RESILIENT COMMUNITIES

Community-based responses to high rates of HIV among indigenous peoples

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Abstract

Throughout history, indigenous peoples have demonstrated remarkable resilience in the face of significant adversity with this being demonstrated in the response of indigenous peoples to HIV, one of the greatest threats to health and well-being faced by people and communities today. High rates of HIV infection, combined with significant social determinants of health, intensify and compound the vulnerability of indigenous peoples and communities to HIV. Evidence shows that indigenous peoples in some countries have been disproportionately affected by HIV and suffer from significant disparities related to high rates of chronic conditions, including long-term HIV infection. This article discusses how community-based initiatives can play a key role in overcoming the challenges associated with HIV faced by indigenous peoples. The discussion demonstrates how the inherent resilience of indigenous communities contributes to beneficial outcomes for indigenous communities affected by HIV.

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Keywords

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Introduction

Historically, indigenous peoples throughout the world have demonstrated remarkable reserves of resilience in their struggle to resist the imposition of colonialist views and paradigms (Hickson et al., 2004; McIntosh, 2006; Smith, 2006; Wuttunee, 2004). The historical encounters between indigenous peoples and colonisers have led to the development of a range of protective mechanisms that indigenous peoples have deployed in their efforts to assert their sovereignty and self-determination (Gibson & Klinck, 2005; Walters & Simony, 2002). While these constitute significant historical precedents, it is important to acknowledge that this struggle continues within a contemporary context. Within this context, we can identify a number of protective mechanisms that serve to enhance the resilience of indigenous peoples as they confront health-related challenges such as HIV in the world today.

Within the last few hundred years, indigenous communities around the world have been marginalised and excluded from vital processes that have the potential to bring significant benefit to indigenous communities (McIntosh, 2006). This marginalisation has taken place in a number of domains such as the political arena, educational settings, and in the context of research (Smith, 1999). The exclusion of indigenous peoples from these important processes has been accompanied by the imposition of non-indigenous paradigms, and together these have contributed to significant health disparities between indigenous and non-indigenous peoples living in the same nation. In Australia, Canada and New Zealand, for example, indigenous peoples suffer significantly poorer health status than their non-indigenous peers and have excessive early mortality and lower life expectancy (Alcorn, 2011; Australian Institute of Health and Welfare, 2014; Blakely et al., 2010; Brimley, Hebert, Jackson, & Chassin, 2004; Gracey & King, 2009; Ministry of Health, 2010).

Today, however, there are positive indications that indigenous peoples are taking control of those processes which have an important impact on their lives (Walters, Evans-Campbell, Simoni, Ronquillo, & Bhuyan, 2006). In the area of research, for example, indigenous peoples are reclaiming the right to set the research agenda and to design and implement research paradigms that derive from their cultural context and which, as a result, are more likely to lead to beneficial outcomes for indigenous communities than the non-indigenous research processes which have prevailed since the onset of colonisation. In New Zealand, kaupapa Māori research fulfils the purpose of being Māori-led and being responsive to the needs of the Māori community. The Health Research Council of New Zealand (HRC) has recognised the importance of a kaupapa Māori approach to research by funding Māori health research that is based on this approach (HRC, n.d.). The HRC recognises that kaupapa Māori research has the potential to make a significant positive difference to the health and well-being of Māori and that this will in turn contribute to a reduction of the health disparities that currently exist between Māori and non-Māori. The central role that kaupapa Māori research can play in Māori development is encapsulated in the description of kaupapa Māori methodologies and theories as "a celebration and affirmation of indigenous ways and worldviews" (HRC, 2010, p. 7).

Placing indigenous peoples at the centre of processes which affect them and their communities is fundamental to making a positive difference to the lives of indigenous peoples

and is a key factor in increasing the resilience of indigenous peoples. For thousands of years indigenous peoples have displayed remarkable resilience in the face of considerable adversity, and today there are clear indications that this continues in an ongoing manner. Despite significant challenges to the health and well-being of indigenous communities, there are positive signs that indigenous communities continue to flourish in a way that will ensure their survival into the future (Fleming & Ledogar, 2008).

Among the challenges to the health and well-being of Māori and other indigenous peoples has been the introduction of disease at the onset of colonisation. The onslaught of colonisation brought with it a multiplicity of factors which contributed to a significant decline in the health of indigenous peoples and, as a consequence, a reduction in population numbers. Diseases that were unknown to indigenous peoples in the Pacific region, for example, claimed many lives before people were able to build up resistance that would ensure their ongoing survival (Miles, 1997). Prior to this, indigenous peoples exhibited remarkable resilience and thrived on ancestral land, observing ancient traditions that had been passed down over thousands of generations.

Indigenous peoples and history

By focusing on resilience and the health of indigenous peoples, we avoid applying a deficit model to addressing the health status of indigenous peoples. Rather, a focus on the resilience of indigenous peoples provides a means by which the history of indigenous struggle can be factored into our understanding of contemporary issues. In her commentary on research and indigenous peoples, Linda Smith (1999) has outlined why history is important to indigenous peoples. As she explains it, history for indigenous peoples is centred around a complex array of concepts and ideas, and as such is fundamental to the decolonisation of indigenous peoples. Given that indigenous peoples' versions of their own histories have been strongly contested by non-indigenous peoples, it is even more important that indigenous peoples' accounts of history be incorporated into our understanding of resilience and resiliency today.

A number of commentators have discussed resilience in relation to the vulnerability of population groups (Engle, Castle, & Menon, 1996; Magis, 2010). While it is important to acknowledge that people at different points in their life cycle may be at greater risk because of their perceived vulnerability, it is important that this not be linked to their indigeneity or cultural background. Rather, it is this very feature that acts as a protective mechanism for indigenous communities who confront an array of tensions and challenges within contemporary society. A measure of the resiliency of indigenous peoples can be taken from the ways in which they overcome these challenges despite the adversity and hardship with which they are confronted.

Confronting challenges

Commentators on resilience have noted the cyclical process that indigenous peoples take in adapting to challenging and stressful situations. In their discussion of resilience among indigenous families, McCubbin, Thompson, Thompson, and Fromer (1998) make the point that indigenous families respond in vastly different ways to stressors in their lives and that many of these families have an innate ability to adjust to stressors and then respond in a manner that draws on cultural reserves which in turn contribute to enhanced resilience. They describe resilience as the result of positive behaviour patterns that emerge from negative events and lead to the building of coping strategies which people harness to deal with future stressful events in their lives.

Other commentators have noted that indigenous peoples contribute to an enhanced state of resilience in their struggle to reassert sovereignty

and self-determination. As indigenous peoples emerge from several hundred years of oppression, they are now equipped with remarkable survival skills that ensure their survival in the future (Battiste, 1998). In their report into the effects of residential schooling on Aboriginal people in Canada, Stout and Kipling (2003) noted that the struggle by indigenous peoples to overcome the colonialist legacies of the past has meant that they are well equipped to develop effective promotional activities which are likely to derive considerable benefits for indigenous peoples and their well-being.

It is important, therefore, to note that the term resilience when applied to indigenous peoples has a long history that draws on multiple cultural strands and that, furthermore, it is a testimony to the refusal of indigenous peoples to accept assimilation or integration as an acceptable strategy for their ongoing survival.

> Assimilation of Indigenous peoples did not work, and the alternative to being Okanagan, Cree, Mohawk, Maori, or any other Indigenous identity is dehumanization. The Indigenous reality is one of resilience, refusal to disappear; it is a reflection of the strength and beauty of peoples who have lived here since humans existed on this land, and will continue to be so. The struggle continues, the struggle to maintain Indigenous knowledge, languages, and nations, in the hope that our children will live and flourish, not merely survive. (Cohen, 2001, p. 147)

Indigenous populations have rich reserves from which to draw to shore up their resilience. These include strong attachment to ancestral traditional land, and as a result, interactions with the environment; stories and narratives that derive from these interactions over generations; a sense of one's individual and collective identity; and the revitalisation of language and culture (Kirmayer, Dandeneau, Marshall, Phillips, & Williamson, 2011). In this sense, indigenous resilience is a form of social capital that can be harnessed, especially in times of crisis, to leverage resources and capabilities that allow people and communities to maintain and build health and well-being. For thousands of years indigenous peoples have faced health-related crises that have had the potential to decimate communities, with the latest manifestation of this being the HIV epidemic. As indigenous peoples confront modern day challenges posed by HIV, it is worth exploring the concept of resilience and its relevance to finding solutions to these challenges.

The impact of HIV on indigenous peoples

Today, one of the greatest threats to the health of people around the world is that posed by the AIDS epidemic. The global report on HIV produced by UNAIDS (2014) estimated that more than 35 million people were living with HIV, with this representing an increase on previous years because of the availability of anti-retroviral treatment. While the overall number of people living with HIV is increasing, the annual rate of new diagnoses is decreasing. Given that there is no imminent vaccine in sight, however, HIV is likely to continue to place significant health, social and economic burdens on people and communities well into the future.

In this, the beginning of the fourth decade of the epidemic, it is apparent that some sectors of our society have been adversely affected by HIV, with women, sex workers, people who inject drugs, and men who have sex with men having disproportionately higher rates of HIV infection than other people. While some of these disparities have been apparent since the beginning of the epidemic, others have only come to our attention in more recent times, with indigenous peoples being one of those population groups that have been adversely affected by HIV. In Canada, for example, significant HIV disparities exist between indigenous and non-indigenous peoples, where in 2011 indigenous

peoples made up more than 12% of HIV notifications and almost 20% of AIDS cases, while making up just over 4% of the total population (Public Health Agency of Canada, 2011). The number of HIV notifications is likely to be considerably higher because ethnicity data are not collected in Ontario and Quebec, the two provinces with the largest proportions of indigenous peoples. This issue highlights one of the problems associated with the collection of ethnicity data and its impact on indigenous peoples and the allocation of resources. Under-counting of indigenous peoples can lead to the misapprehension that they enjoy the same health status as others and this allows decision-makers to abrogate their responsibility to ensure adequate resources to meet the health needs of indigenous peoples. With regard to HIV, it is likely that under-reporting of ethnicity data is a factor in the perception that indigenous peoples in some countries have not been adversely affected by the AIDS epidemic. Given the complexity of issues surrounding the reporting of ethnicity data, it is often difficult to know how accurate our understanding of the impact of the epidemic is on indigenous peoples (Dean & Fleming, 2003). Consequently, the involvement of affected communities is vital to developing and implementing effective surveillance systems to monitor the impact of HIV on indigenous communities.

In Australia, distinct differences can be seen in the pattern of HIV infection among Aboriginal and Torres Strait Islander people when compared with that among non-indigenous peoples. A greater proportion of infections among the indigenous population of Australia are due to heterosexual transmission than homosexual transmission, as is the case with the non-indigenous population. Furthermore, a higher proportion of indigenous women than non-indigenous women have been infected with HIV in Australia (Kirby Institute, 2013). Community-controlled health services have an important role to play by exercising leadership and ensuring that accurate information and resources reach all indigenous Australians, especially those who face barriers such as poor access to services, geographical distance and financial hardship.

In New Zealand, the number of HIV infections among Māori, the indigenous people of that country, has been relatively small. Nevertheless, there appear to be factors that indicate a higher risk of HIV infection among Māori than non-Māori. Higher rates of HIV infection among Māori women suggested an elevated level of vulnerability (Shea et al., 2011). Additionally, recent analysis has shown that Māori men are more likely than others to test late for HIV, with this leading to poorer health outcomes for those who test positive (Dickson, McAllister, Sharples, & Paul, 2011). Moreover, this would suggest that Māori may not have the same level of access to HIV health services as non-Māori and this would place them at risk of a number of HIV-related morbidities.

Across the three countries, it is clear that there are valuable lessons to be learned from one another. In light of the contemporary threat posed by HIV to the health and well-being of indigenous peoples it is worth reflecting on the meaning of resilience and the role that it plays in ensuring the good health of generations to come. How these lessons and insights might be applied across the three countries needs to be considered in a way that will enhance HIV prevention strategies among indigenous peoples as we continue to grapple with the challenges posed by the AIDS epidemic.

A study conducted across Australia, Canada and New Zealand has confirmed that significant HIV disparities exist between the indigenous and non-indigenous populations within each country (Shea et al., 2011). Data from the official HIV surveillance agencies of the three countries were analysed and comparisons with non-indigenous data were made within each country as well as across the three countries. The age-standardised rates of HIV diagnoses among indigenous and non-indigenous peoples in Australia, Canada and New Zealand for

the five-year period from 2004 are outlined in Table 1.

As this table shows, rates of HIV diagnosis were much higher among indigenous males and females in Canada than they were among non-indigenous Canadians. At almost 200 per 100,000, rates among the indigenous population of that country were alarmingly high. In Australia, while rates among indigenous and non-indigenous men were similar, this was not the case for females. In fact, the significantly higher rates among Aboriginal and Torres Strait Islander females than among non-indigenous Australian females are cause for considerable concern. In New Zealand where overall rates of HIV infection are relatively small, standardised rates among Māori and non-Māori were similar. However, Māori women had slightly higher rates than non-Māori but because of the small numbers of total diagnoses among females for this five-year period it was not possible to establish whether the difference was significant.

Community-based responses to HIV

In response to high rates of HIV among indigenous peoples, a number of innovative community-based initiatives have been developed, both within countries and internationally. In the process, a durable and sustainable network of people and communities has been established globally to raise awareness of HIV and its impact on indigenous peoples.

In contrast to initiatives developed by non-indigenous agencies, these initiatives are led by indigenous peoples themselves and are firmly grounded within indigenous communities. These responses draw on the resilience and innate strengths of indigenous communities that have been passed down through many generations. Just as indigenous communities have shown remarkable resilience in the face of major trauma and upheaval throughout history, today we can see evidence of indigenous communities responding in a way that will ensure they overcome the challenges presented by HIV and AIDS. Three recent community initiatives provide clear evidence that, after three decades of HIV, indigenous communities are taking charge of strategies to prevent the ongoing transmission of HIV among indigenous peoples and to provide care and support for those people affected by HIV.

These initiatives exemplify the key concepts that underpin a participatory approach to research with community groups (Israel, Eng, Schulz, & Parker, 2013). For the purposes of this article, therefore, a community-based initiative is one which is based on partnership with affected communities, an assessment of community strengths, identification of priority health concerns, the design and development of policy and practice, active involvement of community members in the processes of the organisation, and regular evaluation of these processes. These components identify these indigenous HIV initiatives as community-based and are vital to their ongoing success as well as

TABLE 1 Standardised rates of HIV diagnosis among the indigenous peoples of Australia, Canada and New Zealand (adjusted rate per 100,000)

	Australia		Canada		New Zealand	
	2004–2008		2004–2008		2004–2008	
	Male	Female	Male	Female	Male	Female
Indigenous	48.5	12.9	178.1	178.4	41.9	4.3
Non-Indigenous	50.6	4.4	49.2	9.04	44.5	2.5

Source: Shea et al., 2011

their acceptance and endorsement by the communities that they serve.

The Toronto Charter: Indigenous peoples' action plan on HIV and AIDS

The Toronto Charter is an action plan on HIV and AIDS for indigenous people around the world and was launched at the 16th International AIDS Conference in Toronto in 2006. The development of the charter was led by the Planning Committee of the International Indigenous Peoples Satellite meeting that took place in the lead up to the international conference. As part of this process, members of the committee consulted with indigenous communities in a number of countries, including Australia, Canada, New Zealand and the United States as well as with representatives of the United Nations Permanent Forum on Indigenous Issues. Overwhelmingly, the charter was endorsed at these meetings, with this support in evidence when the charter was launched in Toronto in 2006. Overwhelming endorsement by the indigenous delegates at the Toronto AIDS Conference confirmed that there was a need for a document that could guide the development of HIV policy in the countries from which delegates came.

The charter calls for a complete reorientation of the ways in which HIV care, support and prevention programmes are conducted within indigenous communities around the world and emphasises the need for indigenous people to be at the forefront of designing and implementing HIV programmes for indigenous peoples.

The recommendations of the charter are based on the acknowledgement that successful initiatives to overcome the impact of HIV in indigenous communities must be based on partnership and collaboration. The charter calls on government agencies and HIV decision-makers to:

- Ensure the central participation of indigenous peoples in all programmes related to the prevention of HIV and programmes for the care and support of indigenous peoples living with HIV and AIDS.
- Provide adequate resources to indigenous peoples to design, develop and implement HIV and AIDS programmes.
- Increase current resources so that indigenous communities can respond in a timely and effective way to the demands placed on communities by the AIDS epidemic.
- Ensure the process of participation of indigenous peoples in United Nations forums is strengthened so their views are fairly represented.
- Incorporate this Charter in its entirety in all policy pertaining to indigenous peoples and HIV and AIDS.
- Monitor and take action against any States whose persistent policies and activities fail to acknowledge and support the integration of this Charter into State policies relating to HIV and AIDS. (Planning Committee of the International Indigenous Peoples Satellite, 2006)

Eight years after the launch of the Toronto Charter, there are indications that it is having some impact at national and international levels. In New Zealand, the charter features prominently in the work of INA (the Māori, Indigenous and Pacific Island HIV/AIDS Foundation), and has provided contextual information for recent successful government grant applications. Internationally, the charter informed discussions and outcomes of an international policy dialogue convened by Health Canada (Health Canada, 2009). And more recently, the Toronto Charter was tabled and discussed at a side event of a meeting of the United Nations Permanent Forum on Indigenous Issues. The Toronto Charter is hosted by the Canadian Aboriginal AIDS Network and is currently being reviewed and evaluated to ensure that it meets future needs of indigenous peoples and communities affected by HIV and AIDS.

International Indigenous Working Group on HIV and AIDS (IIWGHA)

IIWGHA was established soon after the Toronto Conference. To date, it has been made up of indigenous leaders from countries that include Australia, Bolivia, Brazil, Canada, Chile, Guatemala, Mexico, New Zealand and the United States. A key role of the group is to build and consolidate international networks to increase awareness of HIV and to develop strategies to influence the development of indigenous HIV policy. The forum was established in response to increasing rates of HIV among indigenous peoples internationally and in the face of limited and inappropriate government response to HIV among indigenous peoples in many parts of the world. The high rates of HIV among the indigenous people of Canada provide a salient example of how inadequate government responses to multiple social and health risk factors can contribute to disproportionate rates of HIV among First Nations, Métis and Inuit peoples (Craib et al., 2003; Ford, Daniel, & Miller, 2006).

In response to the lack of national and international government action in the face of HIV-related challenges to the health of indigenous peoples, IIWGHA was established with the following objectives:

- Increase the integration of HIV, AIDS and indigenous peoples at the international level;
- Improve meaningful inclusion of indigenous people in research, policy and programme development;
- Ensure indigenous peoples are more accurately represented in HIV and AIDS data collection;
- Increase support for HIV capacity development;
- Develop an indigenous specific approach to the social determinants and health; and
- Ensure that indigenous HIV and AIDS issues are presented at international AIDS conferences. (International Indigenous Working Group on HIV and AIDS, n.d., p. 3)

Since its inception, IIWGHA has achieved significant success, both nationally within countries and internationally. Tangible achievements include the development and implementation of a strategic plan, as well as the development of an international indigenous HIV research plan, with these being underpinned by a robust network of indigenous researchers, communities and people living with HIV in many parts of the world. This network has been responsible for coordinating and organising international meetings that have brought people together from countries throughout the world. As a result, there has been a strong and visible presence of indigenous participants at international AIDS conferences since the meeting in Toronto in 2006. This increased visibility of indigenous peoples at international meetings has been a driving factor in ensuring that indigenous peoples and HIV figure prominently on the agendas of these meetings.

INA—The Māori, Indigenous and Pacific Island HIV/AIDS Foundation

In New Zealand, a recently established national Māori community-based initiative demonstrates clearly that Māori are building strong networks to deal with the impact of HIV on communities and individuals. INA, the Māori, Indigenous and Pacific Island HIV/AIDS Foundation, is evidence of Māori resilience in the face of adversity. As well as providing significant local community development, INA has established a strong and enduring international presence through their representation at international forums and networks. The work of INA is based on three key objectives:

- To improve the quality of life for people living with HIV and AIDS.

- To improve the quality of information on HIV given to our communities.
- To advocate for the rights of all Indigenous people. (INA, n.d.)

The success of INA can be measured by the fact that the organisation has achieved government recognition in the form of a formal contract. Today, INA provides HIV services throughout New Zealand while maintaining a strong international focus which allows the organisation to play a valuable membership role in the International Indigenous Working Group on HIV and AIDS.

Indicators of success

Community engagement is an essential element of initiatives to improve the health of indigenous communities and is an important indicator of the success of community-based programmes in addressing high impact health issues (Hurst & Nader, 2006). Sustainable community engagement in HIV-related health initiatives can contribute to community resilience by preventing ongoing HIV transmission. The Toronto Charter, IIWGHA and INA are tangible examples of initiatives that contribute to indigenous community resilience in the face of ongoing challenges posed by HIV and AIDS. Tangible evidence that these initiatives have had a significant impact include increased government and community awareness of the HIV disparities among indigenous populations, the growth and consolidation of national and international networks of indigenous peoples in response to HIV, relationship-building between indigenous communities and government decision-makers, and a visible presence of indigenous peoples at international HIV meetings and conferences. Community-based initiatives based on these principles can make a substantial contribution to the reduction of health disparities, while making tangible contributions to the building of community resilience (Celentano et al., 2005).

By building resilience among indigenous peoples, communities will be well-placed to confront and overcome the ongoing challenges associated with HIV. After three decades of a top-down approach, heavy reliance on biomedical paradigms, and no sign of a cure in the near future, community-based responses based on the bolstering of community resilience provide viable alternatives to stem the transmission of HIV within community settings (Thomas-Slayter & Fisher, 2011). By identifying and understanding the elements that contribute to the success of community-based HIV initiatives, we can contribute more effectively to the prevention of HIV. These three community-based initiatives have been underpinned by participation, critical learning, a shared vision, a strong sense of community, leadership, knowledge building, skill and resource development, and effective communication. Each of these elements is important in the building of community capacity and resilience and all are fundamental to future initiatives to overcome HIV within indigenous communities (Durie, 2004; Littlejohns & Smith, 2008).

While resilience is an important element in providing protection from disease, it is important to consider how resilience might be strengthened and enhanced. Facilitating enhanced resilience has tangible benefits for indigenous communities. Bell (2001) identifies multiple factors which serve to enhance the resilience of young people and these have applicability to the health and well-being of indigenous communities confronting illnesses such as those related to HIV. Among the factors that he identifies are physical health, connectedness to others, family-oriented interventions, and increased social skills, all of which have been identified as fundamental to effective HIV health promotion programmes. Strategies that identify the qualities that enhance resilience are fundamental to bringing about positive change and improvement in indigenous communities.

Looking towards the future

While resilience has been instrumental in helping indigenous peoples to confront challenging and stressful encounters within the context of colonisation, it is also fundamental to assisting indigenous peoples to capitalise on the past with a view to enhancing health and well-being in the future. In the case of HIV, we can see these principles being applied as indigenous communities struggle to overcome this modern day assault on our health and well-being. As indigenous peoples, we grow up knowing that our ancestors have overcome similar threats to their well-being. This knowledge, together with the strong desire to thrive into the future, is a core component in community-based efforts to overcome HIV and build community resilience.

Sodeke (2004, p. 254) describes the ability to apply past lessons to the future as integral to the concept he describes as human flourishing, a concept that is fundamental to the self-determination of indigenous peoples. As he describes it, human flourishing is fundamental to the development of indigenous communities in all their diversity and complexity. Human flourishing allows indigenous peoples and other vulnerable communities to reach their full potential and to succeed at all levels, including human, social, economic, political and spiritual.

In summary, therefore, our understanding of resilience draws on our past and applies these lessons to the present so that the strategies we develop and implement might allow us to flourish for the good of future generations. Successful HIV initiatives draw inspiration from our ancestral past and acknowledge the role that our ancestors play in guiding us towards the future.

This discussion has identified a number of key concepts that need to be considered in an analysis of resilience and resiliency as they apply to indigenous peoples confronting HIV-related challenges. Integral to this approach is an acknowledgment that resilience today has historical origins that go back many generations. By drawing on this knowledge we are well placed to understand and define resilience so that it might be deployed in a way that will contribute significantly to the health and well-being of indigenous peoples affected by the modern day threat of HIV.

To overcome HIV, we must understand the multiple factors that contribute to good health. Historically, resilient people and communities have played a major role in the flourishing of indigenous communities and ensuring health and well-being. Mindful of these historical precedents, we need to understand and acknowledge the role that community resilience plays in helping indigenous peoples to confront and overcome contemporary challenges to good health such as those posed by HIV. Understanding the complexity of resilience and its role in boosting the strength of indigenous communities will be fundamental to overcoming the ongoing impact of the HIV epidemic.

Glossary

kaupapa Māori	Māori ideology

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