Multivariate models confirm that there is a higher likelihood of unemployment among those people who had an HIV/AIDS-related illness . . . and were older. There was a lower likelihood of unemployment among those who . . . had been living with HIV/AIDS for shorter amounts of time . . . and had a tertiary education."

## HIV/AIDS AND EMPLOYMENT: DISCUSSION

A considerable body of research exists to provide a perspective on [un]employment as it applies to the HIV positive population in Australia. Much of the research incorporates further detail of employment status for positive people with several providing data on the variables of part-time and full-time employment, length of time out of the workplace, impact of diagnosis and antiretroviral therapy on employment, circumstance surrounding interruption to employment, intent to enter or exit the workplace, and aspects affecting respondents in relation to disclosure, stigma and discrimination in the workplace.

It is not possible to draw an aggregate rate of [un]employment from the literature as the data is derived from differing methodologies, research time zones, sampling and sampling bias. Definitions of employment and insufficient clarification of employment status further problematise aggregation. In some instances it can be argued that a respondent may indicate that they are indeed unemployed, however, if the respondent is in receipt of a Commonwealth Disability Support Pension (DSP), is a self-funded retiree sustained by superannuation or annuities, or is a student, the respondent may not be required, or indeed, may not be able to take on employment. It's also the case that some research measures *employment* whilst others measure *unemployment*. Whilst ongoing systemic regulatory amendments to the DSP during the period of review, including those aspects of regulation that require the undertaking of volunteer work, further complicate the picture. It is noteworthy that aspects of volunteerism are not considered in the research, so too, the research provides little insight to aspects of underemployment, surprising perhaps, given the high incidence of part-time employment reported by respondents.

However, the variables of employed and unemployed consistently return responses confirming that the rates of *unemployment* for the respondents, during the period under review were indeed high. Fogarty, Zablotska et.al (2007,ps37) citing (Bernell SL, Shinogle JA 2005 and Dray-Spira R, Peroz A et.al 2005) suggest that "Currently reported unemployment rates among PLWHA vary across countries and settings, but are still high (23-65%)." It would appear from the research reviewed here that the unemployment rates for HIV positive people in Australia concur with this finding.

This high incidence of unemployment for HIV positive people can be usefully compared with the trend unemployment rates experienced across the same period in the broader Australian community where in March 2002 trend unemployment was 6.5%, in March 2005 trend unemployment was 5.1%, whilst in March 2007 trend unemployment stands at 4.5% (Australian Bureau of Statistics, Labour Force Australia Preliminary).

## HIV/AIDS, EMPLOYMENT AND THE SOCIAL DETERMINANTS OF HEALTH: DISCUSSION

Repeatedly in the literature, employment (or unemployment) status is acknowledged as only part of the picture with all research discussions concluding that psychosocial and socio-demographic factors play a substantial part in employment outcomes. However, apart from offering these observations, very little of the literature attempts to comprehensively detail the consistently high unemployment rates among HIV positive people in relation to the social determinants of health.

Likewise, little of the research describes a comparative account of the impact of socio-demographic factors on the employment outcomes for HIV positive women, Indigenous peoples, people from culturally and linguistic diverse (CALD) backgrounds, positive heterosexuals, and older HIV positive people. The research instruments employed by most of the researchers does not provide for a detailed account of the social and structural barriers to employment and the relationships with, and access to, the social determinants of health as they relate to the HIV positive population.

Importantly, the literature consistently affirms that differing employment outcomes for HIV positive people correlate with socio-demographic and psychosocial factors, and seldom correlate solely in terms of clinical factors. The discussions in the literature consistently state a need for further research into the social aspects of living with HIV and employment outcomes. Fogarty A, Rawstorne P et.al (2003 p55) point to the complexity of the lived experience of people living with HIV/AIDS, arguing that it is indeed paradoxically possible *"that clinical markers may suggest that a person is healthy and doing well, whereas the subjective experience – particularly in terms of side effects – may be quite the opposite."* And, that *"the experience of HIV is not just physical – it is also psychological and social, each with multiple facets."*

It appears from the literature reviewed that the complexities of an HIV diagnosis and the interplay with the social, psychosocial and socio-demographic aspects of health and well being require further investigation. Fogarty, Zablotska et.al (2005, p40) argue that their results *"indicate that a person's demographic background or social standing is as important to unemployment as their mental and physical health. It is therefore important to understand the factors that affect the employment of PLWHA in order to improve prospects for those who wish to work."*

## HIV/AIDS AND INCOME INEQUALITY: THE RESEARCH

### *HIV Futures 2, Aboriginal and Torres Strait Islander people living with HIV*

Willis J, McDonald K, Saunders M and Grierson J, The Living With HIV Program, Australian Research Centre in Sex, Health and Society, La Trobe University 2002 Monograph series number 30:

- Willis J, McDonald K et.al (2002, 12) report that *"One quarter (6) of the Aboriginal and Torres Strait Islander respondents are living below the poverty line."* This is consistent with the proportion of non-indigenous respondents living below the poverty line (25.6%) who comprise the HIV Futures 2 survey, from which the data was drawn.
- *"More than one half of Aboriginal and Torres Strait Islander respondents . . . are primarily dependent on a government benefit or pension."*
- Likewise, Willis J, McDonald K et.al conclude that both indigenous and non indigenous respondents surveyed for HIV Futures 2 *"reported difficulty meeting costs of daily living and this was not necessarily a consequence of having an income below the poverty line."* (p13)

### *Futures 3, Positive Australians on services, health and wellbeing*

Grierson J, Misson S, McDonald K, Pitts M, The Living With HIV Program, Australian Research Centre in Sex, Health and Society, La Trobe University. May 2002 Monograph series number 37

- "Over thirty percent of PLWHA are living below the poverty line" (based on quarterly Henderson Poverty Lines published by the Institute of Applied Economics and Social Research (IAESR 2001).
- Of the survey respondents in paid employment (47.8%) "very few" reported incomes below the poverty line.
- Over half those receiving government benefit (48.7) are living in poverty.
- Grierson J, Misson S et.al conclude, "there are other factors that are peculiar to living with HIV. These include . . . the experience of discrimination and disadvantage in employment and the costs of living with a chronic or intermittently debilitating illness that are not covered by the health system." (p99)

### *Juggling with HIV: The intricacies of positive women's lives in Australia today*

K McDonald, S Misson, J Grierson, The Living With HIV Program, Australian Research Centre in Sex, Health and Society, La Trobe University. 2002 Monograph series number 38

- 50.7% of respondents are in receipt of government pension or benefit as their main source of income, of which 53% are living in poverty (IAESR 2001).
- 40% of women are living below the poverty line.
- "Paid employment did not exempt women from poverty with 27% . . . reporting incomes below the poverty line." A substantially different experience when compared to male respondents comprising the HIV Futures 3 survey from which the data was drawn and for whom the majority receive an income above the poverty line.
- According to the IAESR 2001 measure, (39.6%) of the women were living below the poverty line.

### *Positive Health, Then and Now . . . Following HIV-positive lives over time.*

Fogarty A, Rawstone P, Prestage G, Grierson J, Grulich A, Kippax S, Worth H, Murphy D, Monograph 9/2003, National Centre in HIV Social Research, Faculty of Arts and Social Sciences, University of NSW

This survey does not provide data directly in relation to poverty and income inequality, but reports that:

- "about 60% of the cohort reported an annual income of \$26,000 or less."
- In relation to respondents prevented from accessing services due to cost: 15% reported that cost 'often' prevented them from accessing both alternative therapies and alternative health practitioners.
- At time 2 of the survey (between September 2000-April 2001) "about one quarter of the cohort was receiving some financial assistance, from sources other than Medicare or private health insurance, to assist with accessing [health care] services." (p36)

*HIV Futures 4. State of the [positive] nation.* J Greirson, R Thorpe, M Saunders, M Pitts, The Living with HIV Program, Australian Research Centre in Sex, Health and Society, La Trobe University, 2004 Monograph series number 48

- Over half of the respondents (54.6%) identified a government benefit or pension as their main source of income, with around half (49.3%) living in poverty, based on IAESR 2003 September quarter data.
- 26.9% of respondents are living below the poverty line, with "very few" respondents in paid employment reporting incomes below the poverty line.
- "More than half of the respondents reported experiencing at least some difficulty with meeting the cost of daily living." (pxv) And "Disturbingly, among those living below the poverty line, one quarter rated paying for medical services as very difficult." (p67)

### *The Journey Continues: Women Living with HIV/AIDS in Australia, HIV Futures 4*

K McDonald, R Thorpe, J Grierson. The Living With HIV Program, Australian Research Centre in Sex, Health and Society, La Trobe University, 2005 Monograph series number 51

- 49.1% of respondents were in receipt of a government benefit or pension as their main source of income, with over half (58.8%) living in poverty, based on IAESR 2003 September quarter measures.
- 33.0% of the respondents were living below the poverty line, with those women earning a salary (41.9%) significantly less likely to be classified as living below the poverty line.

### *Health and wellbeing of HIV-positive Australians: findings from the third national HIV Futures Survey*

JW Grierson, MK Pitts and S Misson, *International Journal of STD and AIDS* 2005; 16: 802-806

- 31% of the survey's 894 respondents are described as living in poverty.

### *Growing Older with HIV: A Study of Health, Social and Economic Circumstances for People Living with HIV in Australia over the Age of 50 Years*

Pitts M, Grierson J, Misson S, Australian Research Centre in Sex, Health and Society, La Trobe University, *AIDS Patient Care and STDs* Volume 19, Number 7, 2005

- According to IAESR (June 2001 quarter) data, 38% of older PLWHA respondents were living below the poverty line.

### *HIV Futures 5, Life as we know it*

J Greirson, R Thorpe, M Pitts, The Living with HIV Program, Australian Research Centre in Sex, Health and Society, La Trobe University, 2006 Monograph series number 60

- According to IAESR (December 2005 quarter) measures, over one quarter of respondents (28.3%) were living below the poverty line, with those in paid employment significantly less likely to be living below the poverty line (7.1%) whilst almost half those respondents not in paid employment (51.2%) are living below the poverty line.
- As with previous HIV Futures surveys, around half respondents (45.7%) were in receipt of government pension or benefit, with over half these respondents (58.0%) living in poverty.
- "Disturbingly, among those living below the poverty line, one quarter rated paying for medical services as very difficult." (p65)

### *Men and women living heterosexually with HIV. The Straightpoz study, Volume 1*

Persson A, Barton D, Richards W, National Centre in HIV Social Research, Faculty of Arts and Social Sciences, The University of New South Wales Monograph 2/2006

- No specific data available on socioeconomic status of respondents.

### *Factors distinguishing employed from unemployed people in the Positive Health Study*

Andrea S. Fogarty, Iryna Zablotska, Patrick Rawstorne, Garrett Prestage and Susan C Kippax. *AIDS* 2007, 21 (supl 1):S37-S42

- No specific data available on socioeconomic status of respondents.

## **HIV/AIDS AND INCOME INEQUALITY: DISCUSSION**

A considerable body of data has been collected indicating that, during the time under review, a high percentage of HIV positive respondents reported incomes placing them below the poverty line. Much of the data is calculated using comparable methodology, with the majority calculated upon the IAESR measures. However, the extent to which this poverty is explored within the literature varies considerably, with some research incorporating the incidence of income and poverty as a general descriptor of respondents only, while other research explores income inequalities more closely in relation to socio-demographic and psychological aspects of the respondent's lives.

The HIV Futures surveys consistently explore aspects of HIV, income and poverty and the correlates of a number of variables impacting upon the health and well being of respondents. This research typically provides data on the variates of: accommodation, impact of HIV diagnosis on employment, source of income, poverty by income source, poverty by shared income source, expenditure and debt levels, assessment of benefits, and self-rated health and well being of those living above and below the poverty line. However, the extent to which any direct 'causality' between poverty and the health and well being of HIV positive respondents is, by and large, inconclusive. Repeatedly, the research discussions argue that poverty plays an important role upon health and well being outcomes with Grierson J, Thorpe et.al (2004, p65) asserting, "poverty creates emotional stress, limits social interaction and damages health."

Of considerable concern, and evidenced across much of the research, is the impact of poverty for respondents living below the poverty line in relation to access to health and medical services.

The research indicates that HIV positive people living below the poverty line consistently experience difficulty meeting the costs of medical services, and that those respondents experiencing difficulty paying for medical services, also experience difficulty meeting the costs of living more generally, including experiencing difficulty meeting the costs of HIV treatments (not all data shown here). That Australia has experienced record levels of economic prosperity during the period of review compounds McDonald K, Misson S and Grierson J (2002, p105) statement when observing that “[w]hile the efforts of welfare and financial aid services in community organisations are essential in addressing these needs, it remains a gross indictment of a wealthy society like Australia that people with HIV continue to suffer this level of privation.”

The high incidence of poverty evidenced across the HIV Futures surveys and comparable rates reported in the other literature reviewed here, confirms that the rates of poverty for HIV positive people in Australia have remained stubbornly high over time. Grierson J, Thorpe and Pitts M (2006, p65) observe in the most recently published HIV Futures 5 survey, “*That this figure has remained so high across the HIV Futures surveys suggests that current resources and strategies are inadequate and decisive action must be taken to address this pocket of severe social disadvantage.*”

## **HIV/AIDS, INCOME INEQUALITY AND THE SOCIAL DETERMINANTS OF HEALTH: DISCUSSION**

On the surface, the high incidence of poverty among HIV positive respondents and the high incidence of positive people in receipt of government benefit or pension, of whom a great many live below the poverty line, would seem self evidently correlative. However, as with unemployment, the experiential aspects of poverty for HIV positive respondents are a complex matter. Grierson J, Thorpe and Pitts M (2006, p61) argue that the outcomes for those respondents living above and below the poverty line cannot be explained “*simply by the proportion of PLWHA relying on government pension or benefits. There are financial hardships associated with being HIV positive. Some of these are structural and systemic . . . the negative consequences of treatment, some result from stigma and disadvantage that result from reduced employment options . . . [and] the cumulative effects of living for many years with uncertain or fluctuating health and well being.*”

Consideration of the impact of the social determinants of health upon the populations of HIV positive women, Indigenous peoples, people from CALD backgrounds, positive heterosexuals, and older HIV positive people, is not possible as insufficient data can be drawn from the limited amount of research.

However, in relation to poverty and HIV positive Indigenous peoples, Morrissey M, (2003, p26) in a recent review of literature on Indigenous income and the "pitfalls in applying standard poverty research techniques to Indigenous society", argues strongly that "Quite simply, the **health** gap between Indigenous and non-Indigenous Australians appears to be out of all proportion to the **income** gap between them." Morrissey provides a convincing critique of current explanations of Indigenous poverty, arguing (in short) "Indigenous poverty has been underestimated . . . that income is an inadequate indicator of [Indigenous] poverty . . . and that poverty is only one element in a complex social process which cannot be 'captured' by cross-sectional quantitative techniques." (p27)

In his concluding comments Morrissey M (2003, p28) asserts that poverty cannot be treated in isolation as a risk factor affecting a variety of diseases and death, and to do so "does not explain a great deal. One reason for this is that poverty is not an infection or an environmental contaminate but a social process . . . Social processes cannot be boiled down to 'proximate risk factors'."

It is research into these social processes that is required, not only in regard to Indigenous health, although most importantly Indigenous health would gain substantially but, as this review has shown, so too would the broader HIV positive community for whom social processes do indeed impact in myriad forms upon health and well being outcomes.

## HIV/AIDS AND ACCESS TO SERVICES: THE RESEARCH

Issues relating to HIV/AIDS and access to services necessarily encompass a wide range of stakeholders. The research reviewed here provides varying degrees of consistency and data relating to aspects of service provision and access. For this reason, the data has been presented differently from previous sections; in this section we review the literature as follows:

Firstly, the literature exploring aspects of HIV/AIDS and the sub-populations of positive Indigenous peoples, positive heterosexuals, and older HIV positive people is presented. A small amount of data is drawn from the limited amount of research followed by a brief discussion.

Secondly, a listing of the HIV Futures Surveys (only) is presented along with a selection of data relating to a number of 'service questions' from the HIV Futures surveys. To assist with comparison, the data is reproduced in a series of tables and followed by a discussion.

Finally, we provide a brief review of HIV/AIDS and access to services, drawn from the remaining literature (not reviewed above) and again, this is followed by a brief discussion.

## HIV/AIDS SUB-POPULATIONS AND ACCESS TO SERVICES: THE LITERATURE

- ***HIV Futures 2, Aboriginal and Torres Strait Islander people living with HIV***

Willis J, McDonald K, Saunders M and Grierson J, The Living With HIV Program, Australian Research Centre in Sex, Health and Society, La Trobe University. 2002 Monograph series number 30

- ***Growing Older with HIV: A Study of Health, Social and Economic Circumstances for People Living with HIV in Australia over the Age of 50 Years***

Pitts M, Grierson J, Misson S, Australian Research Centre in Sex, Health and Society, La Trobe University, AIDS Patient Care and STDs Volume 19, Number 7, 2005

- ***Men and women living heterosexually with HIV: The Straightpoz study, Volume 1***

Persson A, Barton D, Richards W, National Centre in HIV Social Research, Faculty of Arts and Social Sciences, The University of New South Wales Monograph 2/2006

## HIV/AIDS SUB-POPULATIONS AND ACCESS TO SERVICES: THE RESEARCH

Although the '*HIV Futures 2, Aboriginal and Torres Strait Islander people living with HIV*' publication utilises data drawn from the broader *HIV Futures 2* survey, this data has not been included in the review of HIV Futures 'services' section as the data is not sufficiently comparable. Rather, we review it here separately.

### *HIV Futures 2, Aboriginal and Torres Strait Islander people living with HIV*

Willis J, McDonald K, Saunders M and Grierson J The Living With HIV Program, Australian Research Centre in Sex, Health and Society, La Trobe University, 2002 Monograph series number 30

- Of the 23 Aboriginal and Torres Strait Islander (ATSI) respondents asked who they usually see for HIV related treatment: 9 identified their HIV specialist, followed by their HIV GP (5) or HIV/AIDS organisations (5).
- For their general health treatment, ATSI respondents again identified their HIV specialist (11), followed by their HIV GP (6) or their GP(4).
- In relation to mental health supports, just over half ATSI respondents were using the counseling services available at HIV/AIDS organisations and other agencies.
- Overall most ATSI respondents reported having 'reasonable levels of support' from their social network, with the 'richest' sources of support coming from partners/spouses (13), close friends (10), parents (7), HIV positive friends (8), and pets (10).
- Almost half ATSI respondents (10) felt they had received less favorable treatment than other people at medical services because of their HIV.
- Most ATSI respondents (20) had some contact with HIV/AIDS organisations, using them mostly for HIV/AIDS treatment advice (15), social contact (11), peer support (11), counseling (9), pharmacy services (8), drug/alcohol treatment (6), library (5), financial assistance and advice (5).
- "The information from this survey suggests that . . . more investigation is required particularly in the areas of culture-specific mental health issues and culturally appropriate delivery of mental health and social support services." (p16)
- "There was simply not enough people in the sample to discern patterns of residential mobility, although further qualitative investigation might reveal whether issues like access to services, changes in health status, or experience of unwanted disclosure of HIV status had contributed to decisions to move." (p19)

### *Growing Older with HIV: A Study of Health, Social and Economic Circumstances for People Living with HIV in Australia over the Age of 50 Years*

Pitts M, Grierson J, Misson S, Australian Research Centre in Sex, Health and Society, La Trobe University, AIDS Patient Care and STDs Volume 19, Number 7, 2005

- The data indicated, "overall, older PLWHA were significantly less likely to make use of services than younger PLWHA. Older PLWHA are also less likely to use services at non-HIV related organisations."

### *Men and women living heterosexually with HIV, The Straightpoz study, Volume 1*

Persson A, Barton D, Richards W, National Centre in HIV Social Research, Faculty of Arts and Social Sciences, The University of New South Wales Monograph 2/2006.

- "The vast majority of heterosexual participants typically had little or no contact with non-medical services, organisations."
- "For their health and medical needs, most participants went to sexual health clinics and major hospitals, with only a few visiting inner city doctors with high HIV case loads."
- "A quarter of participants received regular financial assistance from Pozets" (A peer education program for heterosexuals with HIV/AIDS, funded by NSW Health).
- "Most participants obtained their HIV related information from their doctor, their HIV positive partner and Pozhets via mailouts . . . seen as essential and supportive."
- "Other than for financial and medical support, standard HIV services were not generally seen as ongoing or primary sources of support."
- "As a result of the pressures of secrecy . . . many participants tended to form close connections with trusted **individual** staff within service providers."

## HIV/AIDS SUB-POPULATIONS AND ACCESS TO SERVICES: DISCUSSION

At the outset it must be stated that there is insufficient data available on these populations, as a result no substantive conclusions can be drawn.

For older positive people, Pitts M, Grierson J, and Misson S conclude *"This will be a group of increasing significance for HIV communities and services, it will be important to understand more fully the combined effects of natural ageing, the long-term impact of the virus and of antiretroviral treatments."*

In relation to HIV Indigenous peoples and access to services, the available data provides a unique snapshot of the survey respondents but cannot be seen as a representative sample. The minimal amount of Indigenous specific data describing the impact of HIV on this population, not only in regards to access and provision of services, but also more broadly, strongly suggests that further, culturally sensitive research, is required. Morrissey M (2003, p28) contends that *"many social epidemiologists are now arguing, new research and theoretical paradigms are long overdue"* and that this 'new research' must incorporate suitable methodology and practices, *"not just in the sense of producing greater descriptive accuracy and predictive efficiency, but also suitable in terms of their capacity to inform effective action."*

In relation to positive heterosexuals and access to services, Persson A, Barton D et.al (2006, p40) suggest that there are *"significant cultural barriers to sustained contact with communal forms of positivity"* and that positive heterosexuals find, by and large, that existing HIV services are alienating, do not meet their specific needs and that for positive heterosexuals *"there was a pervasive sense of being cultural outsiders in a positive gay community, but also of being largely invisible or marginalised in the HIV sector."* (p41)

The paucity of descriptive research into aspects of the provision and access to HIV services for positive Indigenous people extends to the broader HIV community, including HIV positive women, positive people from CALD backgrounds, positive heterosexuals, and older HIV positive people. A greater understanding of the specific needs of the sub-populations of HIV positive people in relation to service provision and access is required.

## HIV/AIDS AND ACCESS TO SERVICES – HIV FUTURES SURVEYS: THE LITERATURE

- ***Futures 3, Positive Australians on services, health and wellbeing***

Grierson J, Misson S, McDonald K, Pitts M, The Living With HIV Program, Australian Research Centre in Sex, Health and Society, La Trobe University, May 2002 Monograph series number 37

- ***Juggling with HIV: The intricacies of positive women's lives in Australia today***

K McDonald, S Misson, J Grierson. The Living With HIV Program, Australian Research Centre in Sex, Health and Society, La Trobe University, 2002 Monograph series number 38

- ***HIV Futures 4, State of the [positive] nation***

J Greirson, R Thorpe, M Saunders, M Pitts, The Living with HIV Program, Australian Research Centre in Sex, Health and Society, La Trobe University, 2004 Monograph series number 48

- ***The Journey Continues: Women Living with HIV/AIDS in Australia, HIV Futures 4***

K McDonald, R Thorpe, J Grierson, The Living With HIV Program, Australian Research Centre in Sex, Health and Society, La Trobe University, 2005 Monograph series number 51

- ***HIV Futures 5, Life as we know it***

J Greirson, R Thorpe, M Pitts, The Living with HIV Program, Australian Research Centre in Sex, Health and Society, La Trobe University, 2006 Monograph series number 60

The HIV Futures surveys have consistently sought responses to a range of questions addressing service provision and access for the general HIV population. Importantly, Grierson J, Thorpe R and Pitts M (2006 pxx), whilst claiming that *HIV Futures 5* [in particular] *"has given us one of the most comprehensive pictures of life with HIV in Australia"* they warn that *"data obtained from clinical samples generally tend to over-represent the more problematic aspects of living with HIV, both clinical and social, and data obtained solely from convenience samples [as is the case with the HIV Futures surveys] tend to over represent . . . service utilisation."*

It should also be noted that the HIV Futures Surveys employ cross-sectional sampling, as a result, Grierson J, Misson S, et.al (2003) caution that “*the responses for each survey are not formally linked, so that direct comparison between individuals’ responses over time is not possible*” (p19) however, Grierson J, Misson S et.al argue that “*collectively [these and other studies] . . . lead to a greater understanding of the dynamics of the epidemic and the issues affecting Australian PLWHA.*” (p20)

In an Australian context, positive women constitute a relatively small sub-population of the body positive. On two occasions (HIV Futures 3 and 4) data specific to positive women has been drawn from these surveys and separate publications have been produced, making it possible to draw *some* comparison between the lived experience of positive women and positive men.

To assist with comparison across the surveys, tables have been presented here with data reproduced in chronological order, identifying the eight highest rating responses to each of the survey questions selected for analysis.

## HIV FUTURES SURVEYS, HIV/AIDS AND ACCESS TO SERVICES: THE RESEARCH

**Survey question:** Respondents identified the **physician used for HIV treatment** (percentage of total)

Table 1

	HIV FUTURES 3	HIV FUTURES 3 +WOMEN	HIV FUTURES 4	HIV FUTURES 4 +WOMEN	HIV FUTURES 5
HIV GP/S100					
Prescriber	49.9	35.0	50.2	36.7	46.7
Other GP	21.9	31.6	22.3	30.9	25.1
HIV Specialist at outpatient clinic	16.3	11.0	14.8	17.9	13.7
HIV at inpatient clinic	0.4	No data	0.7	0.0	0.2
Doctor at sexual health clinic	8.6	14.9	9.4	9.9	10.9
Other doctor	2.6	6.3	1.8	3.5	1.8
Other	0.3	No data	0.7	1.2	1.7
No one	No data	1.3	No data	No data	No data
Total HIV GP/specialist					
Total other GP/doctor					

**Survey question:** Respondents identified the **PHYSICIAN USED FOR HIV SPECIFIC/RELATED TREATMENT:** (percentage of total)

Table 2

	HIV FUTURES 3	HIV FUTURES 3 +WOMEN	HIV FUTURES 4	HIV FUTURES 4 +WOMEN	HIV FUTURES 5
HIV GP/S100 Prescriber	47.9	32.7	45.3	37.0	43.2
Other GP	3.6	0.0	4.5	1.3	4.4
HIV Specialist at outpatient clinic	34.6	44.0	32.9	43.3	32.4
HIV at inpatient clinic	1.0	No data	1.4	1.3	0.4
Doctor at sexual health clinic	11.5	21.6	5.5	3.5	17.2
Other doctor	0.7	1.7	9.1	13.6	0.2
Other	0.7	No data	1.2	0.0	2.1
No one	No data	0.0	No data	No data	No data
Total HIV GP/specialist					
Total other GP/doctor					

### *HIV Futures 3, Positive Australians on services, health and wellbeing*

- For general health care treatment 49.9% of respondents see an HIV GP/S100 prescriber, whereas for HIV specific treatment 47.9% see an HIV GP/S100 prescriber and 35.6% see an HIV specialist/physician (reflecting different health care systems in different States and Territories). When these two categories are combined, 83.5% of respondents identify HIV GPs and specialists as their primary physicians for HIV specific management, and 66.0% for general health management.
- "59.5% of respondents said that the doctor they see for general medical services is the same doctor they see for HIV-related treatment." (p44)

### *Juggling with HIV: The intricacies of positive women's lives in Australia today*

- In relation to consulting with HIV GPs/S100 prescribers and/or HIV specialists, and seeking general health care and/or HIV specific treatments, HIV positive women "were significantly less likely than men to report that they see the same physician for both their general and HIV related treatment (46.3% vs 60.9%)." (p44)

### *HIV Futures 4, State of the [positive] nation*

- "Combined, HIV GP's and specialists were the primary physicians for 79.6% of respondents for HIV specific management and for 65.0% of respondents, for general health management." (p33)
- "54.7% of respondents said that the doctor they see for general medical services was the same doctor they saw for HIV-related treatment." (p33)

### *The Journey Continues: Women Living with HIV/AIDS in Australia, HIV Futures 4*

- "Combined, HIV GP's and specialists were the primary physicians for 81.6% of women for HIV specific treatment and for 54.6% of women, for general health treatment." (p33)
  - "43.9% of women said that the doctor they saw for general medical services was the same doctor they saw for HIV-related treatment." (p34)
- "Women were significantly more likely than men to say that they see different doctors for HIV-related treatment and general medical treatment (56.1% vs 44.1%)." (p34)

### *HIV Futures 5, Life as we know it*

- "Combined, HIV GP's and specialists were the primary physicians for 76.0% of respondents for HIV specific management and for 60.6% of respondents, for general health management" (p32)
- "62.3% of respondents said that the doctor they saw for general medical services was the same doctor they saw for HIV-related treatment." (p32)

**Survey question:** Respondents were asked to nominate from a list of potential sources, those that were important sources of information on HIV treatment. The eight most regularly identified sources of **information for HIV treatment** are presented here (percentage of sample).

**NOTE:** In relation to *HIV Futures 5*, the categories of '*HIV treatments*' and '*HIV management*' were combined (these being analysed separately in previous HIV Futures surveys). Here, the same data for *HIV Futures 5* is presented for both the categories: '*HIV treatments*' and '*HIV management*'.

Table 3

	HIV FUTURES 3	HIV FUTURES 3 +WOMEN	HIV FUTURES 4	HIV FUTURES 4 +WOMEN	HIV FUTURES 5
HIV GP/S100 Prescriber	63.5	52.8	64.6	53.5	60.2
HIV specialist at outpatient clinic	46.2	59.8	48.6	49.8	56.8
HIV magazine/newspaper	49.0	53.5	44.8	53.4	45.4
Articles in gay press	37.3		36.4		31.1
HIV positive friends	29.5	40.9	26.8	29.8	34.9
Treatments officer	17.8				
Pharmacist	15.4				
Other HIV/AIDS organisation staff	14.7				
Publications from HIV/AIDS groups	No data	50.4	43.5	59.7	41.3
Positive women's organisation		40.6		31.6	
Positive heterosexuals group		24.4			
Sexual health service		23.0	17.0	26.0	25.1
Internet	No data		21.7	23.4	29.7

**Survey question:** Respondents were asked to nominate from a list of potential sources, those that were important sources of information on HIV management. The 8 most regularly identified sources of **information for HIV management** are presented here (percentage of sample).

**NOTE:** In relation to *HIV Futures 5*, the categories of '*HIV treatments*' and '*HIV management*' were combined (these being analysed separately in previous HIV Futures surveys). Here, the same data for *HIV Futures 5* is presented for both categories: '*HIV treatments*' (Table 3) and '*HIV management*' (Table 4).

Table 4

	HIV FUTURES 3	HIV FUTURES 3 +WOMEN	HIV FUTURES 4	HIV FUTURES 4 +WOMEN	HIV FUTURES 5
HIV GP/S100 Prescriber	53.7	42.9	60.3	48.6	60.2
HIV specialist at outpatient clinic	38.5	51.0	43.3	41.0	56.8
HIV magazine/newspaper	43.3	51.5	43.7	53.3	45.4
Articles in gay press	31.4		34.0		31.1
HIV positive friends	31.9	46.6	30.0	36.0	34.9
Treatments officer					
Pharmacist					
Other HIV/AIDS organisation staff	14.7				
Publications from HIV/AIDS groups		52.1	41.9	60.4	41.3
Positive women's organisation		43.3		35.3	
Positive heterosexuals group				22.8	
Sexual health service	13.1		18.4	28.6	25.1
Internet			18.6		29.7
Alternative therapist	15.9	29.1			
Dietitian	13.7				
Partner/lover	13.1	24.0			

The data suggests that respondents rely heavily upon their HIV GP/S100 prescriber and/or HIV specialist for HIV treatments and HIV management advice. Positive men and women also reported a strong reliance on print media for HIV treatments and management information. For positive men, this includes a reliance on information produced through the gay press, and publications from HIV/AIDS organisations. Whilst positive women also report a strong reliance on print media for information, positive women reported a higher reliance on a range of other information sources including HIV positive friends, peer networks and Positive women's organisations.

**Survey question:** Respondents were asked to nominate from a list of potential sources, those that were important sources of information on living with HIV. The eight most regularly identified sources of **information for living with HIV** are presented here (percentage of sample).

Table 5

	HIV FUTURES 3	HIV FUTURES 3 +WOMEN	HIV FUTURES 4	HIV FUTURES 4 +WOMEN	HIV FUTURES 5
HIV GP/S100 Prescriber	32.5	28.5	38.6	28.1	32.3
HIV specialist at outpatient clinic	21.6	29.7	24.2		27.9
HIV magazine/ newspaper	45.0	49.1	45.3	52.8	49.1
Articles in gay press	35.2		37.6		36.6
HIV positive friends	43.2	61.6	43.8	52.3	47.3
Treatments officer Pharmacist					
Other HIV/AIDS organisation staff	19.7				25.1
Publications from HIV/AIDS groups		48.3	44.6	57.4	44.7
Positive women's organisation		56.5		49.7	
Positive heterosexuals group		29.5		28.2	
Sexual health service					
Internet			17.8		28.6
Alternative therapist	16.8	29.6			
Dietitian					
Partner/lover	22.2		23.9	28.5	
Peer support officer				24.9	

Respondents reported less reliance upon their HIV GP/S100 prescriber and/or HIV specialist for information on living day-to-day with HIV than they do for information on HIV treatment and HIV management. Positive women and men report a strong reliance on positive friends, positive organisations and various print media for information on living day-to-day with HIV, with women reporting a significantly higher reliance on positive friends and positive women's organisations.

**Survey question:** Respondents were asked whether they were currently using a range of services, and if so, whether they used them through HIV/AIDS organisations or through another organisation. The 8 most regularly identified services being used by respondents at **HIV/AIDS organisations** are presented below, (percentage of sample).

Table 6

	HIV FUTURES 3	HIV FUTURES 3 +WOMEN	HIV FUTURES 4	HIV FUTURES 4 +WOMEN	HIV FUTURES 5
Treatments advice	46.9	53.4	48.1	55.6	46.7
Treatments information	41.5	52.3	36.2	46.4	38.4
Social contact with other PLWHA	38.8	54.5	42.9	58.4	40.4
Counselling	30.6	34.1	32.9	35.1	35.1
Peer support group	30.1	61.8	33.7	60.4	32.2
Financial assistance	24.3	25.3	35.2	37.3	26.1
Complementary therapies	22.6	27.4		22.3	24.4
Informal peer support	21.7	41.7	23.9	40.7	25.1
Pharmacy services			22.1		

The data suggests that a high percentage of respondents use services provided by HIV/AIDS organisations, including treatments advice and information, with these organisations also being a strong source of social and peer support, particularly for positive women respondents. The indications are that a consistent percentage of positive women and men utilise HIV/AIDS organisations for counselling services, complementary therapies and financial assistance.

**Survey question:** Respondents were asked whether they were currently using a range of services and, if so whether they used them through HIV/AIDS organisations or through another organisation. The eight most regularly identified **services being used by** respondents at **other organisations** were (percentage of sample):

Table 7

	HIV FUTURES 3	HIV FUTURES 3 +WOMEN	HIV FUTURES 4	HIV FUTURES 4 +WOMEN	HIV FUTURES 5
Pharmacy services	40.2	53.5	41.2	40.6	38.9
Complementary therapies	26.5	43.5	22.3	29.8	23.6
Internet access	24.3	44.3	27.1	36.3	19.0
Treatments advice	24.2	25.0	23.1	23.1	18.8
Library	22.7	43.3	24.9	43.8	21.2
Counselling	21.0	32.4	22.9	27.1	22.2
Housing assistance	19.0		20.0	27.0	17.6
Financial advice	17.7				
Internet based information		25.1			
Treatments information		24.9			
Transport			21.4	35.4	
Mental health services					16.6

The data suggests that, as might be predicted, pharmacy is the predominant service accessed by respondents through organisations other than HIV/AIDS organisations. Respondents accessed a number of services provided by non-HIV/AIDS organisations, including complementary therapies, internet services, treatments advice, library services and counselling. Each featured highly for both positive men and women. However, positive women report a greater reliance upon a range of services from organisations *outside* those provided by HIV/AIDS organisations.

## HIV AND ACCESS TO SERVICES: THE REMAINING RESEARCH

### *Positive Health, Then and Now . . . Following HIV-positive lives over time*

Fogarty A, Rawstorne P, Prestage G, Grierson J, Grulich A, Kippax S, Worth H, Murphy D, Monograph 9/2003. National Centre in HIV Social Research, Faculty of Arts and Social Sciences, University of NSW

- "Participants are now seeing their key doctor less frequently than in the past – in general, a shift from monthly to quarterly visits."
- The likelihood that [participants] . . . received emotional support from their doctor increased over [the time of this longitudinal study].
- "Fewer participants are using hospital services."
- "Around one-quarter of the cohort experienced some problem accessing services. Participants were most likely to experience access difficulties at hospital pharmacies."
- Approximately 20% of participants reported the most common source of 'a lot' of emotional support at Time 2 of the survey (2001-2002) as coming from HIV support organisations; approximately 30% reported that they receive 'a lot' of emotional support from other health workers; approximately 35% receive 'a lot' of emotional support from professional counselors; approximately 35% receive 'a lot' of emotional support from HIV support organisations; with approximately 50% of participants receiving 'a lot' of emotional support from their doctor.
- Respondents reported "few barriers to accessing HIV services. Importantly, very few people were restricted from accessing services due to cost." (p57) This possibly reflects a sample bias, with participants drawn predominantly from inner-metropolitan Sydney, the NSW North Coast and Melbourne.

### *Health and wellbeing of HIV-positive Australians: findings from the third national HIV Futures Survey*

JW Grierson, MK Pitts and S Misson, International Journal of STD and AIDS 2005; 16: 802-806

- 71.4% of respondents had some contact with HIV/AIDS-related organisations.
- 37.7% of respondents had experienced discrimination, while attending a medical service due to their HIV status.

### *Factors distinguishing employed from unemployed people in the Positive Health Study*

Andrea S. Fogarty, Iryna Zablotska, Patrick Rawstorne, Garrett Prestage and Susan C Kippax. AIDS 2007, 21 (supl 1):S37-S42

- No specific data available on access to services.

## HIV/AIDS AND ACCESS TO SERVICES: DISCUSSION

The data drawn from the research suggests that respondents rely heavily upon their HIV GP/S100 prescriber and/or HIV specialist for HIV treatments, HIV management advice, information and general health care. However, following the introduction of Highly-Active AntiRetroviral Treatment (HAART) and the positive impact on morbidity and mortality for the positive population (Fogarty A, Rawstorne P, et.al p54), respondents report visiting their HIV GP and/or HIV specialist less frequently, with positive men more likely to visit their HIV GP for *both* HIV treatment *and* general health treatments, while positive women are more likely to visit *different* doctors for their HIV treatment and general health treatments.

The HIV Futures research indicates that positive men and women source information on *HIV treatments, HIV management and living with HIV* in different ways. Positive women seek information across a broad range of sources, with HIV positive friends, peer networks and positive women's organisations, dieticians, alternative therapist, peer support officer and her family identified among these sources of information (not all data reproduced here). Positive men report similar sources but with a greater emphasis upon sourcing information from their HIV GP, HIV specialist or HIV organisation and/or gay media. A strong reliance on various print media indicates that the gay press and HIV/AIDS organisations printed materials are seen as a valuable resource for positive people.

The high percentage of respondents seeking peer and social support networks for HIV management and living day-to-day with the HIV virus confirms a high importance of social and peer networks for positive people. A high percentage of positive men and women reported that they gain access to peer support networks, social contacts and information through the conduit of HIV/AIDS organisations, and for respondents, this is clearly an important service these organisations provide.

## HIV/AIDS, ACCESS TO SERVICES AND THE SOCIAL DETERMINANTS OF HEALTH: CONCLUSION

The differing lived experiences of HIV positive respondents evidenced throughout the literature reviewed here, confirms that the social determinants of health do impact upon the health and well being of the HIV positive Australians. As Grierson J, Thorpe R and Pitts M (2006 p70) state "*Clearly there are social factors and experiences that influence both health and well being among this [HIV positive] population.*"

As we have seen in relation to HIV/AIDS and employment, clinical indicators are not the only predictor of employment outcomes. Psychological, and social aspects also play a role, and a person's demographic background is as important a factor to their employment prospects as is their mental and physical health.

Likewise, in relation to HIV/AIDS and income inequality, the correlation between HIV/AIDS and poverty is considerably more complex than an individual's source of income. The majority of respondents were in receipt of a government pension or welfare payment, thus restricting income and placing most respondents beneath the [Henderson] poverty line. Other issues, including systemic and structural factors; the financial impact associated with being HIV positive (such as the costly and ongoing purchase of HIV treatments and services); the negative consequences resulting from stigma and discrimination; the difficulties faced by some HIV positive people excluded for extended periods of time from the workplace; and the difficulties of juggling a fluctuating health condition with the needs and demands of employment and employees, complicate the picture and confirm that social factors affect the employment outcomes and have very real implications for people living with HIV/AIDS.

In regards to HIV/AIDS and access to services, the literature indicates that here, too, social, cultural, structural and demographic factors each impact upon service provision and service access for HIV positive people. As we have seen here, positive women, positive Indigenous peoples, positive heterosexuals, positive gay men and older positive people each utilise services and source information in different ways. Also, the increasing reliance upon the HIV GP or HIV specialist and the re-medicalisation of HIV present continuing challenges to the community sector. As Fogarty A, Rawstorne P, et.al (2003, p57) states "*the dynamic interplay between the physical, social, and psychological experience of HIV means that the lived experience is one of change. The changing medical landscape further increases this complexity.*"

The NAPWA Care and Support Audit, of which this literature review is a part, will 'tease out' service provision and access issues. Through the audit's consultative process, including broad engagement with members, the HIV and mainstream health sectors (including national research centres and stakeholders), and with the publication of discussion papers and project reports, the NAPWA Care and Support Audit will inform future research and action into this and other important aspects for the health and well being of HIV positive people in Australia.

## Appendix a.

### Members of the NAPWA Care and Support Reference Group (CRG)

- Gabe McCarthy: Director, NAPWA
- Katherine Leane: Director, NAPWA; HIV Peer Support Worker, Women's Health Statewide, South Australia
- David Menadue: Education Convenor, NAPWA
- Rob Lake: Chief Executive Officer, PLWHA (NSW)
- David Barton: former Program Coordinator, Heterosexual HIV/AIDS Service, NSW
- David Wallace: former Positive Futures Team Leader, Bobby Goldsmith Foundation (BGF)
- Cipri Martinez: HIV Positive Peer Educator, WA AIDS Council
- John Daye: Health and Treatments Convenor, NAPWA
- John Rule: Manager, HIV Living and International Units, NAPWA
- Peter Canavan: NAPWA HIV Living policy analyst
- Ian Rankin, President, Australian Federation of AIDS Organisations (AFAO)
- Bill Whittaker, Health and Treatments Convenor, NAPWA

## Appendix b.

### Databases accessed:

- Medline
- APAIS Health
- Embase
- CINAHL
- NCHSR Library Catalogue
- PubMed
- HIVA
- SSCI
- Web of Science

## Appendix c.

### Internet sites accessed:

- ACON
- AIDS Action of the ACT
- AIDS Council of South Australia (ACSA)
- AIDS MAP
- Australian Bureau of Statistics (ABS)
- Australian Institute of Health Welfare
- Australian National Agency for Health and Welfare Services (AIHW)
- Australian Research Centre in Sex Health and Society (ARCSHS), Faculty of Health Science (La Trobe University)
- Department of Health and Ageing NAPWA
- National Centre in HIV Social Research, Faculty of Arts and Social Sciences (UNSW)
- New South Wales Health
- PLWHA New South Wales
- PLWHA Victoria
- Public Interest Advocacy Centre (PIAC)
- Queensland Association for Healthy Communities (QAHC)
- Queensland Health
- Queensland Positive People (QPP)
- Tasmanian Council on AIDS, Hepatitis and Related Diseases (TasCAHRD)
- The Australian Council on Healthcare Standards (ACHS)
- The Body
- UNAIDS
- Victorian AIDS Council (VAC)
- Victorian Government Health Information
- World Health Organisation (WHO) Commission on the Social Determinants of Health
- Western Australian AIDS Council (WAAC)

## REFERENCES

- Fogarty A, Rawstorne P, Prestage G, Grierson J, Grulich A, Kippax S, Worth H, Murphy D. *Positive Health, Then and Now . . . Following HIV-positive lives over time*. Monograph 9/2003. National Centre in HIV Social Research, Faculty of Arts and Social Sciences, University of NSW
- Andrea S. Fogarty, Iryna Zablotska, Patrick Rawstorne, Garrett Prestage and Susan C Kippax, *Factors distinguishing employed from unemployed people in the Positive Health Study*. AIDS 2007, 21 (supl 1):S37-S42
- Grierson J, Misson S, McDonald K, Pitts M, *Futures 3, Positive Australians on services, health and wellbeing*. The Living With HIV Program, Australian Research Centre in Sex, Health and Society, La Trobe University. May 2002 Monograph series number 37
- J Greirson, R Thorpe, M Saunders, M Pitts, *HIV Futures 4, State of the [positive] nation*. The Living with HIV Program, Australian Research Centre in Sex, Health and Society, La Trobe University. 2004 Monograph series number 48
- JW Grierson, MK Pitts and S Misson, *Health and wellbeing of HIV-positive Australians: findings from the third national HIV Futures Survey*. International Journal of STD and AIDS 2005; 16: 802-806
- J Greirson, R Thorpe, M Pitts, *HIV Futures 5, Life as we know it*. The Living with HIV Program, Australian Research Centre in Sex, Health and Society, La Trobe University. 2006 Monograph series number 60
- K McDonald, S Misson, J Grierson, *Juggling with HIV: The intricacies of positive women's lives in Australia today*. The Living With HIV Program, Australian Research Centre in Sex, Health and Society, La Trobe University. 2002 Monograph series number 38
- McDonald K, R Thorpe, J Grierson, *The Journey Continues: Women Living with HIV/AIDS in Australia, HIV Futures 4*. The Living With HIV Program, Australian Research Centre in Sex, Health and Society, La Trobe University. 2005 Monograph series number 51
- Morrissey M, *Poverty and Indigenous health*. Health Sociology Review, Volume 12 Issue 1 September 2003
- Persson A, Barton D, Richards W, *Men and women living heterosexually with HIV. The Straightpoz study, Volume 1*. National Centre in HIV Social Research, Faculty of Arts and Social Sciences, The University of New South Wales Monograph 2/2006
- Pitts M, Grierson J, Misson S, *Growing Older with HIV: A Study of Health, Social and Economic Circumstances for People Living with HIV in Australia over the Age of 50 Years*. Australian Research Centre in Sex, Health and Society, La Trobe University, AIDS Patient Care and STDs Volume 19, Number 7, 2005
- Saunders Peter, *Disability, Poverty and Living Standards: Reviewing Australian Evidence and Policies*. Social Policy Research Centre, University of New South Wales, paper No. 145 December 2005
- Willis J, McDonald K, Saunders M and Grierson J *HIV Futures 2, Aboriginal and Torres Strait Islander people living with HIV*. The Living With HIV Program, Australian Research Centre in Sex, Health and Society, La Trobe University. 2002 Monograph series number 30