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A POST-2015 DEVELOPMENT AGENDA:

LESSONS FROM GOVERNANCE OF HIV RESPONSES IN ASIA AND THE PACIFIC



Proposed citation:

UNDP (2014). *A Post-2015 Development Agenda: Lessons from Governance of HIV Responses in Asia and the Pacific*. Bangkok, UNDP.

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Design: Ian Mungall/UNDP.

Cover photo: Young mothers and vaccinated children leave a UNDP-sponsored health clinic in Hakha Township, Chin State, Myanmar, April 2013. Tom Cheatham/UNDP.



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Foreword

The HIV response in Asia and the Pacific has produced a new paradigm in the governance of disease responses: shifting from what was once a largely top-down, individual, reactive, mono-sectoral and biomedical-based approach, towards an increasingly bottom-up, collective, proactive, multi-sectoral and rights-based approach with pronounced emphasis on human rights, enabling legal environments and community engagement.

The new approach to governance of health responses has led to one of the greatest MDG successes in the Asia-Pacific region: the number of new HIV infections declined by 20 percent over the last decade on average and by over 50 percent in five countries that account for large numbers of people living with HIV in the region (India, Myanmar, Nepal, Papua New Guinea and Thailand); the number of people on HIV treatment has tripled since 2006; and at least 14 countries in the region have taken positive legal reforms and policy decisions as part of HIV responses, including decriminalization of same-sex relationships, removal of HIV-related travel restrictions, and use of trade-related intellectual property measures to increase access to affordable life-saving HIV medicines.

Further efforts are certainly needed to achieve the “Three Zeros” vision of the Joint United Nations Programme on HIV/AIDS (UNAIDS) – zero new HIV infections, zero discrimination and zero AIDS-related deaths – and ultimately an AIDS-free generation. Nevertheless, the significant progress on reaching HIV targets under MDG 6 (combatting HIV, malaria and other diseases) provides valuable insights for the pursuit of other development challenges, such as the growing threat of chronic non-communicable diseases (NCDs), environmental degradation, and poor maternal and child health (MDGs 4 & 5), where progress is lagging in the region.

As illustrated by numerous examples and analyses throughout this report, the HIV response in the Asia-Pacific region has successfully integrated key democratic governance principles into what had previously been a traditional health sector-focused response. This entails, for example, rights-based approaches; multi-sectoral governance architecture; enabling legal and policy environments; and participatory governance, particularly the empowerment and engagement of marginalized and vulnerable populations, among others.

The 2015 MDG deadline is fast approaching, and we venture into the post-2015 world with a growing focus on sustainable and inclusive development. We should take full advantage of valuable experiences from the HIV response to strengthen and accelerate the global effort towards pursuing each of the MDGs, and to shape the post-2015 development agenda with a strong focus on the most marginalized and vulnerable, social justice and human development that is inclusive of all.



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Acknowledgements

The report was authored by Mr. John Godwin, Consultant. The project was managed by Kazuyuki Uji, HIV, Health and Inclusive Development Policy Specialist, UNDP Asia-Pacific Regional Centre.

Thanks are due to the UNDP Asia-Pacific Regional Centre HIV, Health and Development Practice Team and Democratic Governance Practice Team, especially Mr. Clifton Cortez, Mr. Phil Matsheza, Ms. Pauline Tamesis, Mr. Edmund Settle, Mr. Thomas Beloe, and Ms. Thusitha Pilapitiya.

Appreciation is also extended to the WHO Western Pacific Regional Office, particularly Dr. Zhao Pengfei, Dr. Sivasankara Anand, Dr. Ying-ru Lo, and Dr. Anjana Bushan.

The following individuals are also acknowledged for their contributions: Mr. Everett A. Berg, Ms. Anjani Bhattarai, Ms. Anna Boelens, Ms. Alessandra Casazza, Dr. Mandeep Dhaliwal, Ms. Dilrukshi Fonseka, Ms. Cherie Hart, Ms. Khemtip Khemsaksit, Ms. Tongta Khiewpaisal, Mr. Taimur Khilji, Mr. Atif Khurshid, Mr. Maung Maung Kyaw, Ms. Barkhas Losolsuren, Mr. Peterson Magoola, Mr. Ian Mungall, Dr. Win Mar, Mr. Shiba Phurailatpam, Ms. Nashida Sattar, Mr. Ferdinand Strobel, Mr. Tek Tamata, Ms. Pranee Threekul, and Ms. Marta Vallejo.

Glossary of Acronyms and Terms

3DF	Three Diseases Fund (Myanmar)
AIDS	Acquired Immunodeficiency Syndrome
ADB	Asian Development Bank
ART	Antiretroviral therapy
ARV	Antiretroviral
ASEAN	Association of South East Asian Nations
CBCA	Cambodian Business Coalition on AIDS
CBO	Community-based organization
CCM	Country Coordinating Mechanism
CPN+	Cambodia Network of People Living with HIV/AIDS
CSO	Civil society organizations
DALY	Disability-Adjusted Life Year
DMSC	Durbar Mahila Samanwaya Committee
ESCAP	Economic and Social Commission for Asia and the Pacific
GIPA	Greater involvement of people living with HIV/AIDS
HIV	Human Immunodeficiency Virus
HLP	High-Level Panel of Eminent Persons
IDLO	International Development Law Organization
ILO	International Labour Organization
INP+	Indian Network of People living with HIV/AIDS
KHPT	Karnataka Health Promotion Trust (India)
LAC	Local AIDS Council (Philippines)
MDG	Millennium Development Goal
MSM	Men who have sex with men
NAC	National AIDS Commission / Council
NCD	Non-communicable disease
NGO	Non-government organization
NSP	Needle and syringe programme
OHCHR	Office of the High Commissioner for Human Rights
OSHF	Oil Search Health Foundation
PACER	Pacific Agreement on Closer Economic Relations
PDA	Population and Community Development Association
PDR	People's Democratic Republic (Lao)
PEPFAR	President's Emergency Plan for AIDS Relief
PLHIV	People living with HIV
PMTCT	Prevention of mother-to-child transmission
PNAC	Philippine National AIDS Council
PNG	Papua New Guinea
RAAT	Regional AIDS Assistance Team (Philippines)
SAARC	South Asian Association for Regional Cooperation
SACS	State AIDS Control Society (India)
SPC	Secretariat of the Pacific Community
STI	Sexually transmitted infection
SWING	Service Workers in Group (Thailand)

TB	Tuberculosis
TANSAC	Tamil Nadu State AIDS Control Society (India)
TPP	Trans-Pacific Partnership
TRIPS	Trade-Related Aspects of Intellectual Property Rights
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNFPA	United Nations Population Fund
UNICEF	United Nations Children's Fund
UNDP	United Nations Development Programme
USD	United States Dollars
VNP+	Viet Nam Network of People Living with HIV/AIDS
WHO	World Health Organization
WTO	World Trade Organization

Democratic governance

Governance is the exercise of economic, political and administrative authority to manage a country's affairs at all levels. It comprises the mechanisms, processes and institutions, through which citizens and groups articulate their interests, exercise their legal rights, meet their obligations and mediate their differences. Democratic governance requires institutions and processes that are responsive to the needs of ordinary citizens, including the poor, and that promote development through strengthened electoral and legislative systems, improved access to justice and public administration and greater capacity to deliver basic services to those most in need. Democratic governance brings people together within nations and around the world, fostering partnerships and sharing ways to promote participation, accountability and effectiveness at all levels. It builds effective and capable states that are accountable and transparent, inclusive and responsive, from elections to participation of women. Democratic governance addresses the allocation and management of resources to respond to collective problems. It is characterized by participation, transparency, accountability, rule of law, effectiveness and equity.

Post-2015 development agenda

The 'Post-2015 Development Agenda' refers to a process led by the United Nations that aims to define the global development framework that will succeed the UN Millennium Development Goals (MDGs). The existing MDGs were agreed in 2000 and come to an end in 2015. The MDGs are goals in the areas of poverty alleviation, education, gender equality and empowerment of women, child and maternal health, environmental sustainability, reducing HIV and communicable diseases, and building a global partnership for development.

Key populations

The term 'key populations' refers to the populations who are most likely to be exposed to HIV or to transmit it, and whose engagement is critical to a successful HIV response. These are defined as people living with HIV, men who have sex with men (MSM), transgender people, people who inject drugs, sex workers and their clients, and HIV-negative intimate partners of people living with HIV.

Executive Summary

The purpose of this report is to describe experiences and lessons learned from governance of HIV responses in Asia and the Pacific to inform discussions and debates regarding the post-2015 development agenda.

Effective HIV responses have been characterized by the following elements of democratic governance:

- Strong national political leadership for managing participatory, human rights-based and evidence-informed HIV responses.
- An international system responsive to and aligned with national priorities, advancing shared international commitments to HIV, health, development and human rights and producing results for those most affected.
- Multisectoral governance and coordination mechanisms involving multiple stakeholders and sectors in areas such as health, law and justice, education, labour, social affairs and community development.
- Participation of people living with HIV and other key populations and their community-based organizations in activism, community mobilization, policy development, planning and delivery of HIV services. An empowered civil society with the necessary skills and resources for advocacy has demanded transparency and accountability from governments, while also establishing structures to ensure the accountability of civil society organizations to the communities they represent.
- An emphasis on the social determinants of health and a willingness to tackle the structural factors that influence health outcomes.
- Attention to the legal environment and willingness to pursue pragmatic solutions to overcoming legal barriers to reaching highly marginalized key populations with HIV services.

The report considers how lessons learned from HIV can inform discussions regarding the proposals of the UN Secretary-General and the High-Level Panel of Eminent Persons on the post-2015 development agenda.

The report includes case studies applying governance lessons to non-communicable diseases (NCDs) and child and maternal health. NCDs are highlighted because they present a growing threat to development and require attention as a regional health and development priority in the post-2015 context. Child and maternal health are highlighted because of the slow progress in reaching Millennium Development Goals (MDG) 3 and 4 in Asia and the Pacific.

Leadership, policy and planning architecture

Political leadership has provided the foundation for success of national HIV responses and is key to development efforts that seek to promote the needs and rights of marginalized populations.

Eradication of poverty and marginalization requires strengthened governance that enables political leadership to address the fundamental economic, social and cultural obstacles to development. Inclusive national planning and coordination mechanisms can provide a foundation for strong political leadership.

The 'Three Ones' principle developed in the context of HIV requires national responses that are guided by: one agreed action framework that provides the basis for coordinating the work of all partners; one national coordinating authority with a multisectoral mandate; and one agreed country-level monitoring and evaluation system. This principle could be applied or adapted to guide other development priorities that would benefit from harmonization, alignment and multisectoral coordination, for example climate change, water management or NCD responses.

Governments should be held accountable to time-limited, concrete commitments. Coordination of national responses through comprehensive national strategic plans requires linkages between sectors and agencies working at national, provincial and district levels, documenting and sharing information between agencies and across sectors. Multisectoral responses enable a focus on structural factors that influence development outcomes.

Development efforts must address the political, economic, legal and social determinants that affect outcomes in health, nutrition, gender equality and education.

Vertical approaches in the health sector are justified in the context of emergency responses to epidemics and disease priorities, but as a longer-term strategy can be harmful to health systems. To ensure sustainable responses, donors should avoid supporting vertical, donor-driven, issue-specific responses unless exceptional circumstances exist.

Decentralization

Decentralized governance mechanisms such as local AIDS Councils have been effective in promoting local leadership, ownership and uptake of HIV services. Decentralization combined with local democracy can improve the responsiveness of policies and programmes, provided that there is local leadership and political will, and that local authorities are empowered with sufficient resources and autonomy to meet their responsibilities. Local social norms sometimes restrict wide and equal participation. Norms that discriminate against women and girls or minorities (including people living with HIV and key populations) prevent communities from reaching their full potential for development. Local champions need to be engaged to challenge harmful norms so that decentralized governance can be inclusive and operate to provide benefits to all in the community.

Enabling legal and policy environments

Sustainable development requires a focus on human rights and social justice. A human rights-based approach provides a practical way to address the social determinants of health, including gender inequalities, stigma and discrimination and other socially determined barriers. As described in the report of the Global Commission on HIV and the Law, the HIV response has demonstrated that a focus on laws, access to justice and law enforcement practices is essential to provide an enabling environment for health programmes that seek to reach marginalized populations.

In the context of HIV, legal empowerment efforts have focused on populations that are highly stigmatized and whose conduct is often criminalized. Legal empowerment including legal education, legal aid and access to justice initiatives can help reduce social marginalization by enabling people to actively participate in shaping rights-based development efforts. Legal empowerment is fundamentally concerned with realizing the human rights of the marginalized, and is community driven.

HIV has demonstrated the range of avenues to ensure that human rights obligations and commitments are met. These include national HIV laws and policies, constitutional recognition of the right to health and other human rights, human rights conventions and reporting bodies at the global level, and national mechanisms such as court arbitration, parliamentary oversight, national human rights institutions and community-based monitoring. Advocacy for the rights of key populations is pioneering new approaches.

Principles of human rights, including sexual and reproductive rights and women's rights, social equity and justice, should be central considerations in all fields of development. Applying these principles requires asking whether an approach is informed by examination of issues of power, exclusion and structural injustice, and whether it works at removing injustices and inequalities. The Millennium Development Goals (MDG) failed to include specific goals and targets on human rights. The post-2015 development agenda requires a much stronger focus on the human rights of the most marginalized and the equitable distribution of the benefits of development.

Laws and policies that promote gender equality are essential to provide a supportive environment for HIV responses and can also play a key role in accelerating equitable progress on nutrition, education and child and maternal

health. Gender equality considerations need to be integrated into governance arrangements for all development priorities, such as in approaches to community participation and representation.

Alignment of trade policy with development objectives

A key lesson from HIV has been that health and development objectives must not be given lesser priority than trade objectives when countries are defining national policy on issues such as pharmaceutical patents. This principle should inform the approach of governments when negotiating free trade agreements affecting development priorities. Free trade agreements should not impede the ability of countries to apply laws and policies relating to intellectual property and regulation and taxation of tobacco, alcohol, processed foods and other potentially harmful products that best suit their development needs. Free trade agreements should be consistent with international agreements such as the World Trade Organization (WTO) Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS). All countries should carefully assess the potential adverse impacts of 'TRIPS-plus' provisions on access to medicines and other key development issues. The environmental impacts of free trade agreements should also be considered, for example, the potential for resource depletion and increased carbon emissions associated with expansion of trade and industry.

Participatory governance

HIV responses have been characterized by strong civil society leadership including the central role of people living with HIV and key populations in activism, advocacy, awareness, policy setting, programme design, service delivery, monitoring, evaluation and acting as a watchdog for progress. Participatory governance approaches have strengthened the HIV response and built the capacity of socially and legally marginalized communities to contribute to broader development efforts.

Across all fields of development, governance models are required that are participatory, responsive and inclusive to the needs of all communities, rather than only the needs of political and economic elites or of mainstream society. Inclusive development requires participatory approaches that actively involve marginalized communities. Participation is effective when it allows a safe space for communities that have previously been excluded from power to debate, shape, monitor and hold to account the actions of governments and non-government actors that affect them. Community participation needs to be adequately resourced to ensure that marginalized communities participate meaningfully in governance mechanisms. Development interventions are strengthened by ensuring programme beneficiaries participate in designing, delivering and evaluating the programmes that affect their lives.

Private sector engagement

The Business Coalition model developed in the context of HIV to support business leadership may be useful for a range of other development priorities. The key feature of this model is a structure led by business. Many corporations recognize a corporate social responsibility role. Partnerships between governments and private sector corporations can help to ensure corporate social responsibility programmes align with broader national health and development objectives.

Application of governance approaches to non-communicable diseases (NCDs)

NCD responses should be guided by the principles of universal access and social justice. A rights-based approach requires engaging at the structural level to address the social determinants of health, rather than a more limited, top-down medical approach. The commitment and mobilizing capacity of civil society should play a key role in advocacy and awareness, policy setting, service delivery and acting as a watchdog for progress.

NCD responses require national leadership and coordination mechanisms that are inclusive of multiple stakeholders, particularly key government ministries, affected communities, the private sector and a broad range of civil society organizations. While it is important to engage the legal, trade and education sectors in a coordinated response, the central role of the ministry of health should not be undermined. NCD strategies are required that address:

- i. the role of political, business and civil society leadership, including empowering communities to participate in NCD advocacy;
- ii. advocacy on the legal, regulatory, policy and the human rights environment, particularly in relation to trade policy, the regulation of harmful products and access to medicines;
- iii. coordination of government roles in health, law, trade and education sectors;
- iv. prevention strategies that address the role of the private sector and media;
- v. monitoring and reporting of progress towards commitments and targets; and
- vi. transparency and accountability to stakeholders.

NCD responses should focus on vulnerable populations who bear disproportionate socioeconomic and health burdens from NCDs, including the poor, women, girls, persons with disabilities and indigenous people. An enabling policy and legal environment for NCD responses requires:

- i. Taxation of tobacco and alcohol, regulation of their production and sales, and restriction of advertising and marketing;
- ii. Regulation of production and sale of food (including restrictions on labeling, marketing, advertising and sponsorship) and taxation measures to reduce consumption of foods that contain high amounts of sugars, processed carbohydrates and saturated fats;
- iii. The role of intellectual property laws and treaties in relation to trade and investment in limiting or facilitating access to affordable lifesaving medicines for NCDs;
- iv. Assessment of the impact of trade and investment agreements on capacity to enforce laws and policies relating to producing or selling food and drugs; and
- v. Implementation of universal health insurance and other mechanisms to remove financial barriers to health care.

Application of governance approaches to child and maternal health

Child and maternal health responses require an enabling legal and policy environment for a human rights-based approach and participatory mechanisms that support community engagement in policy and programme development. Responses should be founded on principles of transparency, accountability, participation and human rights including non-discrimination, equity and gender equality.

Legal measures to address the social determinants of health include:

- Ratification and implementation of the *Convention on the Rights of the Child* and the *Convention on the Elimination of all forms of Discrimination Against Women*.
- National laws that place an obligation on the State to provide the services, human resources and infrastructure needed to realize the right to health of all women and children, including universal health coverage and with attention to the most vulnerable and marginalized.
- Child protection laws and laws providing rights of access to family planning, sexual health and reproductive health services.
- Laws that protect women and girls from violence.
- Laws on marketing and promotion of breast milk substitutes to prevent health harms.
- Laws and policies guaranteeing gender equality and the rights of women and girls to non-discrimination in access to health services, education and employment and that address gender discrimination affecting health outcomes, including female infanticide, discriminatory child feeding practices, gender stereotyping and restricted access to services for women and girls.
- Ensuring laws and policies support legal and safe abortion services that are available, accessible and of good quality. Removing legal restrictions that make safe abortions and post abortion care inaccessible especially to poor, displaced and young.

Child and maternal health would benefit from national governance mechanisms that mobilize resources, ensure a coordinated response and facilitate cooperation between government ministries and with civil society stakeholders. Child and maternal health requires transparent and participatory governance mechanisms for policy development

and national planning, and country-led health plans supported by predictable and sustained investments to support functioning health systems.

Mechanisms are required to respond to human rights violations against women and children that affect their access to health services. Governments should actively engage with women and girls to ensure their participation in designing, implementing and evaluating maternal health and violence protection policies and programmes. Health data should be disaggregated by sex and age to detect underlying inequality. National human rights institutions and consumer organizations can play important roles in ensuring transparent and accountable responses.

Response to proposals of the UN Secretary-General and the High-Level Panel of Eminent Persons

The reports of the UN Secretary-General and the High-Level Panel of Eminent Persons on the post-2015 development agenda propose comprehensive and integrated approaches to sustainable development. Consistent with these proposals, the Asia-Pacific MDGs Report 2012/13 (published by the UN Economic and Social Commission for Asia and the Pacific, the Asian Development Bank and UNDP in September 2013) proposes a framework based on the three pillars of sustainable development. The pillars cover economic, social and environmental dimensions of development transformation and entail a people-centred approach that puts a strong emphasis on equity, social justice and human rights for the current and coming generations.

Drawing upon lessons from HIV responses, it is recommended that the following factors be considered to supplement the proposals of these reports:

- The proposed framework should include reference to the specific key populations whose needs and rights are often ignored by development efforts. These populations include people with disabilities, people living with HIV, indigenous people, labour migrants, urban slum dwellers, sex workers, people who use drugs, prisoners, sexual minorities, transgender people and the elderly. The framework should address the factors that contribute to the social exclusion experienced by marginalized populations, recognizing that many of these populations are criminalized, lack legal status and experience systemic or institutionalized discrimination, violence and oppression.
- Proposed health targets should include:
 - A specific commitment to universal health coverage.
 - Health targets that link action to remove harmful laws and policies with positive health outcomes for poor and marginalized populations.
 - A health target that promotes strategic investment approaches that target people most affected and at risk of priority diseases.
 - HIV-specific targets relating to reduction in deaths, new infections and discrimination.
 - A target relating to research and development of new tools including drugs, diagnostics and vaccines to address global health priorities.
- In formulating targets and indicators relating to gender, consideration should be given to the needs of women living with HIV, female sex workers, lesbians, indigenous women, female migrant workers, women with disabilities and incarcerated women. The post-2015 framework should highlight the links between HIV and violence against women (including sex workers) and transgender people, and should address violence in health care settings including forced sterilization. The proposed gender targets should be amended to include protection of transgender people from violence. The need to prevent and eliminate discrimination on the grounds of sexual orientation and gender identity should be recognized.
- The High-Level Panel's proposed governance targets should be amended to include:
 - A stronger emphasis on marginalized populations, rather than the general 'public', in the governance targets.
 - An 'access to justice' target that focuses on empowering people rather than only strengthening legal institutions.

Introduction

1.1 Purpose and structure of the report

Purpose and rationale

The purpose of this report is to describe experiences and lessons learned from governance of HIV responses in Asia and the Pacific to inform discussions and debates regarding the post-2015 development agenda.

Human security, democratic governance, human rights, social justice, equity and sustainability are emerging as prominent themes for the post-2015 development agenda. The experiences and lessons learned from the governance of HIV responses can offer much to these discussions and debates.

Democratic governance is required for sustainable progress to be achieved for all the key development issues facing Asia and the Pacific in the twenty first century, including in relation to health, poverty reduction, inclusive growth, nutrition, sanitation, education, climate change and the environment. Where governance is effective and just, it provides a solid base for sustainability of development outcomes. Robust governance mechanisms are characterized by reinforcing pillars of transparency, accountability, participation, social justice, equality and human rights. These elements enable transformative social and economic changes that benefit the poorest and most vulnerable populations in society. Democratic governance (see definition on page 7), incorporating the principles of a human rights-based approach to development, is critical for a country's equitable and sustainable development.

Structure of the Report

Chapter 1 includes:

- an overview of progress towards achievement of the MDGs (Millennium Development Goals) and HIV epidemic trends and in Asia and the Pacific;
- key features of democratic governance incorporated into HIV responses in Asia and the Pacific; and
- ongoing governance challenges for HIV responses in the region.

Chapter 2 considers the proposals of the Report of the United Nations (UN) Secretary-General¹ and of the Report of the High-Level Panel of Eminent Persons on the Post-2015 Development Agenda,² and provides recommendations to strengthen these proposals drawing from HIV response lessons.

Chapters 3-5 of this report consider the key features and lessons learned from the following aspects of the governance of HIV responses in Asia and the Pacific in the following areas:

- Chapter 3: Leadership, policy and planning architecture
- Chapter 4: Enabling legal and policy environments
- Chapter 5: Participatory governance.

Each of these chapters describes the approaches taken by different countries in Asia and the Pacific when incorporating these aspects of governance in their national HIV responses. At the end of these chapters, there is a summary of the key lessons relevant to the post-2015 development agenda.

1 UN Secretary-General (2013). *A life of dignity for all: accelerating progress towards the Millennium Development Goals and advancing the United Nations development agenda beyond 2015: Report of the Secretary-General*, 26 July 2013, UN General Assembly, A/68/202.

2 High-Level Panel of Eminent Persons on the Post-2015 Development Agenda (2013). *A new global partnership: Eradicate poverty and transform economies through sustainable development*, New York: UN.

The final two chapters describe application of democratic governance principles and approaches to responses to non-communicable diseases (NCDs) (Chapter 6) and to responses to child and maternal health (Chapter 7).

1.2 The MDGs, HIV and development trends in Asia and the Pacific

Many countries of Asia and the Pacific have experienced significant economic growth since 2000. However, this economic growth has not translated into consistent progress towards achievement of the MDGs. Inequalities between the rich and poor have increased in several of the middle-income countries in the region.³ The Asia-Pacific region is still home to nearly two-thirds of the world's poor, with the majority residing in middle-income countries, such as India, China and Indonesia.⁴

The Asia-Pacific region as a whole is on track to meet the headline MDG of halving poverty between 1990 and 2015. As Table 1 indicates, at the regional aggregate level the region has attained 'early achiever' status for:

- Reducing poverty;
- Access to safe drinking water;
- Gender parity in all levels of education;
- Reducing HIV prevalence and TB incidence and prevalence;
- Environmental targets relating to forest cover, protected areas and carbon emissions.

However, regional progress has been disappointingly slow for some of the other goals. Reports of the UN Economic and Social Commission for Asia and the Pacific (ESCAP), the Asian Development Bank (ADB) and UNDP⁵ have found that for many of the key MDGs (such as child health, maternal health and basic sanitation), progress towards development targets has generally been slow in the region and in some countries the situation is regressing.

Of the health-related MDGs, the targets in relation to halting and reversing the spread of HIV and reducing TB incidence and prevalence are the only 'early achievers' at the regional aggregate level. The region has been slow to prevent people from going hungry, stop children from dying, and prevent mothers from dying from causes related to childbirth. The region is classified as a slow achiever in: the reduction of the proportion of children under five years who are underweight; the reduction of child, infant and maternal mortality; the increase of access to maternal health care services; and the increase of access to basic sanitation.

Over 1.8 billion people remain deprived of basic sanitation in the region. Across the region during 2011, around 3 million children under five died and nearly 20 million births were not attended by skilled health personnel. Disparities between countries are widening in some cases, such as children, infant and under-five mortality, maternal mortality, and TB incidence and prevalence.⁶

Steady and sustained progress in HIV responses⁷

At the regional level, progress towards achievement of HIV targets has been very positive. Figure 1 shows trends in the HIV epidemic in the region as a whole. HIV prevalence has stabilized in most countries in the region. Important outcomes have been achieved as seen in falling HIV incidence in many countries and increasing coverage of services for key populations. However, the overall trends in Asia and the Pacific hide significant variations in epidemics, both between and within countries.

3 Larkin J. (2013). Inequality is hitting alarming highs in Asia as the fruits of growth skew to the rich, *Development Asia*, April 2013, 9-14.

4 ADB (2013). *A ZEN Approach to Post-2015: Addressing the Range of Perspectives Across Asia and the Pacific*, Manila: ADB, p.3.

5 See: UNESCAP, ADB, UNDP (2013). *Asia-Pacific Aspirations: Perspectives for a Post-2015 Development Agenda, Asia-Pacific Regional MDGs Report 2012/13*. Bangkok: UNESCAP, ADB, UNDP; UNESCAP, ADB, UNDP (2012). *Asia-Pacific Regional MDG Report 2011/12 – Accelerating Equitable Achievement of the MDGs Closing Gaps in Health and Nutrition Outcomes*. Bangkok: UNESCAP, ADB, UNDP.

6 UNESCAP, ADB, UNDP (2013). *Ibid*, p.7.

7 This analysis is drawn from: UNAIDS (2012). *World AIDS Day Report. Results 2012*. Geneva: UNAIDS; and UNAIDS (2011). *HIV in Asia and the Pacific, Getting to Zero*, Bangkok: UNAIDS.

Table 1: MDG Progress in Asia and the Pacific, 2012 by sub-region

Goal	1	2	3	4	5	6	7	
	\$1.25 per day poverty	Underweight children	Primary enrolment Reaching last grade Primary completion	Gender primary Gender secondary Gender tertiary	Under-5 mortality Infant mortality	Maternal mortality Skilled birth attendance Antenatal care (≥ 1 visit)	HIV prevalence TB incidence TB prevalence	Forest cover Protected area CO2 emissions per GDP Safe drinking water Basic sanitation
Asia-Pacific	●	■	▶	■	■	■	■	■
Excluding China and India	●	▶	■	■	■	■	■	■
South-East Asia	●	▶	●	■	■	■	■	■
South Asia	▶	■	▶	■	■	■	■	■
Excluding India	●	▶	■	▶	■	■	■	■
Pacific Islands			■	▶	■	■	■	■
Excluding Papua New Guinea		●	■	■	■	■	■	■
North and Central Asia	●	■	■	■	■	▶	■	■
Excluding Russia	●	●	■	■	■	▶	■	■
Asia-Pacific LDCs	▶	▶	■	■	■	■	■	■
Asia-Pacific Low Income	▶	▶	■	■	■	■	■	■
Asia-Pacific Middle Income	●	■	●	■	■	■	■	■

● Early achiever

▶ On track

■ Slow

■ Regressing/No progress

Notes: Sub-regions are grouped into the following four categories:

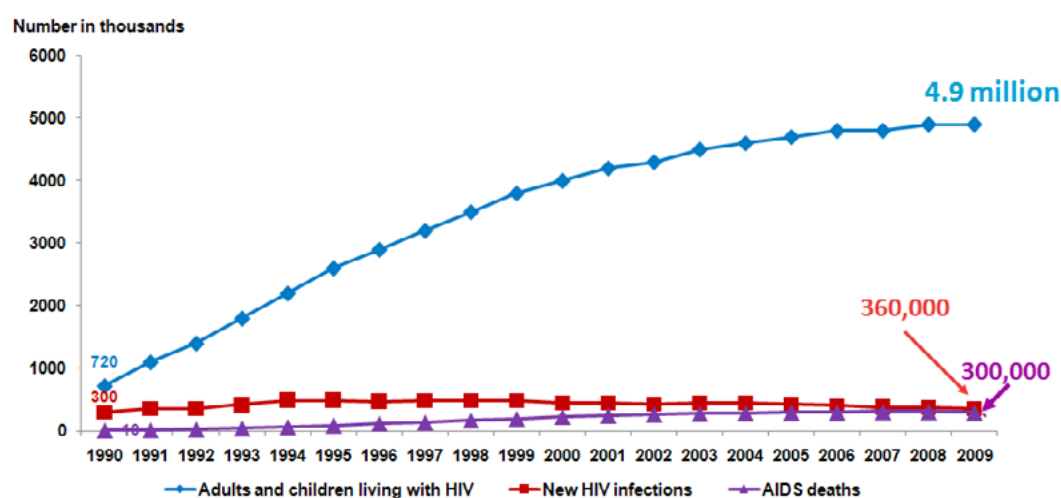
Early achiever: Already achieved the 2015 target

On track: Expected to meet the target by 2015

Off track-Slow: Expected to meet the target, but after 2015.

Off track-No progress/regressing: Stagnating or slipping backwards.

Source: Heyzer N. (2013). *Asia and the Pacific's Perspectives on the Post-2015 Development Agenda*. Presentation, ECOSOC Dialogue with Regional Commissions on the Post-2015 Development Agenda, Geneva, 5 July 2013.

Figure 1: Estimated number of adults and children living with HIV, new infections, and AIDS related deaths in the Asia-Pacific region (1990-2009)

Source: UNAIDS Regional Support Team Asia-Pacific, based on data compiled for the UNAIDS Report on the Global AIDS Epidemic, 2010.

In many countries, trends toward safer sexual and injecting behaviours are being observed. In prevention terms, some national successes stand out. Cambodia, India, Myanmar and Thailand have reduced their HIV infection rates with intensive, targeted HIV prevention programmes among people who buy and sell sex. In the period 2001-2011, Cambodia reduced new HIV infections by 88 percent. India, Myanmar and Thailand reduced new HIV infections by more than 50 percent in the period 2001-2011.⁸

In South and South-East Asia, new HIV infections declined from 370,000 in 2001 to 280,000 in 2011. However, in East Asia, new infections increased with an estimated 89,000 people newly infected with HIV in 2011, compared to 75,000 in 2001 (most of these were in Viet Nam and China). In Bangladesh, Indonesia, the Philippines and Sri Lanka, the rate of new HIV infections increased by more than 25 percent between 2001 and 2011.

The HIV epidemic in the Pacific region is small compared to other regions, with the vast majority of cases occurring in Papua New Guinea (PNG). Excluding PNG, there is a very low HIV prevalence across the region.⁹ Five countries (Cook Islands, Nauru, Niue, Pitcairn and Tokelau) currently have no reported people living with HIV. The estimated prevalence among adults aged between 15-49 years in the remaining 16 Pacific countries and territories is low and ranges from 0.002 percent to 0.078 percent.¹⁰ Between 2005 and 2011, AIDS-related deaths in Oceania¹¹ fell from 2,300 to 1,300 and new HIV infections declined from 3,700 in 2001 to 2,900 in 2011.¹² The primary mode of HIV transmission in the 21 Pacific island countries and territories is reported as heterosexual contact, although men who have sex with men and transgender people are considered to be the most-at-risk populations¹³. Over one quarter (27 percent) of HIV infections were via sex between men and five percent via injecting drug use.¹⁴

In PNG the rate of growth of the HIV epidemic has slowed since 2005. In a 2011 modelling and projection project, the prevalence of HIV for PNG among the adult population (15-49 years) was estimated to be 0.8 percent in 2010 and 2011.¹⁵ Another model estimated an adult HIV prevalence of 0.85 percent in 2010, increasing to 1.0 percent by 2020.¹⁶

Although the overall picture for the region is positive, significant challenges remain. HIV epidemics in Asia and the Pacific remain largely concentrated among key populations of people who inject drugs, men who have sex with men (MSM), transgender people and sex workers (female, male and transgender) and their clients. In many countries in Asia, HIV epidemics start with the virus spreading rapidly among people who inject drugs. HIV transmission to the female sexual partners of people who inject drugs is also a factor. Many people who use drugs may also buy or sell sex, allowing HIV to spread to larger networks of sex workers and their clients. HIV prevalence among people who inject drugs remains high even in countries with overall declining epidemics, and it is increasing in areas with expanding epidemics. Male clients of sex workers, who comprise an estimated 75 million men across Asia and the Pacific, also play a key role in the spread of HIV epidemics, as they are the biggest single group that transmits HIV to their regular intimate partners.¹⁷

The rapid growth of HIV epidemics among MSM across the region is a major source of new HIV infection, threatening to reverse prevention gains in countries such as Myanmar and Thailand. The rate of new HIV infections in MSM continues to increase particularly in urban areas. HIV data for transgender people remains very scarce.

8 UNAIDS (2012). *World AIDS Day Report: Results 2012*. Geneva: UNAIDS, p.10.

9 The term 'low-level epidemic' is used for epidemics where HIV prevalence has not consistently exceeded one percent in the general population nationally, and has not exceeded 5 percent in any sub-population.

10 Wanyeki I. (2013). *HIV surveillance in Pacific Island countries and territories: 2011 report*. Noumea: Secretariat of the Pacific Community, p.4.

11 Oceania is the term used by UNAIDS to describe Pacific island countries, Australia and New Zealand.

12 UNAIDS (2012). *Asia-Pacific Regional Factsheet 2012*. Geneva: UNAIDS.

13 Bavinton B, Singh N, Naiker DS, Deo MN, Talala M, Brown M, Singh RR, Dewan S, and Navokavokadrau S. (2011). *Secret Lives, Other Voices: A community-based study exploring male-to-male sex, gender identity and HIV transmission risk in Fiji*. Suva, Fiji: AIDS Task Force of Fiji

14 SPC (2012). 2011 HIV Epidemiological Update: Pacific Island countries & territories, SPC.

15 See reference to model jointly developed by the PNG Institute of Medical Research and the Kirby Institute, University of New South Wales: Tropical Health Solutions (2012). *Systematic Literature Review of HIV / AIDS research in PNG from 2009-2012*, available at: <http://www.tropicalhealthsolutions.com/pnghiv>

16 Ibid., assumes the model parameters stayed the same as they were in 2010-2011.

17 UNAIDS (2011). Op cit., p.18.

However, wherever data are available, transgender people appear to have very high HIV prevalence.¹⁸

There has been mixed progress in access to HIV treatment. In 2011, coverage of antiretroviral therapy was 47 percent in South and South-East Asia and 18 percent in East Asia. In India, the country with the greatest disease burden, only one third of people living with advanced HIV infection receive ART. In Oceania, 69 percent of people eligible for antiretroviral therapy were accessing it in 2011. In Thailand and Papua New Guinea, more than 60 percent of people eligible for antiretroviral therapy were receiving it. Cambodia is one of only eight countries in the world that provides antiretroviral therapy to more than 80 percent of those eligible for it.¹⁹

1.3 The role of democratic governance in effective HIV responses

A variety of factors have contributed to the success of HIV responses in the region. Political commitment has been important, and resources have been mobilized at an unprecedented scale for a single-disease response. There has been an increasing willingness to target resources to key populations at higher risk of HIV, informed by evidence of epidemic trends and the effectiveness of prevention and treatment interventions.

Support to national HIV programmes from bilateral donors and global health initiatives such as the Global Fund to Fight AIDS, Tuberculosis and Malaria (the Global Fund), the Bill and Melinda Gates Foundation, and the Clinton Health Access Initiative has been key in enabling national programmes to achieve the global goals of halting and reversing the spread of HIV and universal access to HIV treatment. External funding (often the major source of funding for HIV response in countries) has often played a key role in influencing adoption of governance structures and principles. External funders have often required transparency, participation, accountability and other aspects of democratic governance as a condition of ongoing support.

Effective HIV responses have been characterized by the following elements of democratic governance:²⁰

- Strong national political leadership for managing participatory, human rights-based and evidence-informed HIV responses.
- An international system responsive to and aligned with national priorities, advancing shared international commitments to HIV, health, development and human rights and producing results for those most affected.
- Multi-sectoral governance and coordination mechanisms involving multiple stakeholders and sectors.
- Participation of people living with HIV and key populations (sex workers, people who inject drugs, MSM and transgender people) in activism, community mobilization, policy development, planning and delivery of HIV services.
- Attention to the legal environment and willingness to pursue pragmatic solutions to overcoming legal barriers to reaching key populations with HIV services.
- An emphasis on the social determinants of health and a willingness to tackle the structural factors that influence health outcomes. In the context of HIV, the defining characteristic of structural approaches is that they aim to change the social, economic, political or environmental factors that determine HIV risk and vulnerability.²¹

Ongoing governance challenges for HIV responses

Although there has been significant progress in many countries in Asia and the Pacific in grounding effective HIV responses in democratic governance, much more work remains to be done to ensure that people living with HIV and key populations are treated with respect and dignity and they have equal rights of access to basic services

18 See: Baral S. et al. (2013). Worldwide burden of HIV in transgender women: a systematic review and meta-analysis. *Lancet Infect Dis*, 13:214-22.

19 See: UNAIDS (2012). *Asia-Pacific Regional Factsheet 2012*. Geneva: UNAIDS; UNAIDS (2011). *HIV in Asia and the Pacific, Getting to Zero*, Bangkok: UNAIDS, p.20.

20 See: Piot P, Timberlake S., Sigurdson J. (2009). Governance and the Response to AIDS: Lessons for Development and Human Rights, in: Clapham A., Robinson M. (ed) *Swiss Human Rights Book Vol. 3 Realizing The Right To Health*.

21 Rao Gupta G., Parkhurst J., Ogden J., Aggleton P., Mahal A. (2008). Structural approaches to HIV prevention, *The Lancet*, 372:9640, 764-775.

such as health, education, sanitation, employment and housing. The *People Living with HIV Stigma Index, Asia Pacific Regional Analysis*²² found that HIV-related stigma and discrimination continue to affect people living with HIV in multiple aspects of their lives, including in the key areas of employment and health care.²³ Criminalization of key populations at high risk of HIV exposure remains an obstacle to their effective participation in governance of programmes in many countries.²⁴ The practice of administrative detention of sex workers and people who use drugs for lengthy periods continues to occur in many Asian countries, and has been subject to widespread criticism on public health and human rights grounds.²⁵

While there has been progress in HIV responses at national level, this does not always translate into effective responses down to district and local levels. Authorities at the local level play a key role in influencing opinions and decisions within areas under their political, administrative, social and economic control. This points to the need to target local politicians, local government officials and traditional leaders for education and awareness raising.

Improved access to and quality of health services can be supported by ensuring HIV responses are better integrated with national health systems. Governance arrangements should be supportive of integrated approaches, rather than competitive, vertical approaches. Although not yet curable, HIV is treatable as a chronic manageable condition. HIV programmes should be integrated and synergistic with other health programmes, particularly sexual and reproductive health services, maternal and child health services and services for treatment of other chronic diseases.

Effective HIV responses also need to take into account demographic changes that impact governance systems and create new groups of vulnerable people. For example, rapid urbanization²⁶ may increase the risk of HIV among migratory groups with increasing numbers of young people looking for employment and some being drawn into sex work. Drug use is also higher among these new entrants to urban and peri-urban areas. Refugees and internally displaced persons affected by conflict who live in temporary homes and camps are also overlooked vulnerable populations. All these groups fall through the cracks in the traditional systems of governance due to their inability to register in systems such as voter registers or at health clinics. These needs and rights of these groups also need to be taken into account in governance systems for HIV prevention.

The critical role of structural approaches to enable HIV prevention

A greater focus on structural interventions to address underlying social drivers can reduce HIV transmission and produce a more sustainable prevention response. Structural approaches include efforts to improve single policies or programmes (e.g. legal actions to combat or reform a discriminatory practice) and wider societal or 'transformational' processes (e.g. community mobilization).

The long-term benefits of structural approaches was demonstrated by a study conducted by the 'aids2031 Costs and Financing Working Group'. The Working Group compared three scenarios for the future of the HIV epidemic.²⁷ The scenario that included a greater focus on measures to address structural factors reduced the annual number of new infections by more than the scenarios that omitted structural factors (Figure 2). Examples of structural changes

22 GNP+, ICW, IPPF, UNAIDS (2011). *People Living with HIV Stigma Index, Asia Pacific Regional Analysis 2011*, Geneva: UNAIDS.

23 Bangladesh, Cambodia, China, Fiji, Myanmar, Pakistan, Philippines, Sri Lanka, and Thailand.

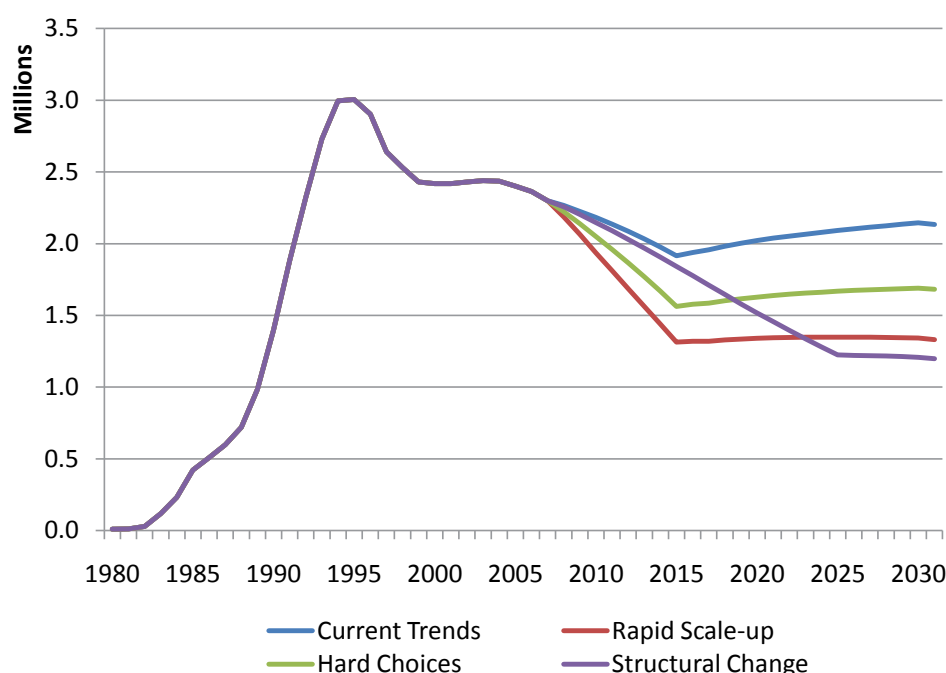
24 See: Global Commission on HIV and the Law (2011). *Report of the Asia Pacific Regional Dialogue of the Global Commission on HIV and the Law*, Bangkok: UNDP; Godwin J. (2010). *Legal environments, human rights and HIV responses among men who have sex with men and transgender people in Asia and the Pacific*, Bangkok: UNDP; Godwin J. (2012). *Sex work and the Law*, Bangkok: UNDP.

25 ILO, OHCHR, UNDP, UNESCO, UNFPA, UNHCR, UNICEF, UNODC, UN Women, WFP, WHO and UNAIDS (2012). *Joint statement: compulsory drug detention and rehabilitation centres*, March 2012; WHO (2009). *Assessment of compulsory treatment of people who use drugs in Cambodia, China, Malaysia and Viet Nam: An application of selected human rights principles*, Manila: WHO WPRO.

26 While Asia-Pacific hosts over half of the world's 20 megacities, over 60 percent of the region's urban population live in urban areas. UN-HABITAT and UN-ESCAP (2010). *State of Asian Cities 2010/11*, Bangkok: UN-Habitat and UN-ESCAP

27 The other scenarios were: 1. *Rapid Scale-Up*: Political will to achieve universal access is strong and resource availability continues to expand rapidly. The focus is on scaling-up direct approaches to preventing HIV and providing care and support. All countries achieve universal access to prevention, care, treatment, and child support services by 2015; 2. *Current Trends*: Coverage of key interventions continues to expand as it has in past years. Some countries achieve universal access for some services but not others, and some countries do not achieve universal access until well past 2015; 3. *Hard Choices*: Scaling-up only the most cost-effective approaches to achieve maximum impact with the resources available. For prevention, this entails emphasis on most-at-risk-populations and less emphasis on general population interventions.

Figure 2: New Infections Among Adults Aged 15-49 by Scenario for 139 Countries



Source: aids2031 Costs and Financing Working Group. (2010). *Costs and Choices: Financing the Long-Term Fight Against AIDS*. Washington, DC: Results for Development Institute, p.37.

considered in this scenario included programs to reduce violence against women, modify employment practices that lead to the separation of workers and their families (resulting in sexual risk taking), removal of legal and other stigma-related barriers, and strengthening of health systems.²⁸

Democratic governance and the UNAIDS Investment Framework

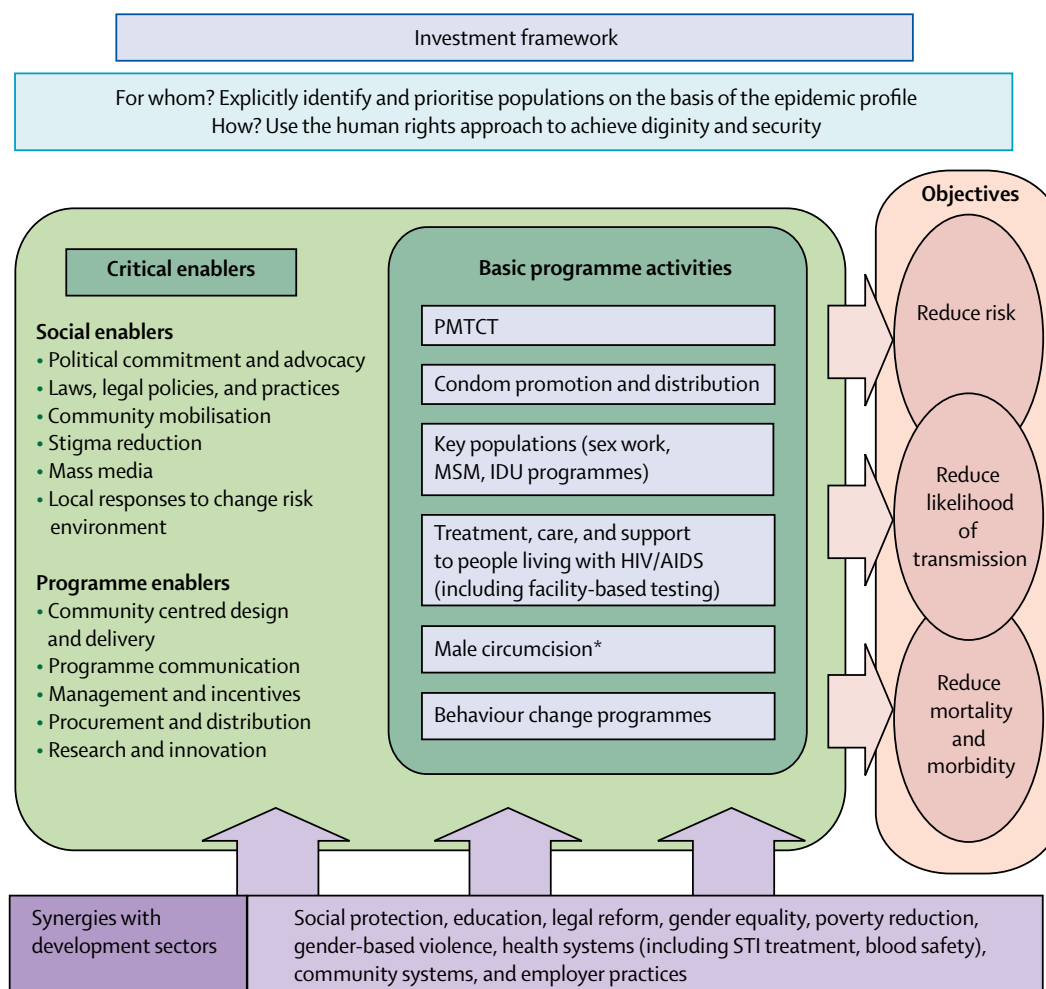
The UNAIDS Strategic Investment Framework²⁹ (Figure 3) has guided national approaches to strategic investment in HIV responses since 2011. The Investment Framework is intended to facilitate dialogue between civil society, national HIV programmes and funding, planning and development authorities when planning HIV responses.³⁰ The

28 Hecht R. (2010). *Costs and choices: financing the long-term fight against AIDS*, Washington: Results for Development Institute, p.29. The other scenarios were: Rapid Scale-Up: Political will to achieve universal access is strong and resource availability continues to expand rapidly. The focus is on scaling-up direct approaches to preventing HIV transmission and providing care and support. All countries achieve universal access to key prevention, care and treatment, and child support services by 2015, and continue at that level to 2031. 2. Current Trends: Coverage of key interventions continues to expand as it has in the past few years. Some countries achieve universal access for some services but not others, and some countries do not achieve universal access until well past 2015. 3. Hard Choices for Prevention: Resources for AIDS programs are limited, so there is a focus on scaling-up only the most cost-effective approaches in order to achieve maximum impact with the resources available. For prevention, this entails greater emphasis on programs for most-at-risk-populations and less emphasis on general population interventions, particularly in low prevalence and concentrated epidemics. 6. In generalized epidemics, lower scale-up rates occur for interventions such as mass media, safe medical injections, and community mobilization.

29 Schwartlander B., Stover J., Hallett T. et al. (2011). Towards an improved investment approach for an effective response to HIV/AIDS, *The Lancet*, Vol 377, Issue 9782, pp. 2031-2041.

30 UNAIDS (2012). *Investing for results: results for people, A people-centred investment tool towards ending AIDS*, Geneva: UNAIDS, p.3.

Figure 3: UNAIDS Strategic Investment Framework



*Applicable in generalized epidemics with a low prevalence of male circumcision. MSM=men who have sex with men. IDU=injecting drug user. PMTCT=prevention of mother-to-child transmission. STI=sexually transmitted infection

Source: Schwartlander B., Stover J., Hallett T. et al. (2011). Towards an improved investment approach for an effective response to HIV/AIDS, *The Lancet*, Vol. 377, Issue 9782, pp. 2031-2041.

Framework is being applied to ensure resources are better targeted to the key populations at highest risk of HIV in each country and to addressing the structural factors that drive the epidemic.³¹

The Framework requires consideration of the value of HIV investments within the context of broader development objectives. The Framework conceptually links basic programme activities such as condom promotion to broader governance elements. These elements include stigma reduction, human rights advocacy, monitoring of the equity and quality of programme access and results, strategic planning and research, development of community-based organizations, and community mobilization. Community mobilization underpins the delivery and scale up of

31 The Asia Pacific Council of AIDS Service Organizations is advocating the application of the framework by national funding and planning bodies in partnership with the China HIV/AIDS Information Network, the HIV/AIDS Coordinating Committee in Cambodia, the Lao Positive Health Association and the Supporting Community Development Initiatives in Viet Nam. See: *Applying the Investment Framework in concentrated epidemics: Civil society consultation on community mobilization*, Bangkok, 3-5 September 2012, <http://www.apcaso.org>; UNAIDS (2012). *Case Study: The Royal Government of Cambodia at the forefront in applying new investment approach*, UNAIDS/PCB (31)/12.CRP.1.

treatment and care and supports changes in social norms. Strategic investment approaches rely on increased community engagement, which requires strong linkages between government and community systems. In this model, HIV activities align with broader development objectives and thereby support the strengthening of social, legal and health systems to enable effective responses. For example, development areas relevant to HIV include gender equality, justice, social protection, welfare and community systems. These critical enablers and development synergies:

- enable the efficacy, equity and roll-out of basic programme activities;
- encourage sustainability of HIV responses through integration into broader health and non-health sectors;
- are determined and prioritized by country contexts;
- support the human rights and empowerment of people affected; and
- require mechanisms for multi-sectoral financing and governance.³²

The Framework requires participatory mechanisms involving civil society groups such as national AIDS commissions, Global Fund Country Coordinating Mechanisms (CCMs) and partnership forums. These mechanisms provide an opportunity for civil society including representatives of people living with HIV and key populations to participate in decisions on policies and resource allocations, and advocate for strengthening of community systems, capacity development and enhanced civil society roles in designing, implementing and evaluating programmes.

32 UNDP and UNAIDS (2012). Understanding and Acting on Critical Enablers and Development Synergies for Strategic Investments. New York: UNDP, p.3.

Recommendations of the UN Secretary-General and the High-Level Panel of Eminent Persons

KEY POINTS

The reports of the UN Secretary-General and the High-Level Panel of Eminent Persons on the post-2015 development agenda propose comprehensive and integrated approaches to sustainable development. Consistent with these proposals, the Asia-Pacific MDGs Report 2012/13 (published by the UN Economic and Social Commission for Asia and the Pacific, the Asian Development Bank and UNDP in September 2013) proposes a framework based on the three pillars of sustainable development. The pillars cover economic, social and environmental dimensions of development transformation and entail a people-centred approach that puts a strong emphasis on equity, social justice and human rights.

Drawing from lessons from HIV responses, the following factors can be considered as supplement to the proposals of these reports:

- To ensure a more inclusive approach, the proposed framework should include reference to the specific key populations whose needs and rights are often ignored by development efforts. These populations include people with disabilities, people living with HIV, indigenous people, labour migrants, urban slum dwellers, sex workers, people who use drugs, prisoners, sexual minorities, transgender people and the elderly. The framework should address the factors that contribute to the social exclusion experienced by marginalized populations, recognizing that many of these populations are criminalized, lack legal status and experience systemic or institutionalized discrimination, violence and oppression.
 - Proposed health targets should include:
 - A specific commitment to universal health coverage.
 - Health targets that link action to remove harmful laws and policies with positive health outcomes for poor and marginalized populations.
 - A health target that promotes strategic investment approaches that target people most affected and at risk of priority diseases.
 - HIV-specific targets relating to reduction in deaths, new infections and discrimination.
 - A target relating to research and development of new tools including drugs, diagnostics and vaccines to address global health priorities.
 - In formulating targets and indicators relating to gender, consideration should be given to the needs of women living with HIV, female sex workers, lesbians, indigenous women, female migrant workers, women with disabilities and incarcerated women. The post-2015 framework should highlight the links between HIV and violence against women (including sex workers) and transgender people, and should address violence in health care settings including forced sterilization. The proposed gender targets should be amended to include protection of transgender people from violence. The need to prevent and eliminate discrimination on the grounds of sexual orientation and gender identity should be recognized.
 - The High-Level Panel's proposed governance targets should be amended to include:
 - A stronger emphasis on marginalized populations, rather than the general 'public', in the governance targets.
 - An 'access to justice' target that focuses on empowering people rather than only strengthening legal institutions.
-

2.1 Overview

The release of the Report of the UN Secretary-General³³ in July 2013 and the Report of the High-Level Panel of Eminent Persons (the HLP report)³⁴ in June 2013 marked significant steps towards defining the post-2015 development agenda. The Secretary-General's report and the HLP report signal a more comprehensive and integrated approach to development than that provided by the MDG framework, with a stronger emphasis on development enablers such as social justice, social inclusion, gender equality, good governance, peace and security. These themes have been further explored in the Asia-Pacific Regional MDGs Report 2012/13, published by UNESCAP, the Asia Development Bank and UNDP in September 2013 (discussed further at 2.4 below).³⁵

This Chapter provides some observations as to how the frameworks proposed by the HLP report and Secretary-General's report could be supplemented, drawing from lessons from governance of HIV responses.

HLP Report

The HLP report gives clear recognition to the importance of addressing inequity in all its forms. The HLP report proposes a post 2015-agenda informed by five principles, described as 'transformative shifts':

- i. *Leave no one behind;*
- i. *Put sustainable development at the core;*
- ii. *Transform economies for jobs and inclusive growth;*
- iii. *Build peace and effective, open and accountable institutions for all; and*
- iv. *Forge a global partnership.*

The HLP report argues for a new global partnership based on the principles of universality, equity, sustainability, solidarity, human rights, the right to development and responsibilities shared in accordance with capabilities.³⁶ It calls for the realization of human rights regardless of "ethnicity, gender, geography, disability, race or other status".³⁷ The focus of the HLP report on human rights and accountability means that a governance component is integrated into all aspects of the proposed agenda. Governance is described as "a core element of wellbeing".³⁸ The human rights dimension implies identifying the economic, political and social structural determinants of poverty. All of these aspects of the HLP report correspond strongly with the positive aspects of the governance of effective HIV responses, as described in Chapters 3-5 below.

The UN Secretary-General's Report

The UN Secretary-General's Report builds on many of the themes addressed by the HLP. The Secretary-General's Report proposes an agenda of sustainable development, enabled by the "integration of economic growth, social justice and environmental stewardship" with the aspiration "to create a just and prosperous world where all people realize their rights and live with dignity and hope".³⁹ Features of this agenda are that it is:

"universal in nature yet responsive to the complexities, needs and capacities of individual countries and regions; bold in ambition but simple in design; combining the economic, social and environmental dimensions while putting the highest priority on ending poverty and reducing inequality; protective of the planet, its biodiversity, water and land; rights-based, with particular emphasis on women, young people and marginalized groups; eager for new and innovative partnerships; and supported by pioneering approaches to data and rigorous accountability mechanisms."⁴⁰

33 UN Secretary-General (2013). Op cit.

34 High-Level Panel of Eminent Persons on the Post-2015 Development Agenda (2013). *A new global partnership: Eradicate poverty and transform economies through sustainable development*, New York: UN. The HLP was co-chaired by Susilo Bambang Yudhoyono, President of Indonesia, Ellen Johnson-Sirleaf, President of Liberia, and David Cameron, Prime Minister of the United Kingdom.

35 UNESCAP, ADB, UNDP (2013). Op cit.

36 Ibid, p.9.

37 Ibid, p.29.

38 Ibid, p.29.

39 UN Secretary-General (2013), op cit., p12.

40 UN Secretary-General (2013). Op cit., p.4.

The Secretary-General's Report proposes "transformative and mutually reinforcing actions" that apply to all countries, including actions to tackle exclusion and inequality, empower women and girls, improve health and build effective governance based on the rule of law and sound institutions.⁴¹ The Secretary-General's report also emphasizes multi-stakeholder partnerships to implement the agenda, which include not only governments but also businesses, private philanthropic foundations, international organizations, civil society, volunteer groups, local authorities, parliaments, trade unions, research institutes and academia. These partnerships can channel commitments and actions from a wider set of actors, and their success depends on assigning roles, responsibilities and accountability.⁴²

These aspects of the Secretary-General's report correspond strongly with the positive aspects of the governance of human rights-based, participatory and multi-sectoral HIV responses, as described in Chapters 3-5 below.

2.2 Social inclusion and the commitment to 'leave no one behind'

The HLP report proposes that the development agenda be informed by the 'transformative shift' to 'leave no one behind', which is explained in the following terms: "We must ensure that no person – regardless of ethnicity, gender, geography, disability, race or other status – is denied basic economic opportunities and human rights."⁴³ The HLP report also proposes the principle of 'forge a new global partnership', which is inclusive of "people living in poverty, those with disabilities, women, civil society and indigenous and local communities, traditionally marginalized groups".⁴⁴

Similarly, the Secretary-General's report emphasizes that the principle of universality requires efforts to "mobilize all developed and developing countries and leave no one behind"⁴⁵ so that no person should face social or economic exclusion or live without access to basic health services and education. The Secretary-General's report observes that tackling exclusion and inequality requires equality of opportunity, so as to build societies where all people can contribute and participate in national and local governance.⁴⁶

While the focus on the poorest and most marginalized is strongly welcomed, both the HLP report and Secretary-General's report do not identify many of the specific key populations central to development responses. Given that HIV remains a global pandemic that imposes a very high disease burden on many low and middle-income countries, it is important that people living with HIV and key HIV-affected populations such as men who have sex with men (MSM), transgender people, sex workers, and people who inject drugs, among others, are named in the post-2015 agenda.

Despite recent declines in AIDS mortality, globally HIV was still the fifth leading cause of disability-adjusted life years (DALYs) lost in 2010. HIV/AIDS ranks as the leading cause of DALYs lost for those aged 30-44 years in both males and females globally.⁴⁷ In 2010, HIV/AIDS was the leading cause of DALYs lost in Thailand, a country where the epidemic is highly concentrated among key populations particularly MSM.⁴⁸

41 The Secretary-General's 15 proposed actions are: Eradicate poverty in all its forms; Tackle exclusion and inequality; Empower women and girls; Provide quality education and lifelong learning; Improve health; Address climate change; Address environmental challenges; Promote inclusive and sustainable growth and decent employment; End hunger and malnutrition; Address demographic challenges; Enhance the positive contribution of migrants; Meet the challenges of urbanization; Build peace and effective governance based on the rule of law and sound institutions; Foster a renewed global partnership: UN Secretary-General (2013), op cit., pp.13-15.

42 Ibid, p.16.

43 High-Level Panel of Eminent Persons on the Post-2015 Development Agenda (2013). Op cit., p.29.

44 Ibid, Executive Summary.

45 UN Secretary-General (2013). Op cit., p.13.

46 Ibid.

47 Ortblad K., Lozano R., Murray C. (2013). The burden of HIV: insights from the Global Burden of Disease (GBD) Study 2010, *The Lancet* 381: S103.

48 Ibid.

HIV has highlighted the vulnerability of legally marginalized populations who have largely been neglected in previous development efforts, including prisoners, sex workers, people who inject drugs, MSM, transgender people, and labor migrants. These populations lacked visibility in most health and development efforts prior to the advent of HIV. Over time, HIV responses have become increasingly responsive to the needs and rights of these populations, informed by evidence of the key role of these populations in the epidemiology of HIV.⁴⁹ This has led to recognition of the need to address HIV within the context of a broader package of measures addressing physical and mental health, welfare, advocacy and legal needs, such as repeal of homophobic laws⁵⁰ and removal of punitive laws and law enforcement practices relating to sex work and drug use including disbanding of mandatory detention centres.⁵¹ It is therefore important that the future development agenda explicitly identifies these populations.

People living with HIV and key HIV-affected populations are amongst the most marginalized groups whose human rights remain unfulfilled and who have been excluded from many of the benefits of rapid economic development as well as social protection in Asia and the Pacific. The HLP report states that targets should only be considered achieved if all relevant social groups meet the targets. This commitment must include people living with HIV and other key affected populations.

2.3 Building peace and effective governance

The HLP report and the Secretary-General's report both emphasize the centrality of governance to development.

The HLP report proposes the required transformative shift as: 'Build Peace and Effective, Open and Accountable Institutions for All'. The HLP report observes: "freedom from violence, conflict and oppression is essential to human existence, and the foundation for building peaceful and prosperous societies."⁵²

The Secretary-General's report uses similar language in calling for action to:

...build peace and effective governance based on the rule of law and sound institutions. Peace and stability, human rights and effective governance based on the rule of law and transparent institutions are outcomes and enablers of development...sustainable development cannot be fully realized without respect for human rights and the rule of law. Transparency and accountability are powerful tools for ensuring citizens' involvement in policymaking and their oversight of the use of public resources, including to prevent waste and corruption.⁵³

This principle would be strengthened by recognition of the diverse ways in which violence, oppression and conflict marginalize people living with HIV and key populations, and thereby exclude them from effective participation in policymaking and decisions affecting their lives. These populations can be highly vulnerable to violence, even in communities where 'rule of law' is well established, particularly if the law and the culture of law enforcement agencies discriminate against particular populations, for example, due to criminalization of conduct such as drug use, selling sex, same sex behaviours and non-disclosure of HIV status. For such populations, although society as a whole may appear 'peaceful', their illegal (or not legally recognized) status can mean that violence and oppression may occur that is seldom reported or officially recognized, such as police abuses and community ostracism.⁵⁴

49 Commission on AIDS in Asia (2008). *Redefining AIDS in Asia: Crafting an effective response*, New Delhi: Oxford University Press.

50 See e.g. Avrett, S. 2011. *Human Rights Considerations in Addressing HIV among Men Who Have Sex with Men*. Arlington: USAID.

51 ILO, OHCHR, UNDP, UNESCO, UNFPA, UNHCR, UNICEF, UNODC, UN Women, WFP, WHO and UNAIDS (2012). Op cit.

52 High-Level Panel of Eminent Persons on the Post-2015 Development Agenda (2013). Op cit., p.29.

53 UN Secretary-General (2013). Op cit., p.15.

54 See: Godwin J. (2010). *Legal environments, human rights and HIV responses among men who have sex with men and transgender people in Asia and the Pacific*, Bangkok: UNDP; Godwin J. (2012). *Sex work and the Law*, Bangkok: UNDP.

2.4 Proposed goals and targets

The HLP report provides an illustrative framework of 12 goals and 54 targets.⁵⁵ The Secretary-General's report does not propose specific goals or targets, but notes that illustrative goals and targets have been developed by the High-Level Panel and other initiatives. The Secretary-General's report states that goals and targets should take into account cross-cutting issues such as human rights, gender, disability, age and other factors leading to inequality, demographics, migration and partnerships.

Lessons from HIV are particularly relevant to the following goals proposed by the HLP report:

- *Empower Girls and Women and Achieve Gender Equality;*
- *Ensure Healthy Lives;*
- *Ensure Good Governance and Effective Institutions; and*
- *Create a Global Enabling Environment and Catalyse Long-Term Finance.*

The Goal of 'Ensure Healthy Lives' specifies the following targets:

- a. *End preventable infant and under-5 deaths.*
- b. *Increase by x% the proportion of children, adolescents, at-risk adults and older people that are fully vaccinated.*
- c. *Decrease the maternal mortality ratio to no more than x per 100,000.*
- d. *Ensure universal sexual and reproductive health and rights.*
- e. *Reduce the burden of disease from HIV/AIDS, tuberculosis, malaria, neglected tropical diseases and priority non-communicable diseases.*

Lessons from governance of HIV responses are particularly relevant to formulation of goals and targets concerning health, gender equality, good governance, peaceful societies and a global enabling environment.

For Asia and the Pacific, the Asia-Pacific MDGs Report 2012/13 proposes a framework with the following twelve 'goal areas': 1. Zero income poverty; 2. Zero hunger and malnutrition; 3. Gender equality; 4. Decent jobs for everyone of working age; 5. Health for all; 6. Improved living conditions for all; 7. Quality education for all; 8. Liveable cities; 9. Environmental responsibility and management of natural resources; 10. Disaster risk reduction; 11. Accountable and responsive governments; 12. Strong development partnerships and reformed global governance.⁵⁶

The framework defined by the Asia-Pacific MDGs Report 2012/13 is informed by principles that align with those proposed by the HLP and the Secretary-General. Of particular relevance are the following principles:

- *Based on the three pillars of sustainable development* – The pillars cover economic, social and environmental dimensions of development transformation. This would entail a people-centred approach that puts a strong emphasis on equity, social justice and human rights for the current and coming generations.
- *Embedded in equity* – Development gains should not systematically bypass sections of the population. This principle can be operationalized by ensuring that indicators under the eventually selected goals track not just aggregate or average progress, but also progress at the lower end such as the bottom quartile. Hence development policies must address social and economic gaps in outcomes, access and opportunities.⁵⁷

The Asia-Pacific MDGs Report 2012/13 includes a framework for ambitious "transformative targets" on social sustainability for consideration by States. According to the report:

(These are intended) to promote mindset changes like genuine acceptance of the equality of all human beings, e.g. through the school curriculum; more stringent targets on governance, accountability, transparency and

⁵⁵ The HLP's suggested Goals are: 1. End poverty; 2. Empower girls and women and achieve gender equality; 3. Provide quality education and lifelong learning; 4. Ensure healthy lives. 5. Ensure food security and good nutrition. 6. Achieve universal access to water and sanitation; 7. Secure sustainable energy; 8. Create jobs, sustainable livelihoods, and equitable growth; 9. Manage natural resource assets and sustainability; 10. Ensure good governance and effective institutions; 11. Ensure stable and peaceful societies; 12. Create a global enabling environment and catalyse long-term finance.

⁵⁶ UNESCAP, ADB, UNDP (2013). Op cit., pp.5-6.

⁵⁷ Ibid, pp.4-5.

people's participation in decision making; targets on energy-efficient public transport. The goal on gender equality to be more transformative than the MDG 3 Goal⁵⁸ and to cover dimensions such as gender-based violence, women workers' rights, rights and participation in situations of conflict and transition to peace, sexual and reproductive health and rights, women's agency and participation in public institutions, access to assets.⁵⁹

Universal health coverage

Achieving universal health coverage would be enormously beneficial to responses to HIV and other priority diseases and would have transformative affects on the lives of poor and marginalized populations. The experience of Thailand over the last decade has demonstrated the dramatic impacts of a policy of universal health coverage on improving outcomes for HIV and other health issues. A policy of universal health coverage has been critically important to the success of Thailand's national HIV response. In 2003, universal access to antiretroviral drugs was approved as the national policy and was achieved rapidly. Since 2006, it was incorporated into the universal health insurance system and based entirely on local resources.⁶⁰ This has supported improved treatment and prevention outcomes, with reduced AIDS mortality rates and HIV incidence declining by more than 50 percent in the decade to 2011.⁶¹

It is important that the post-2015 development agenda acknowledges that universal health coverage is anchored in a human rights-based approach to health, as it aims for all people to have access to health services without discrimination as to HIV status, disability, sex, class, religion, sexual orientation, gender identity, ethnicity, social origin or any other factor. Universal health coverage requires that all people obtain needed health services – promotive, preventive, curative, rehabilitative and palliative – without financial hardship.⁶² Universal health coverage focuses on equity with financial protection. The poorest and most marginalized populations usually face the highest health risks and need more health services. They are also exposed to financial risks associated with health costs, which impoverish an estimated 100 million people.⁶³ Therefore to achieve universal health coverage requires focusing resources on improving access for poor and marginalized populations. Financing for universal health coverage requires systems to be introduced to ensure health costs of the poor are shared by the society as a whole.

In relation to health, the Secretary-General's report specifies the following actions:

Address universal health-care coverage, access and affordability; end preventable maternal and child deaths; realize women's reproductive health and rights; increase immunization coverage; eradicate malaria and realize the vision of a future free of AIDS and tuberculosis; reduce the burden of non-communicable diseases, including mental illness, and road accidents; and promote healthy behaviours, including those related to water, sanitation and hygiene.⁶⁴

Inclusion of reference to universal health coverage is an important feature of the Secretary-General's report. The HLP report calls for steady progress in ensuring universal health coverage, but does not identify universal health coverage as a separate target.⁶⁵ The Asia-Pacific MDGs Report 2012/13 also makes reference to universal health coverage including universal access to sexual and reproductive health.⁶⁶ The UN General Assembly passed a resolution in support of universal health coverage in 2012, noting that the provision of universal health coverage is mutually reinforcing with the implementation of the *Political Declaration on the Prevention and Control of Non-Communicable Diseases* and the *Political Declaration on HIV and AIDS*.⁶⁷

58 The current MDG 3 is: Promote gender equality and empower women.

59 UNESCAP, ADB, UNDP (2013). Op cit., p.63.

60 Global Health Workforce Alliance Technical Work Group Secretariat. (2010). *Human Resources for Health Implications of Scaling up for Universal Access to HIV/AIDS Prevention, Treatment, and Care: Thailand Rapid Situational Analysis*. March 2010. Global Health Workforce Alliance Technical Work Group Secretariat.

61 UNAIDS (2012). *World AIDS Day Report: Results 2012*. Geneva: UNAIDS, p.10.

62 See: UNDP (2013), *Issues brief: Universal Health Coverage in the Post-2015 Development Agenda*, New York: UNDP.

63 WHO (2010). *World Health Report 2010: Health systems financing, the path to universal coverage*, Geneva: WHO.

64 UN Secretary-General (2013). Op cit., p.14.

65 High-Level Panel of Eminent Persons on the Post-2015 Development Agenda (2013). Op cit., p.38.

66 UNESCAP, ADB, UNDP (2013). Op cit., p.59.

67 'Moving Towards Universal Health Coverage' adopted by the UN General Assembly, 12 December 2012.

There is a strong basis for including universal health coverage as a health target, given that it is an essential means to achieving the goals of 'healthy lives' (HLP) or 'health for all' (ESCAP, ADB, UNDP). Focusing on universal coverage also has the benefit of promoting an integrated health sector approach. It can be used to promote integrated primary care services and integration or stronger linkages between HIV services and related services such as sexual and reproductive health services, maternal and child health and tuberculosis services.

The post-2015 health goal should be supplemented by specific targets for expanding universal health coverage, promoting multisectoral action on the social determinants of health and reducing the burden of specific diseases. Countries should be allowed the flexibility to achieve the health goal and related targets based on their unique contexts and priorities, while ensuring a rights-based, equitable approach to health.⁶⁸

Targets addressing laws, policies and the social determinants of health

While the HLP report acknowledges the need to address "discrimination [that] can create barriers to health services for vulnerable groups," the report does not mention the specific needs and human rights concerns of key populations most affected by HIV (sex workers, people who inject drugs, men who have sex with men, transgender people, prisoners and others). The repeal of all punitive and discriminatory legislation affecting these key populations and the introduction of protective measures such as non-discrimination, informed consent and privacy laws and policies would benefit HIV responses, sexual and reproductive health responses and broader aspects of development and poverty eradication for these populations.

The health targets would be strengthened by inclusion of targets that link health outcomes with removal of harmful laws and policies. This would be relevant not just to HIV but potentially efforts to combat a wide range of diseases affecting poor populations globally (see for example the discussion of the laws and policies harmful to NCD responses in Chapter 6, below). Examples of such targets could include:

- *Provide laws and policies that maximize access to affordable essential medicines for poor people;*
- *Removal of the key social determinants of ill health including any punitive laws, policies and law enforcement practices that impede access to health services for poor and marginalized populations;*
- *Ensure that legal and policy frameworks (including regulation of food and drugs, laws and policies in relation to intellectual property, taxation, labeling and marketing) and trade arrangements (including free trade and investment agreements) reduce rather than increase vulnerability of poor people to diseases;*
- *Ensure all marginalized populations (including people living with HIV, tuberculosis and other priority diseases, key populations affected by HIV and tuberculosis, persons with disabilities, indigenous people, and urban slum dwellers, among others) enjoy legal rights of protection from unjust discrimination and other human rights violations, and have access to effective legal redress for rights violations;*
- *Support alliances between health consumer organizations and human rights and gender equality movements to advocate for health equity, social justice, access to justice, the elimination of discrimination, violence and exclusion, and inclusive development;*
- *Fulfill the rights of all people, particularly poor people and people from marginalized populations, to have affordable access to health services and commodities; and*
- *Fulfill the rights of all people, including adolescents and young people, to have access to accurate information and education on health issues affecting their lives including in relation to HIV, sexual and reproductive health, and their health-related human rights.*

Drawing from lessons learned in applying the UNAIDS Strategic Investment Framework for HIV, targets could be formulated that promote more efficient, well-targeted allocation of resources to generate improved health outcomes. For example:

- *Adopt investment approaches to national health strategies and plans that apply an evidence-informed and rights-based programmatic focus targeted at people most affected and at risk of priority diseases.*⁶⁹

68 UNDP (2013). Op cit.

69 Priority diseases for countries should be determined by disease burden data such as disability adjusted life years lost and leading cause of death.

Research and development of new health technologies

The HLP report's proposed framework would be strengthened by inclusion of targets relating to research and development of new tools including drugs, diagnostics and vaccines to address global health priorities. The Secretary-General's report notes that the financing framework for the post-2015 agenda will require:

...commitment by the public and private scientific and research communities to develop new and transformative technologies. Harnessing science, technology and innovative methods will be central in areas ranging from information and communications technology to transportation, the environment and life-saving medicines.⁷⁰

Advances in antiretroviral drugs over the last two decades have revolutionized HIV prevention, treatment and care globally. Governance innovation through public-private partnerships between industry, universities and non-profit research institutes, governments and philanthropic foundations is supporting clinical trials of new drugs, candidate vaccines and new prevention technologies for use in developing countries. An effective HIV vaccine and female-controlled prevention technologies such as microbicides would be transformative and ultimately could help eradicate HIV. Development of new drugs and vaccines for other communicable diseases such as tuberculosis and malaria could revolutionize approaches to prevention and treatment. Advances in vaccines and other cost-effective prevention technologies can be immensely beneficial to health systems by reducing cost pressures associated with long term of life long treatment requirements of HIV and other diseases.

Global frameworks should set targets for government support to coordinated research and product development efforts, with a focus on research and product development for new tools to fight diseases prevalent in poor countries, where market incentives have failed to ensure sustained private sector research funding.

In 2012, the report of the Consultative Expert Working Group on Research and Development established by the World Health Assembly recommended the following global targets:

- *All countries should commit to spend at least 0.01% of GDP on government-funded research and development devoted to meeting the health needs of developing countries.*
- *Developing countries with a potential research capacity should aim to commit 0.05–0.1% of GDP to government-funded health research of all kinds.*
- *Developed countries should aim to commit 0.15–0.2% of GDP to government-funded health research of all kinds.⁷¹*

It would be desirable to frame a target relating to government spending that focuses on medical research for new technologies to address neglected diseases. For example:

- *Ensure x% proportion of total health funding / GDP is allocated to medical research and development of new drugs, diagnostics and vaccines, with a priority to diseases neglected by medical research efforts due to market failure.*

Gender targets

The Secretary-General's report and the HLP report both include strong sections on gender, including attention to sexual and reproductive health rights. The Secretary-General's report highlights empowerment of women and girls as a key action, with a focus on ending discrimination, equality rights, full participation in the political, economic and public spheres, equal access to financial services, infrastructure, the full range of health services, including in the area of sexual and reproductive health rights, and water and sanitation.

The HLP report recommends a separate gender goal, 'Empower girls and women and achieve gender equality', and specifies the following targets:

- a. *Prevent and eliminate all forms of violence against girls and women.*
- b. *End child marriage.*

⁷⁰ UN Secretary-General (2103). Op cit., p.16.

⁷¹ Consultative Expert Working Group on Research and Development (2012). *Research and Development to Meet Health Needs in Developing Countries: Strengthening Global Financing and Coordination*, 5 April 2012, Geneva: WHO, p.84.

- c. *Ensure equal rights of women to own and inherit property, sign a contract, register a business and open a bank account.*
- d. *Eliminate discrimination against women in political, economic, and public life.*⁷²

In many communities, the inability to own and access property is one of the biggest difficulties facing women in households affected by HIV. As the HLP report recommends, targets should address ownership and inheritance issues affecting women and girls, who may be disadvantaged by discriminatory laws, customary laws and traditional practices.

Inclusion of specific reference to the gender equality rights of marginalized groups would strengthen the approach to gender. It is particularly important to highlight the human rights of sex workers and transgender people, including in relation to protection from gender-based violence.⁷³ Specific recognition should be given to the need to prevent and eliminate discrimination on the grounds of sexual orientation and gender identity. Other marginalized populations that should be recognized in the post-2015 framework of targets and indicators include women living with HIV, lesbians, indigenous women, female migrant workers, women with disabilities and incarcerated women.

The HLP report's proposed gender target relating to elimination of violence against women and girls is welcomed and should be extended to encompass violence against transgender people. The post-2015 framework should give explicit recognition to the links between HIV vulnerability and high levels of violence against women (including female sex workers) and transgender people, and should address violence in health care settings including forced sterilization of women living with HIV.⁷⁴

The Asia-Pacific MDGs Report 2012/13 observes that the gender focus of the MDGs was limited and weak in such areas as universal access to sexual and reproductive health or violence against women and girls. The Report argues for gender priorities to be incorporated into each goal, which would be helpful and, as noted by the Report, is already happening in the MDG frameworks of many countries in Asia.⁷⁵ The Report provides examples of 'transformational targets' to change attitudes and behaviours relating to gender, such as curriculum changes, and legal changes for equity, for example on asset ownership by women and to address gender-based violence.⁷⁶

The impacts of HIV on women in the region suggest that targets should encourage attitudes and behaviours to reduce stigma, discrimination and violence affecting female sex workers, women who use drugs, women living with HIV and other marginalized women and girls.

Inclusive governance targets

The HLP report's goal of '*Ensure Good Governance and Effective Institutions*' specifies the following targets:

- a. *Provide free and universal legal identity, such as birth registrations.*
- b. *Ensure people enjoy freedom of speech, association, peaceful protest and access to independent media and information.*
- c. *Increase public participation in political processes and civic engagement at all levels.*
- d. *Guarantee the public's right to information and access to government data.*
- e. *Reduce bribery and corruption and ensure officials can be held accountable.*⁷⁷

72 High-Level Panel of Eminent Persons on the Post-2015 Development Agenda (2013). Op cit., p.34.

73 The International Gay and Lesbian Human Rights Commission (IGLHRC) is conducting research in five Asian countries on violence against lesbian, bisexual, and transgender people. Preliminary findings confirming high levels of violence were presented to the 57th Commission on the Status of Women, 2013: IGLHRC (2013). *Commission on the Status of Women 57 Panel: Documenting Violence Against Lesbian, Bisexual, and Transgender People in Asia*, 3 May 2013.

74 See: Colekessian A. (2013). *Violating Women's Rights: Forced Sterilization, Population Control and HIV/AIDS*, Association for Women's Rights in Development; 19.3 percent of women living with HIV in Cambodia had been 'strongly advised' by health staff to undergo permanent sterilization, a similar finding to China where 17 percent of the respondents had been strongly advised by health staff to opt for sterilization: Cambodian People Living with HIV Network (2010). *People Living with HIV Stigma Index Cambodia*, Phnom Penh: KHANA, p.43.

75 UNESCAP, ADB, UNDP (2013). Op cit., p.49.

76 Ibid, p.64.

77 High-Level Panel of Eminent Persons on the Post-2015 Development Agenda (2013). Op cit., p.50.

Similarly, the Secretary-General's report calls for action to '*Build peace and effective governance based on the rule of law and sound institutions*' noting that:

Peace and stability, human rights and effective governance based on the rule of law and transparent institutions are outcomes and enablers of development. Transparency and accountability are powerful tools for ensuring citizens' involvement in policymaking and their oversight of the use of public resources...⁷⁸

The Asia-Pacific MDGs Report 2012/13 calls for a goal area of '*Accountable and responsive governments*' requiring: ...accountable, transparent and corruption-free public institutions, across all levels from the national to the local. It aims for more capable and efficient management of public resources and delivery of public services. Moreover, governments need to harness capacities to ensure peace and security. Without trust in public institutions of governance, the compact between people and states is under threat.⁷⁹

Approaches to accountability drawn from best practice in HIV responses, characterized by inclusive, people-centred, participatory rights-based governance, should be applied to build trust in governance and transform approaches to health and development. A key lesson from HIV for governance is that health mobilizes people for building democratic accountability. Treatment activists led by people living with HIV in countries such as India and Thailand have been mobilized around an 'access to medicines' agenda, which has resulted in increased accountability of governments to their needs and health rights (see Chapter 4.5). Price reductions of HIV medicines and the production of cheaper generic versions paved the way for cheaper medicines across a range of conditions, with broader implications for poverty reduction. In other contexts, sex worker activism has led to increased sex worker participation in local mechanisms governing their work conditions, resulting in positive outcomes for HIV, health, violence protection and access to finances (see Chapter 5.2.2).

Mindful of these advocacy successes, the governance targets proposed by the HLP report could be strengthened by a stronger emphasis on inclusion of marginalized populations, rather than a general unfocused target relating to the general public. Marginalized populations stand to benefit the most from a more inclusive, rights-based development agenda.

The HLP report's proposed participation target '*increase public participation in political processes and civic engagement at all levels*' could be reformulated as follows:

- *Increase participation of the most marginalized populations (particularly women and girls, indigenous populations, people with disabilities, people living with HIV, sex workers, people who use drugs, sexual minorities and transgender people) in political processes to enable these populations to meaningfully engage in advocacy and the planning, designing, implementing, monitoring and evaluating of policies and programmes that affect their lives.*

Similarly, the proposed participation target '*Guarantee the public's right to information and access to government data*' could be reformulated as follows:

- *Guarantee that all members of the public including in particular marginalized populations are able to access information about government policies and decisions, and that services are provided to ensure marginalized populations receive government information in community languages and accessible formats.*

The HLP report proposes an 'access to justice' target under the goal of '*Ensure stable and peaceful societies*' which is worded as follows:

- 11b. *Ensure justice institutions are accessible, independent, well-resourced and respect due-process rights.*⁸⁰

Similarly, the Secretary-General's report observes: "Legal empowerment, access to justice and an independent judiciary and universal legal identification can also be critical for gaining access to public services."⁸¹

78 UN Secretary-General (2013). Op cit., p.15.

79 UNESCAP, ADB, UNDP (2013). Op cit., p.49.

80 High-Level Panel of Eminent Persons on the Post-2015 Development Agenda (2013). Op cit., p.52.

81 UN Secretary-General (2013). Op cit., p.15.

Access to justice and legal empowerment requires more than a focus on institutions (see 4.4). Legal empowerment is a people-centred process of empowering communities to advocate their rights. Legal empowerment enables marginalized populations to challenge injustices and discrimination, change public attitudes and actively participate in shaping non-discriminatory rights-based responses to their justice needs. In the HIV and NCD fields, legal empowerment approaches have been applied in campaigns and litigation for expanded access to affordable generic medicines for poor people. Targets should focus on beneficiary communities, rather than justice institutions. For example:

- *Ensure poor and marginalized communities are supported by legal empowerment programmes to access the justice system and to advocate their legal and human rights so as to hold duty-bearers accountable for compliance with human rights obligations.*

Leadership, policy and planning architecture

KEY POINTS

- Political leadership has provided the foundation for success of national HIV responses and is key to development efforts that seek to promote the needs and rights of marginalized populations. Inclusive national planning and coordination mechanisms can provide a foundation for strong political leadership.
 - The 'Three Ones' principle developed in the context of HIV requires responses that are guided by one agreed action framework that provides the basis for coordinating the work of all partners, one national coordinating authority with a multisectoral mandate, and one agreed country-level monitoring and evaluation system. This principle can be applied or adapted to other development priorities requiring donor harmonization, alignment with national priorities and multisectoral coordination (e.g. NCDs, climate change, water management).
 - Coordination of national responses through comprehensive national strategic plans requires linkages between sectors and agencies working at national, provincial and district levels. Multisectoral responses enable a focus on structural factors that influence development outcomes.
 - Vertical approaches in the health sector are justified in the context of emergency responses to epidemics, but as a longer-term strategy can undermine national health systems. To ensure sustainable responses, donors should avoid creating vertical, donor-driven, issue-specific responses unless exceptional circumstances exist.
 - Decentralized governance mechanisms such as local AIDS Councils have been effective in promoting local leadership, ownership and uptake of services. Decentralization combined with local democracy can improve the responsiveness of policies and programmes for local development priorities.
 - Partnerships between governments and private sector corporations can help to ensure corporate social responsibility programmes align with broader development objectives.
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3.1 The role of leadership

Political leadership

Political leaders have played pivotal roles in mobilizing resources and support from a broad cross-section of society to raise the profile of HIV responses. Fortright leadership has been key to breaking down HIV-related stigma and discrimination. Political leaders have committed to concrete targets set by the Political Declaration on HIV/AIDS of the UN General Assembly. Governments report progress against these targets to the UN in reports that are publicly available.⁸²

The successes of Cambodia and Thailand in reversing HIV epidemics benefited greatly from strong leadership including from offices of the respective Prime Ministers, which helped to galvanize national efforts and enabled large-scale mobilization of resources and communities. National HIV responses have benefited from political leaders

82 See: *United to end AIDS: achieving the targets of the 2011 Political Declaration: Report of the Secretary-General, Implementation of the Declaration of Commitment on HIV/AIDS and the Political Declarations on HIV/AIDS*, A/66/757, 2 April 2012.

willing to speak publicly on the need to address discrimination and to respect, protect and fulfill the rights of people living with HIV and key populations. For example:

- Prime Minister Hun Sen of Cambodia provided leadership in championing the 100% Condom Use Programme, calling all governors of provinces and municipalities to efficiently apply the programme countrywide.⁸³
- President Susilo Bambang Yudhoyono of Indonesia made a statement in 2009 at the 9th International Congress on AIDS in Asia and the Pacific welcoming the role of people living with HIV, MSM, transgender people, sex workers and people who use drugs as partners in the Indonesian national HIV response;⁸⁴
- Former Premier Wen Jiaobao of China spoke out publicly against HIV-related discrimination and pledged to fill financial gaps left by withdrawal of external donor funding in 2011,⁸⁵ and in 2012 the incoming Premier Li Keqiang called for an end to discrimination against people living with HIV in provision of health care.
- President Ratu Epeli Nailatikau of Fiji regularly gives speeches in national and regional meetings addressing HIV-related stigma and discrimination, promoting the use of condoms and encouraging pragmatism to overcome strong cultural and religious barriers. In 2011 he gave a speech to the 10th International Congress on AIDS in Asia and the Pacific on Fiji's approach to addressing the legal and human rights aspects of the HIV epidemic response.⁸⁶ The same year he also chaired a panel on a new global compact for HIV at a UN High-Level Meeting.

Religious leadership

Religious leadership on HIV has been very important in the region, particularly given the central role of religion in many societies and the moral issues that sexual and drug using behaviours raise. Examples of leadership initiatives include:

- A Buddhist Leadership Initiative on HIV has been implemented in the Mekong, with activities in China, Cambodia and Lao PDR, and along the Thai-Myanmar border.⁸⁷
- Muslim leaders have played a role in advocating harm reduction approaches to prevent HIV among people who inject drugs in Xinjiang, China, and implementing mosque-based interventions against discrimination and stigma.⁸⁸
- In Malaysia, the Department of Islamic Development and the Ministry of Health have cooperated in institutionalizing HIV education into training of Muslim leaders and are promoting non-discrimination towards people living with HIV and key populations.⁸⁹
- In the Pacific religious leaders have been engaged in HIV issues for many years and play a significant role in reducing stigma and discrimination affecting people living with HIV. Transformational leadership programmes working with religious leaders have been implemented in PNG, Fiji and Tonga. Regional faith-based organizations such as the Pacific Council of Churches have developed progressive HIV policies and the 2004 Nadi Declaration on HIV.⁹⁰

83 WHO (2004). *Experiences of 100% condom use programme in selected countries of Asia*, Manila: WHO WPRO, p.4.

84 Speech of H.E. Mr. Susilo Bambang Yudhoyono President of The Republic of Indonesia on The Occasion of the Opening of The 9th International Congress on Aids in Asia and the Pacific, 9 August 2009, Bali.

85 Press statement: UNAIDS applauds China's decision to fill its HIV resource gap, 1 December 2011.

86 UNAIDS (2011). Press Statement, *President of Fiji committed to the AIDS response*, 27 August 2011.

87 UNICEF (2009). *Regional Review, Buddhist Leadership Initiative*, Bangkok: UNICEF East Asia Pacific Regional Office.

88 Hammett T., et al (2008). 'Social evils' and harm reduction: the evolving policy environment for human immunodeficiency virus prevention among injection drug users in China and Vietnam, *Addiction*, 103(1), 137–145.

89 Malaysian AIDS Council (2011). *HIV and Islam: Responsible religious response to HIV & AIDS in Malaysia*, Kuala Lumpur: Malaysian AIDS Council.

90 *Nadi Declaration: A Statement of the World Council of Churches' Pacific Member Churches on HIV/AIDS*, 29 March – 1 April 2004, Tanoa International Hotel, Nadi, available at: http://www.unaids.org/fj/attachments/170_Nadi-Declaration.pdf

3.2 Leadership and coordination structures

3.2.1 National AIDS commissions and councils

National and sub-national governance and accountability frameworks have been a feature of effective HIV responses. Robust governance structures for policy, planning, implementation and coordination of programmes have supported effective national HIV responses. Weak governance structures lead to skewed priorities and lopsided allocation of resources, leading to ineffective service delivery and an accountability vacuum.⁹¹

National strategic plans on HIV and AIDS have enabled large-scale multisectoral planning to provide the framework for sectoral leadership, coordination and harmonization of the activities of diverse partners around common strategies and results.⁹² These partnerships often include organizations of people living with HIV and other community-based organizations (CBOs), non-government organizations (NGOs), faith-based organizations, donors, the UN system and ministries across government. National strategic plans can cover a variety of sectors, and include prevention, care, treatment, impact mitigation and measures to address the legal and policy environment. National strategic plans are effective when they are costed and include clear targets and lines of accountability.

Within countries, many key partnerships have their own internal governance and coordination mechanisms. These include:

- National AIDS commissions and councils (NACs), which are mandated by government to lead the response;
- Government-led partnership forums and working groups involving the broad range of stakeholders in policy and programme development and implementation;
- The UN Joint Team on AIDS and Expanded UN Theme Groups, which have evolved to include other stakeholders outside the UN system; and
- Global Fund Country Coordinating Mechanisms (CCMs), which coordinate the design and implementation of Global Fund programmes. CCMs generally operate in parallel to the NAC and its committees, with representation of people living with HIV and key populations.

Partnerships between law and justice, public security, social welfare and public health sectors have been critical for the successful implementation of HIV responses. Coordination and cross-dialogue ensure that HIV programmes do not operate in isolation from other efforts, such as programmes to eliminate gender-based violence or to address illicit drug use.

During the 1990s, increased donor funding and the recognition of the need for multi-sectoral HIV responses, particularly in countries with expanding epidemics, gave rise to the need for national HIV coordination mechanisms. In Asia, NACs were established in Bangladesh, Cambodia, China, India, Indonesia, Myanmar, Nepal, Philippines, Thailand, and Viet Nam. Different governance models for NACs include:

- Stand-alone multi-sectoral NACs, located outside the health sector, in Cambodia, China, PNG and Indonesia.
- NACs located within the health sector, supporting national HIV programmes, in Lao PDR, Viet Nam, Thailand and the Philippines.

In the Pacific, NACs have played a leadership and coordination role in PNG, Fiji, Samoa and Solomon Islands.⁹³ For Pacific island states, most national programmes have been based on Pacific regional HIV strategies and workplans funded by donors. The Commission on AIDS in the Pacific observed the tendency for the planning and coordination structures to be donor-driven rather than country-led:

91 Commission on AIDS in Asia (2008). *Redefining AIDS in Asia: Crafting an effective response*, New Delhi: Oxford University Press, pp.143-144.

92 UN (2001). *Factsheet for UN General Assembly: HIV/AIDS, a governance challenge*, available at: http://www.un.org/ga/aids/ungassfactsheets/html/fsgovernance_en.htm

93 Pacific Regional HIV Project (2006). *Review of National AIDS Coordination Mechanisms in Pacific Island Countries*, Melbourne: IDSS & Burnet Institute.

Unfortunately, most HIV plans produced since the late 1990s have not proceeded past an initial draft; even fewer have been implemented to any extent; and fewer still have been evaluated as to their impact on the epidemic. These plans were often complicated and ambitious and usually unrelated to the number of known HIV infections in any country.

... (N)ational strategic plans will be more effective if countries themselves develop them, in order to match their specific situations and priorities. This affects the timing, process and content of the plans, which cannot be driven by the timelines of regional agencies or donor partners... In smaller Pacific countries, especially, frameworks and monitoring and evaluation arrangements can be integrated into national health plans or development strategies.⁹⁴

For many Pacific island countries, HIV received initial attention because of donor demands. However, the small numbers of reported HIV cases and competing demands from other more immediate and pressing health priorities, including increasing demands on health systems arising from NCDs, meant that HIV planning was neglected.

An innovative feature of the HIV response has been the role of independent commissions in providing guidance to the region as a whole on strategy and approaches to national planning, including the structure and function of NACs. Independent commissions have provided strategic and technical guidance, which has helped to ensure that national planning has been informed by evidence. These commissions have included:

- Independent Commission on AIDS in Asia (2008);⁹⁵
- Independent Commission on AIDS in the Pacific (2009);⁹⁶
- Global Commission on HIV and the Law, which included an Asia Pacific Regional Dialogue.⁹⁷

Recommendations of these commissions have strongly influenced national HIV responses by disseminating lessons learned, for example the need to be guided by epidemiological evidence, invest in formal leadership and governance structures, to avoid punitive legal approaches and accord a priority to key populations.

The Commission on AIDS in Asia recommended that the role of NACs should be limited to policymaking, coordination and monitoring and evaluation of the response, and that they should not be directly involved in direct implementation or service delivery. The Commission recommended:

- the Health Ministry should be 'first among equals' in the NAC;
- the NAC needs to decide which entity should act as its secretariat. Often the Health Ministry would be well-suited for this task; and
- strong coordination is essential.⁹⁸

The Commission on AIDS in Asia compared the potential effectiveness of NACs in three different hypothetical scenarios: (i) a NAC led by the ministry of health; (ii) a NAC led by another ministry outside of health (such as finance or planning); or (iii) a NAC led by a head of government. The Commission found that a strong NAC led by the head of government appears to be effective only when the head of government is strongly committed to the HIV response. The Commission also observed that only India has been successful in assigning leadership of the programmes to a senior level functionary in the Government.⁹⁹

The nature of each NAC varies depending on membership, legal mandate, structure of its secretariat and relationships with government and external stakeholders. For example, Indonesia's NAC is chaired by the Coordinating Minister of People's Welfare. The Commission is responsible for developing HIV policies and strategies,

94 Commission on AIDS in the Pacific (2009). Report of the Commission on AIDS in the Pacific-Turning the Tide: An OPEN strategy for a response to AIDS in the Pacific. UNAIDS Pacific Region, p.58-59.

95 Commission on AIDS in Asia (2008). *Redefining AIDS in Asia. Crafting an Effective Response*, New Delhi, Oxford University Press.

96 Commission on AIDS in the Pacific (2009). *Report of the Commission on AIDS in the Pacific-Turning the Tide: An OPEN strategy for a response to AIDS in the Pacific*. UNAIDS Pacific Region.

97 Global Commission on HIV and the Law (2012). *Risks, rights and health*. New York: UNDP; Global Commission on HIV and the Law (2011). *Report of the Asia Pacific Regional Dialogue of the Global Commission on HIV and the Law*, Bangkok: UNDP.

98 Commission on AIDS in Asia (2008). Op cit, p.142.

99 Commission on AIDS in Asia (2008). Op cit, p.143.

and to coordinate and monitor implementation. The NAC's members include 18 relevant ministries and government agencies, as well as five civil society organizations, including organizations of people living with HIV. Since 2006, the NAC has reported directly to Indonesia's President. The Commission's secretariat convenes twelve working groups that help formulate technical policies, with each working group responsible for a specific aspect of the HIV response.

Location of the NAC within the health sector may be justified given the normalization of HIV as one of a number of chronic manageable diseases. HIV service provision is increasingly integrated within mainstream health service delivery. Prior to the Commission on AIDS in Asia report of 2008, the consensus was to promote representation on NACs from across all of government. The Commission on AIDS in Asia drew attention to the need for a more focused response for Asian epidemics and recommended that only ministries with direct involvement in the HIV response (for example, Ministries of Education, Police, Justice, Social Welfare) should sit on the NAC. These ministries should allocate some of their own funds and incorporate HIV components into their programmes to ensure their meaningful involvement in and commitment to the response.

As epidemics have evolved, there has been pressure on national governance models to also evolve to remain fit for purpose. The structure of NACs and Global Fund CCMs has often been largely donor-driven and commentators have highlighted the need for structures to evolve to remain relevant to local contexts and evolving epidemics. Governance coordination structures need to be tailored to the context. For example, it is argued:

In spite of the enormous political, institutional and financial investments in NACs and the 'expanded multi-sectoral response', it is critical that leaner, meaner programme responsibilities and accountabilities are salvaged and supported, and embedded within universal access to health care...The concern for the coordination process and architecture that the NACs represent can distract from focusing on scaling up effective programming. Health ministries and health systems have grown dramatically in scope and scale since the days when AIDS presented a major coordination challenge. Effective public health programming for key affected populations as part of Ministry of Health core business is now in place in many countries, and needs to be strengthened.¹⁰⁰

Debates regarding the reorientation of Cambodia's HIV response illustrate the issues confronting many national HIV programmes seeking to ensure appropriate governance in a context of resource constraints and improved understanding of the epidemiology of concentrated epidemics. Cambodia's national management structure for HIV was designed to support a coordinated, multisectoral response aligned with the decentralization policy of the Government. This approach was effective in the 1990s when Cambodia had an expanding generalized epidemic affecting around two percent of the adult population, but has been questioned in the evolving epidemic situation in which HIV incidence has reduced significantly and is concentrated among key populations. Effective governance approaches for Cambodia's epidemic are being rethought through application of the UNAIDS Strategic Investment Framework to ensure efforts are informed by evidence of effectiveness.¹⁰¹ A joint strategic assessment of HIV in Asia found that multi-sectoral HIV governance mechanisms can be unwieldy and inefficient: "Cambodia, for example, has a National AIDS Authority comprising 29 different Ministries. While the 'consensus' for this kind of architecture may have been the right idea at the time, it is now clearly inappropriate for the region."¹⁰²

Ensuring the health sector is able to play an appropriate leadership role is an issue of concern in relation to coordinating the response. Sometimes the establishment of a multisectoral response results in friction and competition between the health sector and the NAC. A review of Pacific HIV responses noted:

While health is the technical agency on HIV for other government departments and sectors, it has often not been given any special status or control (in the overall national HIV response)... This is creating significant tensions in some countries, especially around management and disbursement of funding for HIV programs. In countries where HIV prevalence is low, Ministries of Health are usually managing and coordinating the

100 Godwin P, Dickinson C. (2013). *Five ways to begin the end of AIDS*, London: HLSP Institute, p.3.

101 UNAIDS (2012). *Case Study: The Royal Government of Cambodia at the forefront in applying new investment approach*, UNAIDS/PCB (31)/12. CRP.1

102 Godwin P, Dickinson C. (2012). *HIV in Asia – Transforming the agenda for 2012 and beyond Report of a joint strategic assessment in ten countries: Final Report*, Canberra: HLSP, p.19.

response. However its role in overseeing the implementation of the response is often compromised by its lack of authority over other government agencies.¹⁰³

The position of civil society within NACs is variable. Some countries maintain government-dominated NACs, where community representation is largely on a token basis. Others have broadened membership and supported meaningful participation of community organizations. The Commission on AIDS in the Pacific observed:

Most Pacific countries in the region have established national HIV coordination bodies to strengthen multisectoral responses. However, a recent AusAID programme review noted that: 'the coordination role of NACs, while improved in many countries, is still often performed inconsistently. The relationship between CSOs (civil society organizations) and government agencies also varies in strength across the region and has been a significant problem in some countries.'¹⁰⁴

The existence of national coordinating bodies and strategic frameworks does not always translate into effective action. For example, an analysis of national coordinating bodies in the Pacific found weaknesses of some national coordinating authorities to include:

- Absence of strong mandates and support. Some bodies lacked accountability, authority and legitimacy and overall leadership of response.
- Absence of human resource capacity and/or management and institutional authority.¹⁰⁵

In the Pacific, there has been a tendency for NAC structures to be imported without adequate attention to the local epidemic context because the set-up of these structures has been a precondition of funding. Capacity of national HIV authorities for planning, resource mobilization, coordination, information management, and monitoring and evaluation is often very limited.¹⁰⁶

The establishment of multisectoral governance mechanisms in low prevalence countries can contribute to resource expenditure distortions. For example, a 2009 National AIDS Spending Assessment in Fiji found that 34 percent of expenditures went to 'coordination and governance', which was the same as the amount spent on prevention of HIV and STIs, and three times more than was spent for treatment. The bulk of the resources for capacity development are often spent on consultative planning and coordination. As a result, insufficient funds may remain for developing capacities of front-line workers to deliver programmes.¹⁰⁷

3.2.2 Global Fund CCMs

The Country Coordinating Mechanisms (CCMs) of the Global Fund are an innovative multi-sectoral national governance structure. CCMs have often operated in parallel to NACs over the past decade. In the Pacific, a Regional Multi-Country Coordinating Mechanism provides oversight to grants implemented in eleven small island states. CCMs often cover not just HIV but also tuberculosis and malaria. CCMs develop proposals, monitor progress, analyze results and provide oversight and accountability of Global Fund moneys.

In many countries the Global Fund provides a major source of funding for HIV and much of this funding is managed through ministries of health. This gives rise to the need to manage tensions that can arise between the NAC and ministry of health regarding who manages funds and has oversight of their implementation. A joint strategic assessment conducted in 2011-2012 reported:

Inconsistencies and territorialities between (National AIDS Councils / National AIDS Programmes) and CCMs are tending to create anomalies in accountability, planning, resource mobilisation and programming. Division of

103 Pacific Regional HIV/AIDS Project (2006). *Review of national AIDS coordination mechanisms in Pacific island countries*, Melbourne: IDSS & Burnet Institute, p.7.

104 Commission on AIDS in the Pacific (2009). Op cit, p.59.

105 Pacific Regional HIV/AIDS Project (2006). Op cit.

106 Ibid.

107 Communication from UNDP Pacific office, May 2013.

labour over major programmatic areas...is reported by informants to fragment program coherence and has an impact on the continuum of care for people living with HIV.¹⁰⁸

Each country manages these tensions differently. There have been efforts to rationalize some CCM arrangements through coordination of CCMs with NACs and health sector coordination arrangements.

The Commission on AIDS in Asia's analysis of CCMs in Asia reported mixed successes. Although CCMs are meant to act as multisectoral bodies like NACs, with strong civil society representation, health ministries dominate most CCMs. Civil society representatives in many countries lack capacity and scope for participation and even non-health government structures appear not to participate effectively in the CCMs.¹⁰⁹

3.3 Decentralized governance

Many countries in Asia and the Pacific have pursued decentralization policies as a core element of development strategy in recent decades. The *United Nations Development Strategy 'Beyond 2015'* defines decentralization of government as the administrative, fiscal and democratic devolution of power and resources by government from its top tiers to its bottom tiers.¹¹⁰ It aims to give communities a direct voice and influence over the issues that affect their daily lives. Decentralized governance is a broader concept than 'decentralized government' and embraces community involvement in governance and includes mechanisms to involve traditional and religious leaders at the local level.¹¹¹ There are many obstacles to local governance becoming significantly participatory. Religion, caste, class, gender, ethnicity, and other social divisions as well as historical factors affect meaningful participation.

Decentralized structures have been an important feature of effective HIV governance, particularly in the larger countries in Asia and the Pacific. A decentralized and scaled-up response to HIV (and other health and development priorities) can support involvement of communities through multi-sector, multi-level approaches. Decentralization can result in greater community ownership and mobilization in support of responses and greater involvement of local authorities, communities and private sector bodies in decisions and policy making at each level. To varying degrees, decentralized governance mechanisms can facilitate local community participation as well as traditional leadership in decisions regarding programming.

In the context of the HIV epidemic, effective governance has frequently been dependent on the ability to mobilize and support local-level action. National plans are often well resourced at central level, however this does not always result in adequately resourced programmes at local level. In recognition of this problem, some countries have devolved budgetary and political responsibility for most aspects of HIV prevention and treatment (e.g. China, Cambodia, India, Viet Nam, Indonesia, the Philippines and PNG). Provincial, district and/or state AIDS Committees or Councils play an essential coordination role in HIV responses in these countries. The effectiveness of such structures in planning and implementation is supported where linkages to the existing local government system are strong, including formalization of lines of accountability and authority.

Decentralization can give rise to significant challenges for HIV and other development responses, particularly if local political and social factors create obstacles to community participation. In some communities, local religious and cultural norms and conservative traditions affecting women and key populations impede participation in decentralized governance. Human rights-based advocacy and engagement of local leaders can be effective in challenging these barriers.

108 Godwin P, Dickinson C. (2012). Op cit., p.22.

109 Commission on AIDS in Asia. (2008). Op cit., p.143.

110 UN Development Committee (2012). *The United Nations Development Strategy Beyond 2015, Policy Note*, New York: UN, p.40.

111 Ibid., p.41.

Participatory, decentralized governance can enhance the status of marginalized groups. Autocratic, centralized governments are typically removed from the realities of development challenges facing poor, rural and marginalized communities. Development strategies that concentrate power in a central bureaucracy can entrench the power of political and business elites and aggravate inequalities between urban and rural areas. Decentralization combined with local democracy can improve the responsiveness of policies and initiatives to the health and human rights priorities and needs of citizens, provided that there is local leadership and political will to implement human rights-based responses, and that local authorities are empowered with sufficient resources and autonomy to meet their responsibilities.

Sub-national AIDS Commissions in Indonesia

Indonesia's experience demonstrates how national and subnational structures have facilitated leadership and community participation in HIV responses and supported increased uptake of prevention and treatment services. Overall coordination of the national HIV response rests with the NAC. Regulations assign to the NAC and subnational AIDS Commissions at the provincial and district level the responsibility to lead, manage, regulate, monitor and evaluate the implementation of HIV responses at each level of government.¹¹² The NAC Secretariat promotes multi-level partnership, consultation and collaboration with provincial AIDS commissions and their partners and encourages exchange of experience among provincial teams.

There has been a concerted effort since 2006 to strengthen local AIDS commission secretariats. Regulations and policies were issued at the provincial and district level for scaling up HIV services and providing enabling policy environments for delivery of services in the priority districts and cities where the burden of the epidemic was highest.¹¹³ There are now AIDS commission secretariats in all of Indonesia's 33 provinces.

A challenge for decentralization of HIV governance in Indonesia is that some conservative provinces and districts are reluctant to implement participatory rights-based approaches due to local political, religious and cultural factors. Some provinces and districts have enacted local regulations that undermine rather than support HIV responses. For example, some local governments have criminalized homosexual conduct and sex work, which are not criminalized at the national level. The National AIDS Commission and UN agencies have sought to promote good practice by undertaking a comparative study of legal environments for HIV responses in several different provinces in 2013.

State AIDS Control Societies in India

State AIDS Control Societies (SACS) are autonomous state bodies. Their boards have representation from government departments, civil society, the private sector and people living with HIV. SACS are responsible for medical, welfare and public health services, communication, administration, planning, coordination, monitoring and evaluation, finance and procurement.¹¹⁴ District AIDS Prevention and Control Units have also been established to deliver interventions to local communities and coordinate with related local health and welfare services. The District Units share the administrative and financial structures of the National Rural Health Mission. A review of SACS found that while the convergence of a decentralized delivery system with other health systems is helpful in long term sustainability of the programme, in practice there is often poor integration of HIV-specific interventions within broader reproductive and child health services. These decentralized structures have been important for delivery of targeted interventions to key populations, although constrained by weak infrastructure, and limited human and financial resources.¹¹⁵

Local AIDS Councils in the Philippines

The Philippine National AIDS Council (PNAC) leads the national multisectoral response. However, consistent with the national system of decentralized government, operational responsibility for HIV prevention and control falls on

¹¹² Presidential Regulation No. 75/2006; Ministerial Regulation No. 20/2007 of Ministry of Home Affairs.

¹¹³ National AIDS Commission (2010). *National HIV and AIDS Strategy and Action Plan 2010 – 2014*, Jakarta: National AIDS Commission.

¹¹⁴ See National AIDS Control Organisation (2007). *National AIDS Control Program III (2007-2012)*. New Delhi: NACO.

¹¹⁵ Sogarwal R., Bachani D., Venkatesh S. (2010). Challenges in HIV/AIDS prevention, care and treatment programme in India, Policies and Priorities under National AIDS Control Programme Phase-III (2007-12). *SAARC J. Tuberculosis, lung disease and HIV/AIDS* 2010 VII(1) 1-7, p.7.

Local Government Units and local AIDS councils (LACs). Some LACs actively involve civil society, but the situation varies widely across the country due to the high degree of autonomy of Local Government Units.¹¹⁶

Over one hundred LACs have been formed. In 2013, the Department of the Interior and Local Government issued a Circular to all city Mayors and Provincial Governors enjoining all cities to promote leadership by creating a LAC to promote synergy between LGUs, NGOs, faith based organizations, local businesses, academics, and other civil society organizations.¹¹⁷ The Circular states that membership of the LACs should include a representative of an organization of people living with HIV and that LACs should act to protect the rights of people living with HIV by using HIV champions to eliminate stigma and discrimination and promote confidentiality, thereby supporting the uptake of services.

City governments are required to enact local ordinances to define LAC functions, allocate funding to programmes and provide a framework for multisectoral plans. LACs are encouraged to function as an advocacy group to work for policy development and reform, to organize HIV and communication programmes in schools, conduct surveillance to track the epidemic and better understand risk practices, and ensure standardized approaches to testing and counselling.

LACs receive support from Regional AIDS Assistance Teams (RAATs). UNDP has worked with the Local Government Association and local government departments to establish RAATs. In addition to a technical support role, RAATs serve as advocates at the local level to obtain commitment from political and civil society leaders.¹¹⁸

Thailand: Commission on Stigma, Discrimination and Protection of AIDS Rights

In Thailand, focal advocacy groups have been created at national and local levels to advise on HIV-related policies and monitor the HIV and human rights situation. The National AIDS Committee established a Commission on Stigma, Discrimination and AIDS Rights Protection.¹¹⁹ The Commission consists of representatives from diverse organizations including networks of people living with HIV, the Foundation of AIDS Rights, the Ministry of Justice, and other relevant public and private organizations. As part of this initiative, seven provincial committees on AIDS rights protection have been established to conduct advocacy and awareness raising on HIV-related human rights issues.

3.4 Harmonization and alignment in national planning

HIV responses and the 'Three Ones' principle

The 'Three Ones' has been an important principle for governance reform of national HIV responses since 2004. The 'Three Ones' principle is aimed at achieving the most effective and efficient use of resources and to ensure coordinated, sustainable, country-led planning, consistent with aid effectiveness principles that encourage donor harmonization and alignment with national plans. The 'Three Ones' calls for:

- one agreed national HIV framework (National AIDS Strategy and implementation plan) that provides the basis for coordinating the work of all partners;
- one national HIV coordinating authority (NAC), with a broad-based multi-sectoral mandate; and
- one agreed country-level monitoring and evaluation system.

Governments have often had to deal with multiple monitoring and reporting demands to demonstrate progress to external funders as well as domestic stakeholders. In some countries large bilateral HIV programmes operate alongside the Global Fund and the national health sector response to HIV. Application of the Three Ones principle

¹¹⁶ See: de la Cruz (2011). *Policy Review: The AIDS Prevention Ordinance of Quezon City and Pasay City*, Pasig City: Local Government Academy.

¹¹⁷ Department of the Interior and Local Government, *Memorandum Circular 2013-29, Strengthening local responses toward more effective and sustained responses to HIV and AIDS*, 3 April 2013, Quezon City: DILG.

¹¹⁸ See: UNDP (2011). *Innovative Approaches. Decentralizing AIDS Responses - Local Government*, UNDP Philippines.

¹¹⁹ Order 3/2544 on Monitoring and Protection of AIDS Rights.

encourages donors to harmonize their programmes and align their planning with national frameworks. Application of this principle has helped to reduce the fragmentation caused by parallel projects and donor-driven management structures that are sometimes established outside of the national framework. Countries that have at times experienced fragmented HIV responses due to the presence of multiple donor programmes (such as Viet Nam, Indonesia and Cambodia) have worked with UN partners to improve the coordination of responses by promoting principles of harmonization and alignment among the donor community and NGOs.

A global review of health governance observed that national and subnational coordination structures with a remit for HIV are proliferating, and in some countries the multiplicity of parallel coordination structures has challenged the effective governance of HIV/AIDS programmes. Global health initiatives ('GHIs', such as the Global Fund and the US Government's PEPFAR programme) are having some positive effects on HIV coordination structures, but serious challenges remain:

For instance GHIs have widened stakeholder participation in coordination structures, although engagement from non-health government departments and civil society remains modest. Country ownership of national and subnational coordination is undermined by the weak decision making authority of many coordination structures and limited or perfunctory engagement among GHIs and other donors, particularly at the subnational level. There is evidence that strong leadership within coordination structures and broad political commitment to coordinated approaches to HIV/AIDS programmes have been improving, although weak secretariat capacity, poorly defined roles and responsibilities among members of coordination structures, limited transparency and communications and competition for scarce resources remain persistent problems undermining effective coordination.¹²⁰

Transitioning from 'vertical' to 'horizontal' responses

Funding of HIV responses has often been targeted through 'vertical' disease-specific HIV programmes, rather than 'horizontal' or health system-wide approaches. Particularly in the early years of the epidemic, a vertical approach was preferred because of the perceived need for an emergency response that enabled rapid scale-up in the context of expanding HIV epidemics. Partly this was in response to concerns that Asia-Pacific epidemics might become generalized in the population if urgent action was not taken. In some instances, targeted large-scale HIV-specific national programmes proved effective, such as in Cambodia and Thailand where well-funded and politically supported programmes successfully reversed epidemic trends. However, such vertical responses can be difficult to sustain in the long-term and have been criticized for skewing resources away from other disease priorities and broader health systems.¹²¹

Vertical approaches typically develop planning, funding, human resource and logistics systems separate to standard health care delivery systems. Lamptey and colleagues identify lessons from vertical HIV responses regarding approaches that should be avoided in responding to other disease priorities:¹²²

While AIDS programs have strengthened related aspects of health services, they have also fuelled competition between AIDS and other health programs, hampering efforts in some countries to improve the capacity of the health system to address other priority health issues. These constraints are apparent across each of the WHO's six key health-systems' components and have become more evident as development partners have accelerated efforts to respond to tuberculosis, malaria, and vaccine-preventable diseases. These disparities include: (1) distortion of resource allocation for national health priorities, (2) imbalance in access and quality of health services, (3) disparities in workforce compensation, (4) poor coordination and collaboration within the health sector, and (5) creation of parallel structures such as supply chain management, health care financing, and monitoring and evaluation programs.

120 Spicer N., Aleshkina J., Biesma R. et al (2010). National and subnational HIV/AIDS coordination: are global health initiatives closing the gap between intent and practice? *Globalization and Health* 6:3.

121 Whereas Thailand had a strong and supportive horizontal health structure, Cambodia's health system was comparatively weak.

122 Lamptey, P., Merson, M., Piot, P., Reddy, K. and Dirks, R. (2011). Informing the 2011 UN session on non-communicable diseases: applying lessons from the AIDS response. *PLoS Med*, 8: e1001086.

In moving away from vertical approaches, national HIV responses have increasingly recognized the need to link with broader efforts to support health systems strengthening. In recent years, efforts have focused on linking or integrating responses to HIV with health systems strengthening and responses to related disease priorities such as sexual and reproductive health, child and maternal health, tuberculosis, hepatitis and management of chronic diseases including NCDs.¹²³ There is increased momentum among HIV funders, including the US President's Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund, to give greater priority to strengthening of national health systems so that investments benefit not just HIV but a variety of other health priorities.¹²⁴ The Global Fund's New Funding Model is anchored in robust country owned national disease or health sector strategies.¹²⁵

Harmonization of funding

Donors and partner governments have developed innovative funding mechanisms to support HIV responses. Lessons can be identified from these experiences regarding the benefits of pooled funding and alignment of multiple donors with a single defined agenda of strategic priorities. Examples of effective donor coordination mechanisms for harmonized responses include:

- The Indonesia Partnership Fund was managed by UNDP from 2005-2012 and funded the work programme of the NAC to implement the National AIDS Strategy. The fund was supported by United Kingdom, Australia and the United States.
- In Myanmar, the Three Diseases Fund (3DF) was a multi-donor fund (2006-2011) that resourced responses to HIV, tuberculosis and malaria.¹²⁶ The structure enabled sharing of political risk between donors, so that these donors were able to engage with the Government of Myanmar when bilateral engagement in the health sector was considered problematic. While this model of aid coordination was donor-driven, the success of the 3DF contributed to the development of its successor, the '3MDG Fund' that commenced in 2012, as well as other pooled funding initiatives outside of health,¹²⁷ which can facilitate greater engagement with government. The 3DF proved that it was possible to deliver a coordinated programme of aid to the health sector in Myanmar.

3.5 Regional HIV governance architecture

Many regional partnerships have developed in response to HIV including partnerships between governments through existing regional platforms, such as the Secretariat of the Pacific Community (SPC), Association of South East Asian Nations (ASEAN) and the South Asian Association for Regional Cooperation (SAARC); partnerships between governments and development partners such as UN agencies, development banks, bilateral donors, the Clinton Health Access Initiative, Bill and Melinda Gates Foundation and the Global Fund; and partnerships between development partners including through funding modalities such as the Pacific HIV and STI Response Fund, the 3DF / 3 MDG Fund in Myanmar and regional donor initiatives such as AusAID's HIV/AIDS Asia Regional Programme.

Regional mechanisms provide vehicles for peer learning and leadership exchange, and preventing and responding to cross-border HIV transmission. The *ASEAN Declaration of Commitment on HIV*¹²⁸ commits countries to scaling up HIV prevention programmes for key populations and includes a "pledge to eliminate gender inequalities and

123 See: Rabkin M., Wafaa M. (2011). Why reinvent the wheel? Leveraging the lessons of HIV scale-up to confront non-communicable diseases, *Global Public Health*, 6:3, 247-156.

124 Lamptey P., Dirks R. (2012). Building on the AIDS response to tackle non-communicable diseases. *Global Heart*, 7(1); Lamptey P., Merson M., Piot P., Reddy K., Dirks R. (2011). Informing the 2011 UN session on non-communicable diseases: applying lessons from the AIDS response. *PLoS Med*, 8: e1001086.

125 Global Fund to Fight AIDS, Tuberculosis and Malaria (2013). *The Global Fund to Fight AIDS, Tuberculosis and Malaria, Fourth Replenishment (2014-2016): The Global Fund's New Funding Model*, Geneva: Global Fund to Fight AIDS, Tuberculosis and Malaria; See also: AusAID (2011), Supporting health in the Pacific, A Guidance note for AusAID staff, Canberra: AusAID.

126 *The 3 Diseases Fund, Final Evaluation Final Report*, available at: <http://www.ausaid.gov.au/countries/eastasia/myanmar/Documents/3df-evaluation-final-incep-report-april-2012.pdf>

127 Ibid, p.15.

128 ASEAN (2011). *Declaration of Commitment: Getting To Zero New HIV Infections, Zero Discrimination, Zero AIDS-Related Deaths*.

gender-based abuse and violence especially by protecting and promoting the rights of women and adolescent girls, strengthening national social and child protection systems, empowering women and young people to protect themselves from HIV...". There is also an ASEAN regional workplan on HIV, although much of the work remains unfunded.

SAARC has a *Regional Strategy on HIV/AIDS 2006-2010 supported by an implementation plan and a Strategy on Children Affected by HIV/AIDS*.¹²⁹ The SAARC HIV/AIDS Strategy provides that policies and advocacy will form the backbone of the regional strategy including in the areas of prevention strategy, the continuum of treatment and care, surveillance, stigma and discrimination, empowerment of people living with HIV, mainstreaming HIV into relevant line ministries conducive to a multi-sectoral and integrated approach; and, resource mobilization for both SAARC and individual Member States. The Strategy states that SAARC will encourage Member States to promote political and civil society leadership including religious, women, youth, media, business and other leaders.¹³⁰

In the Pacific, political leaders endorsed the *Pacific Regional Strategy on HIV and other STIs 2009-2013* through the Pacific Islands Forum. The Strategy's objective is: "to attain good governance and effective coordination through collaborative, transparent and accountable decision-making processes in both national and regional responses to HIV and other STIs".¹³¹ The Strategy has been supported by a regional Implementation Plan and a pooled funding mechanism (Pacific Islands HIV & STI Response Fund). The plan was also supported by regional and multi-country projects of the Global Fund and Asian Development Bank, operating budgets of regional development partners including bilateral donors and UN agencies, and national budgets attached to national strategic plans. The Strategy assists government in achieving and reporting on their national and international MDG and universal access targets. The Implementation Plan addressed prevention, treatment and care as well as leadership and the enabling environment, strategic information and communication, and governance and coordination.

3.6 Private sector engagement

Across Asia and the Pacific, businesses have been effective in addressing a range of HIV issues, including HIV prevention programmes and responses to stigma and discrimination, both in workplaces and in local communities where corporations operate. The motivation for business responses to HIV are highly variable and dependent on factors such as the HIV prevalence rate within their area of operation, the level of benefits available to the workforce and the level of knowledge and awareness by the business leadership of the potential economic and social impacts of the epidemic. Companies become engaged for a range of reasons including a commitment to corporate social responsibility, protection of workforce health, and legal requirements for workforce protection.

National Business Coalitions on AIDS

The formation of national 'business coalitions on AIDS' has been an innovation in governance. Business coalitions are independent legal entities owned and controlled by a group of businesses. These coalitions are led by the private sector and hence are governed by independent non-executive boards. Typically boards are made up of chief executive officers or senior executives from the major corporate sponsors. They have emerged as a platform for companies to come together to coordinate business responses to HIV. They can enable the implementation of effective workplace policies and community programmes. Larger companies that already have good programmes act as role models for other companies. They can also form a platform for effective communication to the broader community and for advocacy.

The Asia Pacific Business Coalition on AIDS is a network of country based business coalitions in Papua New Guinea, Indonesia, Cambodia, Fiji, Thailand, Myanmar, Singapore, Malaysia, Sri Lanka, the Philippines and Nepal. This regional Coalition has led the establishment of new business coalitions in Papua New Guinea, Indonesia, Cambodia,

129 SAARC (2007). *Regional Strategic Framework for the Protection, Care and Support of Children Affected by HIV/AIDS*. New Delhi: SAARC.

130 SAARC (2006). *SAARC Regional Strategy on HIV/AIDS 2006-2010*. New Delhi: SAARC.

131 SPC (2009). *Pacific Regional Strategy on HIV and other STIs 2009-2013*. Noumea: SPC.

Fiji, the Philippines, Malaysia and Sri Lanka, which are coordinating the business response to HIV in these countries. The Coalition has integrated tuberculosis into its activities in recognition that tuberculosis is a major health challenge in the region.

An example of an active national business coalition is the Cambodian Business Coalition on AIDS (CBCA), which advocates for greater business involvement in the national HIV response and represents the private sector in national policy processes. CBCA promotes sharing of good practice, supports enterprises to develop workplace policies consistent with legal requirements, and delivers training and education on HIV prevention and management, the impact of HIV on business, the management of HIV in the workplace and strategies to gain management and employee support for the company HIV policy. CBCA also helps to connect employees with local prevention, treatment, care and support services.¹³²

Oil Search Health Foundation's PNG HIV Programme¹³³

Oil Search Limited is an oil and gas company operating in PNG. Over the past decade the company has become increasingly involved in developing and supporting community health interventions related to HIV, malaria and maternal and child health. In 2007, Oil Search partnered with the National Department of Health and the Asian Development Bank, provincial governments and faith based health services to manage prevention and treatment programmes in rural communities in the company's areas of operations.

In 2011, Oil Search was selected to be the Principal Recipient for a Global Fund grant responsible for implementation of a USD\$46 million HIV and malaria programme. The National Department of Health had resigned as Principal Recipient. Oil Search assumed responsibility for a programme addressing prevention, testing and treatment, health systems strengthening and addressing gender-based violence. The programme was designed to address cost sharing with the PNG Government, development partners and the private sector. Oil Search collaborates with the PNG National Department of Health to ensure the initiative aligns with national health plans and programmes.

In 2011 the company established the Oil Search Health Foundation (OSHF) as a non-profit organization with an independent Board of Trustees to administer the Global Fund grant. This private-public partnership is characterized by financial accountability, programme monitoring and performance based disbursements. An HIV team provides clinical training and mentorship, monitoring and evaluation support and logistical assistance to ensure a continuous supply of HIV test kits, medication and condoms to rural and remote health facilities. OSHF has played a major role in the scale-up of HIV testing in the Southern Highlands and Gulf provinces of PNG.¹³⁴

3.7 Lessons for the post-2015 development agenda

Leadership has been key to the success of national HIV responses and is essential to tackling all complex development challenges. Eradication of poverty and ensuring development efforts reach the most marginalized requires political leadership to address the fundamental economic, social and cultural obstacles to development. Inclusive national planning and coordination mechanisms can provide a foundation for strong political leadership. Strategies that engage traditional and religious leaders in promoting health and development priorities can be effective, particularly when sensitive social and moral issues must be addressed and new community norms established.

Governments should be held accountable for progress towards development targets by being bound by time-limited, concrete commitments. Coordination of national responses through comprehensive national strategic plans

¹³² See: <http://www.cbca-cambodia.org>.

¹³³ Miles K., Weeden D., Donovan P., Fontanellaz O., Martin J., Guise M., Hutton R. (2012). *One year on: surviving the Global Fund as a corporate sector Principal Recipient in Papua New Guinea* Port Moresby: Oil Search Health Foundation; Oilsearch (2012). *Strategy on Track: 2012 Sustainability Report*, Oilsearch Ltd.

¹³⁴ Oil Search Health Foundation (2013). *Oil Search Health Foundation reaches 30,000 HIV tests*, OSHF.

requires linkages between sectors and agencies working at national, provincial and district levels, documenting and sharing information between agencies and across sectors.

The 'Three Ones' principle can be applied or adapted to other development priorities requiring donor harmonization, alignment with national priorities and multisectoral coordination (e.g. NCDs, climate change, water management). However, it would be inappropriate to duplicate multisectoral national AIDS council models for other diseases or development challenges without considering suitability to each issue. Due consideration needs to be given to the added value of a multisectoral response architecture for each development priority and issues of sustainability and capacity constraints.

Public health programming for issues such as tuberculosis, NCDs, malaria control, maternal and child health have generally not been able to achieve the multi-sectoral and multi-stakeholder nature of the HIV response at national levels, although they may be characterized by multisectoral coordination at local levels. Governance innovation can help to address this. However, positioning planning and coordination of public health responses outside the ministry of health can sometimes present an unintended opportunity cost to the health sector that needs to be considered when designing structures for multisectoral coordination.¹³⁵

In terms of health sector policy, WHO emphasizes health systems strengthening, including improved national health plans, strategies and policies, to reinforce the leadership and governance role of the health sector. This role also extends to catalyzing multisectoral action for health.

The post-2015 development agenda should encourage governance approaches that promote analysis of health impacts across sectors. For example 'HiAP' (Health in All Policies) is a strategy that includes health considerations in policy development across all sectors that influence health, such as transportation, agriculture, land use, housing, public safety and education. HiAP has been defined as: "an approach to public policies across sectors that systematically takes into account the health and health systems implications of decisions, seeks synergies, and avoids harmful health impacts, in order to improve population health and health equity. It emphasizes the consequences of public policies on health determinants, and aims to improve the accountability of policy-makers for health impacts at all levels of policy-making."¹³⁶

Vertical approaches in the health sector are justified in the context of emergency responses to disease priorities, but as a longer-term strategy can be harmful to broader efforts to build health systems. To ensure sustainable responses to health and development challenges, donors should avoid creating vertical, donor-driven, issue-specific responses unless exceptional circumstances exist.

Local social norms affecting governance at local, district and provincial levels sometimes restrict wide and equal participation. Norms that discriminate against women and girls or minorities (including people living with HIV, people with disabilities, sexual minorities, transgender people, indigenous people, people who use drugs and sex workers) prevent communities from reaching their full potential for development. Local champions need to be engaged to challenge harmful norms so that decentralized governance can be inclusive and operate to provide benefits to all in the community.

Private sector engagement can mobilize additional skills and resources for development. The Business Coalition model developed in the context of HIV may be useful for supporting business leadership for a range of other development priorities. The key feature of this model that supports ownership is a structure that is led by business. Many corporations give a priority to their corporate social responsibility role. Partnerships between governments, donors and private sector corporations can help to ensure corporate social responsibility programmes align with broader development objectives.

¹³⁵ See Godwin P., Dickinson C. (2012). Op cit., p.20.

¹³⁶ Statement of the 8th WHO Global Conference on Health Promotion, Helsinki, 10-14 June 2013.

Enabling legal and policy environments

KEY POINTS

- Sustainable development requires a focus on human rights and social justice. Principles of human rights, including child rights and women's rights, social equity and justice, should be central considerations in all fields of health and development.
 - The HIV response has demonstrated that a focus on laws, access to justice and law enforcement practices is essential to provide an enabling environment for health programmes that seek to reach marginalized populations.
 - Similarly, child and maternal health responses require a strong focus on gender inequalities and removal of harmful laws such as restrictive abortion laws and laws that restrict access to sexual and reproductive health services.
 - Gender equality considerations need to be integrated into governance arrangements, such as in approaches to community participation and representation.
 - The range of avenues to ensure that human rights commitments are met include national HIV laws and policies, constitutional human rights guarantees, human rights conventions and reporting bodies at the global level, and national mechanisms such as court arbitration, parliamentary oversight, national human rights institutions and community-based monitoring.
 - Legal empowerment including legal education, legal aid and other access to justice initiatives can help marginalized populations to actively participate in shaping rights-based development efforts. In the context of HIV, legal empowerment efforts have focused on populations that are stigmatized or criminalized (e.g. people living with HIV, MSM, transgender people, prisoners, people who use drugs and sex workers).
 - Health and development objectives must not be given lesser priority than trade objectives when countries are defining national policy on issues such as pharmaceutical patents. This principle should inform the approach of governments when negotiating free trade agreements affecting development priorities. Countries should assess possible adverse health and environmental impacts when negotiating trade agreements.
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4.1 Human rights-based legal and policy approaches

Prior to HIV, public health responses to infectious or communicable diseases were characterized by disease control measures that focused on restricting the rights of affected populations to protect the public from spread of diseases. Most countries in the region have had public health legislation in place for many years. However, these laws generally emphasized powers of isolation, quarantine and compulsory testing and treatment to prevent the spread of diseases, rather than human rights protections for the infected.¹³⁷

¹³⁷ See e.g. *Prevention and Control of Infectious Diseases Act 1988*, Malaysia; *Prevention and Control of Communicable Diseases Law 1995*, Myanmar; *Infectious Diseases Act*, Singapore, and see: Commission on AIDS in the Pacific (2009). *Turning the tide: Report of the Commission on AIDS in the Pacific*, Suva: UNAIDS, Attachment 4.

This model was poorly suited to HIV prevention, given the risk that imposing compulsory measures would only drive the people most-at-risk of HIV away from HIV testing and other health services. As HIV epidemics continued to spread among marginalized populations and in response to the high levels of stigma associated with the epidemic, governments introduced new laws that emphasized the human rights of those living with the disease. It is now generally recognized that curtailing the rights and liberties of people living with HIV is counterproductive to public health, because it adds to stigma and drives the epidemic underground. A policy consensus has emerged that behaviour change programmes and HIV testing and treatment services are much more effective in reaching the populations at greatest risk when human rights protections are in place.

The strong focus of HIV responses on introducing protective laws and promoting the human rights of people living with HIV is partly because of the high degree of discrimination associated with HIV, and partly because the key populations at risk of HIV typically experience legal marginalization. The behaviours of key populations (sex workers, people who use drugs, MSM and transgender people) are often criminalized, they experience police abuses that drive them away from health services, and they lack legal protections from discrimination.

The key features of a rights-based response were described in detail by the United Nations *International Guidelines on HIV/AIDS and Human Rights*, first published in 1998 and updated in 2006. Political Declarations on HIV and AIDS of the United Nations General Assembly in 2001, 2006 and 2011 have confirmed international commitments to human rights-based responses.¹³⁸

In 2012, the landmark report of the Global Commission on HIV and the Law was published. The Commission's report provides a comprehensive analysis of the evidence regarding the impact of legal environments on HIV responses from countries across the globe. The report contains more than 70 recommendations detailing actions that governments can take to ensure enabling legal environments for HIV responses that defend and promote internationally recognized human rights and legal norms.¹³⁹ The report recommends, inter alia, that governments: outlaw all forms of discrimination and violence directed against those who are vulnerable to or living with HIV or are perceived to be HIV-positive; ensure that existing human rights commitments and constitutional guarantees are enforced; repeal punitive laws; and enact laws that facilitate and enable effective responses to HIV prevention, care and treatment services for all who need them.¹⁴⁰

The Global Commission on HIV and the Law's report emphasizes that the legal environment comprises not just laws, but also law enforcement practices, legal aid services and justice systems. The Global Commission concluded that the HIV epidemic is being fueled by punitive laws, discriminatory and brutal policing practices that create and punish vulnerability, and denial of access to justice for people with and at risk of acquiring HIV. It found that these practices promote risky behaviour, hinder people from accessing prevention tools and treatment, and exacerbate the stigma and social inequalities that make people more vulnerable to HIV infection and illness.¹⁴¹ The Global Commission also noted the positive role of law enforcement practices. For example, it found that where the police cooperate with community workers, condom use can increase and violence and HIV infection among sex workers can decrease. It found that effective legal aid can make justice and equality a reality for people living with HIV, and this can contribute to better health outcomes.¹⁴²

A human rights-based approach necessitates analysis of the role of the law in each country to assess whether the law is protective of rights and plays an enabling role, or whether the law is punitive and impedes HIV responses. It requires analysis of whether laws promote gender equality and do not discriminate on grounds such as health status, sex, sexual orientation and gender identity. It also involves looking at the ways in which laws are enforced

138 See: *Political Declaration on HIV and AIDS: Intensifying Our Efforts to Eliminate HIV and AIDS* (2011) A/Res/65/277.

139 Global Commission on HIV and the Law (2012). Op cit. The Global Commission on HIV and the Law undertook 18 months of research, consultation, analysis drawing from the testimony of more than 700 people affected by HIV-related legal environments from 140 countries, in addition to expert submissions and the large body of scholarship on HIV, health and the law. See also: Grodin M., Tarantola D., Annas G. and Gruskin S. (eds) (2013). *Health and Human Rights in a Changing World*. New York: Routledge.

140 Ibid, p.9.

141 Ibid, p.7.

142 Ibid, p.9.

in practice, and the access that people living with HIV and key populations have to justice through the formal legal system or alternative dispute resolution mechanisms. In recognition of the importance of an enabling legal and policy environment for human rights-based HIV responses, UNAIDS recommends seven key programme components that should form part of every national HIV response:

1. Stigma and discrimination reduction programmes;
2. HIV-related legal services;
3. Law review and reform;
4. 'Know your rights' legal literacy programmes;
5. Training and sensitization of police, lawyers and judges;
6. Human rights training for health care workers; and
7. Reduction of harmful gender norms and violence against women.

Another legal and human rights dimension to the HIV epidemic is access to antiretroviral drugs (ARVs), which is key both for treatment and prevention of HIV. ARVs first became available in the mid-1990s and many of these drugs are still protected by patents and priced beyond the reach of ordinary people and government health budgets. Therefore, enabling access to ARVs to poor communities has required an unprecedented focus on the human rights impacts of patent laws and related aspects of trade policy.

The human rights-based approach to public health recognizes the responsibility of governments to respect, protect and fulfill the human rights of all populations, particularly the most marginalized, including the human right to the highest attainable standard of health.¹⁴³ The human rights-based approach asserts that governments are responsible for enabling their populations to achieve better health outcomes through respecting and therefore not violating rights, preventing rights violations, and creating policies, structures, and resources that promote and enforce rights. This responsibility extends beyond the provision of essential health services to tackling the social determinants of health.¹⁴⁴ This means addressing the policy and legal issues that are needed to respect and protect the rights of key populations, as well as making appropriate, accessible and affordable health services available to people who need them.

UNAIDS Executive Director Michel Sidibé and colleagues note that HIV responses globally have emphasized the promotion of human rights. Empowering people to know and claim their human rights has proven essential to progress in the HIV response and to address the social justice issues that drive the epidemic:

The AIDS response has been a champion of human rights, addressing HIV-specific concerns as an important vehicle to achieve broader social justice. The response provides an opportunity to strengthen the social fabric of societies, combat inequalities that undermine human rights, improve social justice and reinforce the systems that deliver critical services for the most vulnerable members of our communities. By reinforcing positive norms, ...for example, the involvement of affected communities in governance, the response has been a pioneer in shifting harmful social norms, particularly by focusing on the manner in which legal, political and social environments drive risk and vulnerability of marginalized populations...¹⁴⁵

Framing the HIV response as a human rights issue has assisted efforts to extend interventions to marginalized populations and supported these communities to mobilize and lead prevention efforts. Important progress has been made where governments have adopted pragmatic approaches. For example, in China, India and Thailand governments have supported condom programming in sex worker communities in contexts where the sex

143 Article 12, *International Covenant on Economic, Social and Cultural Rights*, New York: United Nations, 1966; Committee on Economic, Social and Cultural Rights. *The right to the highest attainable standard of health*: 11/08/2000. E/C.12/2000/4, CESCR General Comment 14. Twenty-second session Geneva, 25 April—12 May 2000 Agenda item 3.

144 Gruskin S., Tarantola D. (2008). Health and human rights: An overview, in Heggenboug K, Quah S (ed.). *International Encyclopedia of Public Health*, edn. 1, Academic Press, San Diego, pp.137-146; Tarantola D., Gruskin S. (2008). Human rights approach to public health policy, in Heggenboug K, Quah S. (ed.). *International Encyclopedia of Public Health*, edn. 1, Academic Press, San Diego, pp. 477-486 Tarantola D., Hallgath L., 2008, A rights-based approach to the assessment of global health initiatives, *Australian Journal of Human Rights*, vol. 13, pp. 157-180; Gruskin S., Mills E, Tarantola D. (2007). 'Health and Human Rights 1 - History, principles, and practice of health and human rights', *Lancet*, vol. 370, pp. 449-455.

145 Sidibé M., Tanaka S., Buse K. et al (2010). People, Passion & Politics: Looking Back and Moving Forward in the Governance of the AIDS Response. *Global Health Governance*, Volume IV, No. 1.

industry is illegal, and in Cambodia, China, Indonesia, Malaysia and Viet Nam peer education, needle and syringe programmes and methadone maintenance programmes have been introduced in contexts where drug use attracts heavy penalties.

4.2 Policy recognition of human rights-based HIV responses

A human rights-based approach is given explicit recognition in the national HIV policies, plans and strategies of many countries in the region. Examples include:

- Fiji's *National Strategic Plan on HIV and STIs 2012-2015* provides that prevention will be integrated with the promotion of human rights and respect for all Fijians, including sex workers, transgender people and men who have sex with men.
- Objectives of Indonesia's *National AIDS Strategy and Action Plan 2010-2014* include to enhance structural interventions and involve all stakeholders in programme implementation, and to engage in policy development "to ensure a supportive environment and human rights and gender-based approaches".
- The Mongolian *National Response to HIV and AIDS and STIs 2010-2105* builds on the fundamental human rights of all citizens, including freedom from discrimination, the right to health, the right to participation and the right to information. This approach "emphasizes the legal obligations of the state in realizing the rights of all its citizens – including the right to health – as well as the importance of empowerment and active involvement of communities and individuals infected or affected by HIV and AIDS."
- Protection of human rights is a guiding principle of Myanmar's *National Strategic Plan on HIV and AIDS 2011-2015*. The plan addresses gender issues and the reduction of stigma and discrimination and supports empowerment and social transformation to change norms and provide structural protections for people living with HIV and key populations.
- PNG's *National HIV and AIDS Strategy 2011-2015* is anchored in the principles of fundamental human rights of all citizens and recognizing that gender inequalities are a key driver of PNG's epidemic.¹⁴⁶ The Strategy requires reform to legislation to reduce stigma and discrimination and improve the environment for prevention, treatment and care, and specifically draws attention to the obstacles created by laws that criminalize sex work and same-sex practices, which impede access to services.
- In the Philippines, the *5th AIDS Medium Term Plan 2011- 2016* includes support for stigma reduction and protection from discrimination, including human rights education and the fulfillment of human rights guarantees through legal redress mechanisms.
- Sri Lanka's *National HIV/AIDS Strategic Plan 2007-2011* recognizes "the intimate link between HIV/AIDS and human rights. People who have a higher risk of HIV exposure are often the most difficult to reach, because homosexuality, soliciting and drug use and trafficking are illegal, and drives them underground." Guiding principles of the *National Strategic Plan* and the *National AIDS Policy* are universal human rights, including non-discrimination on the basis of gender, HIV status, sexual behaviour or sexual orientation.

The extent to which these policies have been implemented varies greatly. For example, although the PNG Plan calls for review of laws that criminalize sex work and homosexual conduct, the law reform process has not advanced since 2011. In most countries, people living with HIV and key populations continue to confront stigma, discrimination and criminalization. Nonetheless, these human rights-based policies provide supportive frameworks for programme implementation and advocacy efforts that link human rights issues to health and HIV vulnerability.

¹⁴⁶ PNG's *HIV/AIDS Management and Prevention Act 2003* provides a legal basis for a human rights-based national HIV response, although other laws remain in place criminalizing sex work and homosexual conduct.

4.3 Legislative recognition of human rights-based HIV responses

Eight countries of the Asia-Pacific region have enacted omnibus national AIDS laws that provide human rights protections, such as prohibitions on discrimination and breach of confidentiality, and rights to information and informed consent (Cambodia, China, Fiji, Lao PDR, Mongolia, PNG, the Philippines and Viet Nam).¹⁴⁷ Enacting disease-specific laws is unusual in public health. Stand-alone national AIDS law have been preferred by these countries to signal that HIV requires focused resources, leadership and a new style of response anchored in a rights-based framework. These AIDS laws typically address a wide range of issues, including:

- public health requirements (such as regulation of HIV testing and safety of the blood supply);
- civil and political human rights and fundamental freedoms (such as rights to non-discrimination, equality, liberty, security of the person and privacy);
- social and economic human rights (such as the right to health and the right to information and education); and
- roles and responsibilities of sectors participating in the national HIV response.

Several of these national laws include a statement of principles that firmly position the national HIV response in a human rights framework. For example, Fiji's *HIV/AIDS Decree* is prefaced by a statement that in interpreting the Decree courts should apply the principles of international human rights laws as defined by UN instruments.¹⁴⁸ The national HIV law of Lao PDR states the principle that HIV control and prevention should be carried out "ensuring that equality, justice, compassion, and non-discrimination and non-stigmatization principles are respected", and "ensuring the principles of confidentiality and privacy for people living with HIV/AIDS".¹⁴⁹ The *Philippine AIDS Prevention and Control Act* is also prefaced with a statement of principle, as follows:

The gravity of the AIDS threat demands strong State action... discrimination, in all its forms and subtleties, against individuals with HIV or persons perceived or suspected of having HIV shall be considered inimical to individual and national interest.¹⁵⁰

To complement these national AIDS laws, some countries have taken action to remove discriminatory provisions from other laws. For example, HIV-related travel restrictions have been repealed in China, Fiji and Mongolia.¹⁵¹

UNDP has published a series of regional reports to promote sharing of lessons learned from enactment and implementation of human rights-based laws to support national HIV responses in Asia and the Pacific.¹⁵²

4.4 Implementing rights-based approaches through legal empowerment

Although the language of human rights has been widely incorporated into national HIV policies and laws, in practice the human rights agenda remains highly challenging. There is often a significant gap between the aspirations of policies and the realities of the epidemic on the ground. Even with strong political leadership and

147 Cambodia: *Law on Prevention and Control of HIV/AIDS 2002*; China: *Regulations on AIDS Prevention and Control 2006*; Fiji: *HIV/AIDS Decree 2011*; Lao PDR: *Law on HIV/AIDS Control and Prevention 2010*; Mongolia: *Law on HIV/AIDS Prevention 1993*; PNG: *HIV/AIDS Management and Prevention Act 2003*; Philippines: *Philippine AIDS Prevention and Control Acts 1998*; Viet Nam: *Law on HIV/AIDS Prevention and Control of 2006*.

148 *International Guidelines on HIV/AIDS and Human Rights* and the United Nations Declaration of Commitment on HIV/AIDS: Section 3, *HIV/AIDS Decree 2011* (Fiji).

149 Article 6, *Law on HIV/AIDS Control and Prevention 2010* (Lao PDR).

150 Section 2, *Philippine AIDS Prevention and Control Act of 1998*.

151 UNAIDS (2013). *UNAIDS applauds Mongolia for removing restrictions on entry, stay and residence for people living with HIV*, Press statement, 31 January 2013, Geneva: UNAIDS; UNAIDS (2011). *Fiji lifts travel ban for people living with HIV*, Press statement, 26 August 2011, Geneva: UNAIDS; WHO (2010). *WHO commends China on lifting entry and travel restrictions for HIV-positive people*, Press statement 27 April 2010, Geneva: WHO.

152 Ibid; Godwin J. (2010). *Legal environments, human rights and HIV responses among men who have sex with men and transgender people in Asia and the Pacific*, Bangkok: UNDP; Godwin J. (2012). *Sex work and the Law*, Bangkok: UNDP; Global Commission on HIV and the Law (2011). *Report of the Asia Pacific Regional Dialogue of the Global Commission on HIV and the Law*, Bangkok: UNDP.

good policy intent, implementing a human rights-based HIV response at community level remains very much a 'work-in-progress' in most countries. There are entrenched cultural, social and political divisions of opinion within the region about the most appropriate legal and socio-cultural responses to illicit drug use, homosexuality and sex work.

Efforts to legally empower marginalized populations help to build an enabling environment for HIV responses from the bottom up, complementing 'top down' measures such as law reform. A legal empowerment approach seeks to empower individuals to actively engage with and, if necessary, challenge and change laws and the legal system, to make it more accessible and responsive to the rights of the marginalized. Legal empowerment enables marginalized populations to challenge injustices and discrimination, change public attitudes and actively participate in shaping non-discriminatory rights-based HIV responses. The 'legal empowerment' approach to HIV has been described as follows:

The concept of legal empowerment emphasizes strategies that use "legal services and related development activities to increase disadvantaged populations' control over their lives". Legal empowerment is fundamentally concerned with realizing the human rights of the poor, disenfranchised and marginalized, and is community driven...Legal empowerment does not preclude engagement with government or legislative change. However, it is fundamentally concerned with strategies that may be more nuanced and broader than orthodox rule of law approaches, and that emerge and are driven by the needs of those at the centre of the HIV epidemic.¹⁵³

Legal empowerment programmes have sought to tackle obstacles faced by people living with HIV and key populations in seeking access to justice. Although people living with HIV may in theory enjoy legal protections, enforcement of these laws remains highly problematic. Obstacles to access to justice include lack of legal aid services, ignorance of the law, the expense and complexity of legal processes, lack of confidence in legal systems that are often perceived as corrupt or oriented towards economic and political elites, and concerns regarding publicity and disclosure of identity.

A range of legal empowerment programmes have been implemented in Asia and the Pacific, including:

- 'know your rights' campaigns delivered by community-based organizations such as networks of people living with HIV and key populations;
- support to community-level paralegals, who can provide legal information, advice and referral through outreach to settings such as clinics and drop-in centres;
- specialist HIV legal advice, litigation and paralegal services;
- education of the legal profession and judiciary in HIV-related legal and human rights issues; and
- education of key sectors such as police, health care services and schools on HIV-related legal and human rights issues.

Examples of legal empowerment initiatives include:¹⁵⁴

- i. Specialist HIV legal services in Cambodia, China, India, Indonesia,¹⁵⁵ Nepal¹⁵⁶ PNG and Viet Nam have been effective in reaching sex workers, people who use drugs, MSM and transgender people.¹⁵⁷ Legal services have extended their reach by providing access to advice through telephone hotlines and outreach sites such as methadone clinics, self-help groups of people living with HIV, and drop-in centres for sex workers and people who use drugs.
- ii. In Viet Nam, legal aid clinics of the Vietnam Lawyers Association have advised thousands of clients on HIV-related legal issues such as discrimination, breach of privacy and health care rights. An HIV legal training

153 Stephens D., Urbano M (2010). *HIV and Legal Empowerment*, IDLO Working Paper Number 12, Rome: IDLO, p.5, quoting Golub S. (2003). *Beyond rule of law orthodoxy: the legal empowerment alternative*, Carnegie endowment for international peace, Rule of Law Series Working Paper 41.

154 Godwin J. (2013). *HIV-related human rights protections. Experiences and lessons learned from national HIV laws in Asia and the Pacific*, Bangkok: UNDP, pp.34-35.

155 The Community Legal Aid Institute (LBH Masyarakat) is an NGO that provides legal aid to people who use drugs and other poor populations in Jakarta, Indonesia.

156 In-house lawyers provide HIV-related legal advice at two NGOs in Nepal: the Blue Diamond Society and the Forum for Women and Law in Development.

157 IDLO funded needs assessments in Yunnan (China), Indonesia, Nepal and PNG.

manual is used to train law students and lawyers about HIV-related rights, and to promote legal literacy among people living with HIV.

- iii. The Papua New Guinea Development Law Association has established a specialist HIV legal service, which has initiated court claims to test the legal protections of the national HIV law on behalf of people living with HIV. A community-based advocacy organization, Kapul Champions, was established in PNG to advocate for the rights of MSM and transgender people. Agree... rights of MSM, Sex Workers and Transgender groups. d to further Ps and hence requires further reforms ...specifically people.
- iv. In India, legal aid services for people living with HIV have been delivered through a range of models including community legal aid clinics, in-house lawyers at community organizations or service centers, legal outreach at healthcare sector clinics and hospitals, specialized government legal aid clinics and specialized NGO legal aid service providers. These various legal aid services are generally well connected with communities or community led.¹⁵⁸
- v. In Myanmar a community based legal project is implemented in cooperation with the national networks of sex workers, MSM and people who use drugs. The project aims to facilitate access to justice by funding peer paralegals to provide legal advice and health information and engages in advocacy on justice issues.
- vi. In Nepal, the legal empowerment of the Blue Diamond Society provides legal advice, documentation of human rights violations to help to build an understanding about the nature and extent of such incidents, public interest litigation in the Supreme Court, and legal empowerment training to increase community knowledge of human rights and build skills about how to claim these rights.¹⁵⁹

Engagement with the law enforcement sector has been adopted as a legal empowerment strategy by some community-based HIV responses. Sex workers, transgender communities, MSM and people who use drugs have challenged police practices that undermine HIV responses through dialogue, education and advocacy. Examples of good practice in community engagement with police include:

- *Poros Sapot Project, PNG*
Sex work and homosexual conduct are illegal in PNG. Save the Children Fund's Poros Sapot Project supports sex workers and MSM to educate police about HIV and the impact of police practices on their lives. Trainings, sensitizations and review meetings are conducted with police officers on HIV, human rights, gender-based violence, stigma and discrimination and other issues facing these populations. Police interactions with key populations have reportedly improved in the communities where police sensitization has taken place.¹⁶⁰
- *SWING (Service Workers in Group), Thailand*
SWING is a sex worker organization that conducts peer education and advocacy. SWING seeks the cooperation of bar owners and the police in HIV prevention efforts. SWING's partnership with the police supports sex workers to improve knowledge of their rights and skills to negotiate with police and cultivates defenders of sex workers' rights within the police service. SWING has delivered HIV training to police cadets and works in partnership with tourist police to improve responses to violence directed at sex workers. This approach has had a positive impact on reducing police abuses.¹⁶¹
- *Tamil Nadu State AIDS Control Society (TANSACS), India*
TANSACS has trained over 35,000 police on HIV and key populations. The mass training has helped to improve the relations between the police and key populations. Police harassment of key populations has reportedly reduced and the police are considered to be more likely to offer support when a person living

158 Godwin J. (2010). *Scaling up HIV-related Legal Services - Case Studies: Ukraine, Kenya, and India*, Rome: IDLO and UNAIDS, p.32.

159 UNFPA, UNAIDS, Asia Pacific Network of Sex Workers (APNSW) (2012). *The HIV and Sex Work Collection: Innovative responses in Asia Pacific*, Bangkok: UNFPA, UNAIDS, APNSW.

160 See: David E., Kilei J., Mohave D., et al (2008) Working with police towards prevention of STIs and HIV amongst PNG's most vulnerable groups: female sex workers, men who have sex with men, people living with HIV, *AIDS 2008 - XVII International AIDS Conference Abstract no. WEPE1094*; Reid E., (2010) Putting values into practice in PNG: Poros Sapot Project and aid effectiveness, *Journal of the Australian Association for the Advancement of Pacific Studies*, Issues 1.2 and 2.1, April 2010.

161 UNFPA, UNAIDS, Asia Pacific Network of Sex Workers (2012). Op cit., pp.57-66.

with HIV, sex worker, MSM or transgender person attends a police station to report violence or other abuses.¹⁶²

Strategic litigation¹⁶³

HIV responses have been supported by litigation that has improved the legal status of people living with HIV and key populations. For example, the Indian case of *MX v. ZY* established that it is unlawful to discriminate against people living with HIV by dismissal from employment. The case involved a worker with HIV who was dismissed after his employer tested him for HIV. The denial of employment on the ground of HIV status was found to infringe rights under the national constitution to equal treatment before the law and the rights to life and personal liberty.¹⁶⁴

Laws criminalizing sex between adult men have been held to be invalid due to violation of constitutionally guaranteed human rights to privacy and equality. Judgments in Fiji,¹⁶⁵ Hong Kong SAR,¹⁶⁶ the Philippines,¹⁶⁷ Nepal¹⁶⁸ and India¹⁶⁹ have interpreted constitutional rights to equality before the law, non-discrimination and/or to privacy to apply to the protection of the rights of homosexual people in a variety of circumstances. These cases drew from international human rights principles, including the rights to equality, non-discrimination and privacy under the *Universal Declaration on Human Rights* and the *International Covenant on Civil and Political Rights*, and the right to health under the *International Covenant on Economic, Social and Cultural Rights*.

HIV activists have argued for the repeal of laws criminalizing consensual same-sex acts between adults to support improved access to HIV services. Advocates have sought to promote state compliance with the *Yogyakarta Principles on the Application of International Human Rights Law in relation to Sexual Orientation and Gender Identity*, which require decriminalization and protective laws to be enacted.¹⁷⁰ In India, an HIV NGO succeeded in obtaining a judgment that effectively decriminalized homosexuality in India in 2009, through the *Naz Foundation case*.¹⁷¹ This was widely recognized as both a civil rights victory and a public health victory that reduced stigma, enabled health services to more easily reach MSM and allowed MSM to be open when attending health services without fear of prosecution.

Judgments in Pakistan,¹⁷² Nepal¹⁷³ and Hong Kong¹⁷⁴ have interpreted constitutional rights to equality before the law to apply to protection of the rights of transgender people. For example, in 2007 the Supreme Court of Nepal

162 Godwin J. (2010). *Scaling up HIV-related Legal Services - Case Studies: Ukraine, Kenya, and India*, Rome: IDLO and UNAIDS.

163 This section draws from Godwin J. (2013). Op cit., pp.23-24.

164 *MX v ZY* (1997) AIR 1997 Bom 406.

165 *Nadan and McCoskar v. State* [2005] FJHC 500. The Court decriminalized homosexual sex between adults taking into account the right to privacy under the Constitution of Fiji and the *International Covenant on Civil and Political Rights*.

166 *Leung T.C. William Roy v Secretary of Justice (HK)* [2006] HKCA 106; *Secretary for Justice v Yau Yuk Lung Zigo & Another* [2007] 3 HKLRD 903.

167 *Ang Ladlad LGBT Party represented by Danton Remoto v. Commissioner of Elections*, Supreme Court of Philippines at Baguio City, 8 April 2010. The Court noted the importance of the right to non-discrimination (including in relation to electoral participation) under the *Universal Declaration of Human Rights* (UDHR) and the ICCPR.

168 *Sunil Babu Pant and others v Nepal Government and others* [2008] 2 NJA L.J. 261-286. This case addressed the rights of transgender persons and same sex couples. The Court noted the importance of the rights to equality and privacy Articles 2, 16 and 17 of the ICCPR in concluding that a state should provide the right of a transgender person to their identity.

169 *Naz Foundation India Trust v. Govt of NCT* (2009) 160 DLT 277; W.P. (C) No. 7455/2001 of 2009 (Delhi HC). The Court based its decision on rights guaranteed under the Constitution of India and noted the importance of the rights to privacy the UDHR and the right to health under the *International Convention on Economic Social and Cultural Rights* (ICESCR) in reading down the offence of unnatural sex so as to decriminalize adult homosexuality.

170 See: www.yogyakartaprinciples.org, (principles agreed by the International Commission on Jurists and human rights experts in 2006).

171 *Naz Foundation India Trust v. Govt of NCT* (2009) 160 DLT 277; W.P.(C) No.7455/2001 of 2009 (Delhi HC). The Court based its decision on rights guaranteed under the Constitution of India and noted the importance of the rights to privacy the UDHR and the right to health under the *International Convention on Economic Social and Cultural Rights* (ICESCR) in reading down the offence of unnatural sex so as to decriminalize adult homosexuality.

172 In response to a petition filed by Islamic jurist Dr Mohammad Aslam Khaki, the Supreme Court made a series of rulings in 2009. See: Khan H. (2010). Eunuchs in Pakistan want laws against harassment, *Central Asia Online*, 20 January 2010.

173 *Sunil Babu Pant and others v Nepal Government and others* [2008] 2 NJA L.J. 261-286.

174 Hong Kong Court allows transgender woman to marry, *The Guardian Online*, 13 May 2013.

ordered the government to amend laws that discriminated against transgender people and include a 'third gender' category in electoral registration.¹⁷⁵

Sex workers' rights have also been advanced through litigation. The Supreme Court of Nepal has ruled that provisions of the criminal law that purported to apply a lighter penalty to rapists in cases where the survivor was a sex worker were unconstitutional.¹⁷⁶ The Court held that sex workers should not be discriminated against in the criminal law with respect to rape, given the constitutional rights to equality and to choose one's own profession.¹⁷⁷ In its judgment in *Karmaskar's case*, the Supreme Court of India has recognized that sex workers are protected by the right to live with dignity guaranteed by the national constitution.¹⁷⁸ In *Tara v State* (2012) the Delhi High Court overturned the detention and transportation of 15 sex workers because it was in violation of their right to live with dignity under the Constitution.¹⁷⁹ The Supreme Court of Bangladesh has recognized the constitutional rights of sex workers who had been evicted from brothels after police raids. The Court held that sex workers enjoy protection of rights to respect, dignity, privacy, life and liberty.¹⁸⁰

4.5 Intellectual property rights and trade policy

4.5.1 Advances in access to HIV medicines

Measures to ensure intellectual property laws support access to affordable medicines are an important aspect of a human rights-based approach to health and development. Significant advances in reaching targets relating to universal access to HIV treatment in the Asia Pacific region have been achieved by countries that have acted to ensure that generic ARVs are widely available as an alternative to more expensive 'brand name' versions of the same drugs.

Some governments have provided leadership in exercising powers to override pharmaceutical patents to ensure people living with HIV have been able to access affordable medicines (Table 2). Treatment activists in India and Thailand have demonstrated that national HIV responses can benefit from a model that recognizes the right to health of citizens, rather than a model based only on protection of the commercial interests of pharmaceutical companies.

Important lessons have been learnt for improving access to essential drugs for other diseases and for ensuring that patent laws and trade policies align more strongly with health and development objectives. This has particular relevance to the financial sustainability and effectiveness of universal health coverage initiatives. Thailand, for example, experienced a significant increase in drug expenditures following the implementation of its universal health coverage scheme. The government was able to reduce costs in subsequent years by issuing government use licenses for HIV, cancer and heart disease medicines.

The focus of HIV activism and litigation has been on challenging overbroad patents and trade agreements that block production and importation of affordable generic versions of HIV medicines. Community activists have called for more assertive use of flexibilities under the World Trade Organization (WTO) Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS Agreement), such as compulsory licensing and parallel importation, to

175 *Sunil Babu Pant and others v Nepal Government and others* [2008] 2 NJA L.J. 261-286.

176 *Muluki Ain* (Country Code), Chapter 14 prescribes the punishment for rape.

177 Supreme Court of Nepal in *Sapana P. Malla for FWLD v. HMG/Nepal*, Publication of Judgments relating to Human Rights: Special Issue (Kathmandu: Supreme Court, 2002) at 144-151; Shreshta P., (2006) *Prostitution and Public Health: Various Forms of Regulating Methods - An Analysis of Current Legal Responses to Prostitution in Nepal*. Available at: http://www.fwld.org/administrator/uploads/free_articles/6.pdf

178 *Budhadev Karmaskar Vs. State of West Bengal* (2011) 11 SCC 538; (2011) STPL Web 133 SC JT (2011) 2 SC 115.

179 W.P. (CRL) 296/2012, High Court of Delhi.

180 *Bangladesh Society for the Enforcement of Human Rights (BSEHR) and Ors v. Government of Bangladesh and Ors* 53 DLR (2001) 1; (2000) 3 CHRLD 217.

POLITICAL SUPPORT FOR A PRO-HEALTH INTERPRETATION OF TRIPS OBLIGATIONS

Report of the UN Special Rapporteur on the Right to Health (2009): “The framework of the right to health makes it clear that medicines must be available, accessible, acceptable, and of good quality to reach ailing populations without discrimination throughout the world. As has been evident, TRIPS and (‘TRIPS plus’ provisions of free trade agreements) have had an adverse impact on prices and availability of medicines, making it difficult for countries to comply with their obligations to respect, protect, and fulfill the right to health. (*Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Anand Grover, to the Human Rights Council, 2009*)

UN General Assembly Political Declaration on HIV/AIDS (2011): “73. Urge relevant international organizations ... to provide national Governments of developing countries with technical and capacity-building assistance ... to increase access to HIV medicines and treatment ... through the use of existing flexibilities under the Trade-Related Aspects of Intellectual Property Rights Agreement...”

Rio+20 outcome document – The Future We Want (2012): “142. We reaffirm the right to use, to the full, the provisions contained in the agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS)...to promote access to medicines for all, and encourage the provision of assistance to developing countries in this regard.”

UN Human Rights Council Resolution 16/28 (2013): “19. Encourages all States to apply measures and procedures to enforce intellectual property rights in a manner that avoids the creation of barriers to the legitimate trade of medicines, and to provide for safeguards against the abuse of such measures and procedures, taking into account, inter alia, the Doha Declaration on the Agreement on Trade-related Aspects of Intellectual Property Rights and Public Health.”

UN Secretary-General’s report on the post-2015 development agenda (2013): “49. A stronger partnership is also needed among governments, pharmaceutical companies, research facilities and philanthropic organizations to make essential medicines more affordable and available in public health facilities, including using the provisions available to developing countries in the Agreement on Trade-Related Aspects of Intellectual Property Rights.”

secure access to affordable medicines.¹⁸¹ The *Doha Declaration on the TRIPS Agreement and Public Health*, adopted by WTO in 2001, brought clarity in the interpretation of the TRIPS Agreement regarding the rights of member countries to protect people’s health and access to affordable medicines:¹⁸²

... the TRIPS Agreement does not and should not prevent members from taking measures to protect public health... the Agreement can and should be interpreted and implemented in a manner supportive of WTO members’ right to protect public health and, in particular, to promote access to medicines for all. In this connection, we reaffirm the right of WTO members to use, to the full, the provisions in the TRIPS Agreement, which provide flexibility for this purpose.¹⁸³

The Doha Declaration confirmed the flexibilities available to governments under the TRIPS agreement for improved access to essential medicines. The *Doha Declaration* permits developing countries to import or manufacture generic medicines through compulsory licensing.

181 WTO (1995). *Agreement on Trade-Related Aspects of Intellectual Property Rights*. And see: WTO (2001) *Declaration on the TRIPS Agreement and Public Health*. (WT/MIN(01)/DEC/220 November 2001)

182 WTO (2001). *Doha Declaration on the TRIPS Agreement and Public Health Adopted on 14 November 2001*, WT/MIN(01)/DEC/220 November 2001.

183 The Doha Ministerial Declaration adopted 14 November 2001, WT/MIN(01)/DEC/2.

Table 2: Examples of compulsory licenses in Asia

Date	Country	Product	Cost saving
2003	Malaysia	HIV: didanosine, zidovudine didanosine+zidovudine	Resulted in price reduction of 83%
2004	Indonesia	HIV: Lamivudine nevirapine	Resulted in price reduction of 53.3%
2006	Thailand	HIV: Efavirenz	No data
2007	Thailand	HIV: lopinavir/ritonavir	Projected price reductions of 80.2% expected
2007	Thailand	Heart disease: Clopidogrel	No data
2007	Indonesia	HIV: Efavirenz	No data
2008	Thailand	Cancer: Letrozole used to treat breast cancer	Projected aggregate price reductions of 96.8%
2012	India	Cancer: Nexavar	Price set by India's Patent Controller will result in 97% price reduction
2012	Indonesia	HIV and hepatitis B: efavirenz, abacavir, tenofovir, lopinavir/ritonavir, didanosine, and fixed-dose combinations tenofovir / emtricitabine and tenofovir / emtricitabine / efavirenz	No data

Sources: Global Commission on HIV and the Law (2012), *HIV and the Law: Risks, rights and health*, New York: UNDP, p.81; World Health Organization (2008) *Briefing Note: Access to Medicines*, Manila: WHO WPRO; Grogan K. (2012). Indonesia to override patents on HIV/hep B drug. *PharmaTimes*, 12 October 2012.

TRIPS flexibilities have been employed in India, Indonesia, Malaysia and Thailand where licenses have been granted for government use of ARVs and medicines for cancer and heart disease. India is a major source of generic medicines for most low and middle-income countries globally – over 80 percent of donor-funded ARVs and over 90 percent of pediatric formulations. Thailand also produces significant quantities of generic HIV medicines. Globally, India, Thailand and Brazil have been able to keep prices of HIV medicines low by supporting their domestic generic pharmaceutical industries to produce ARVs.

Malaysia was the first Asian country to issue a compulsory license for an ARV. In 2003, the Government of Malaysia issued a license to import ARVs from an Indian company for use in government hospitals and clinics. As a result, Malaysia achieved cost reductions of over 80 percent. Indonesia followed by issuing compulsory licenses in 2004 and Thailand in 2006. Other countries faced with similar choices can benefit from these experiences to retain and expand access to affordable medicines. The potential to issue a compulsory license can be useful in negotiating access to drugs. For example, the Government of China gained access to donations of an ARV from the manufacturer in 2011 after threatening to issue a compulsory license.¹⁸⁴

Country experiences: India

Organizations representing people living with HIV and other patient groups have challenged patent applications on medicines. For example, in *Boehringer Ingelheim v. Indian Network for People Living with HIV/AIDS (INP+) and Positive Women's Network (PWN)*, the Delhi Patent Office rejected the patent application on a drug used in the treatment of pediatric HIV.

¹⁸⁴ Tenofovir was donated by the manufacturer Gilead, See: <http://asia.legalbusinessonline.com/contents/features/109318/4/details.aspx>

Patents for hepatitis C drugs have also been challenged. Many people who inject drugs are co-infected with HIV and hepatitis C. In 2012–2013 the Intellectual Property Appellate Board of India determined a claim brought by the Sankalp Rehabilitation Trust, a Mumbai organization that works with drug dependent people. The Board revoked the patent held by the pharmaceutical company Roche for its hepatitis C drug on the grounds that the process used to develop the medicine was insufficiently novel or innovative to warrant a patent. This ruling represented an important step toward making hepatitis C medicines more accessible by allowing for future production of more affordable generic versions of the drug.¹⁸⁵

The Government of India's willingness to issue a compulsory license on cancer drugs in 2012 may indicate a shift to a more interventionist approach. The Indian Patent Office approved the country's first compulsory license to a local firm to make a generic version of a cancer drug. The original patent holder (Bayer pharmaceuticals) challenged the compulsory license, but in 2012 the Intellectual Property Appellate Board rejected its petition. The drug was considered unaffordable (i.e. approximately USD 5,500 per person per month) and had not been made available in sufficient quantities in the country. Issuing the compulsory license led to a 97 percent price reduction for the drug and a 76 percent reduction in price for a competitor drug.¹⁸⁶

A review of global health governance argues that India's approach to generic ARVs offers important lessons for South-South governance innovations:

While countries like Brazil and India have produced generic ARV drugs, most developing countries either do not have the technology to do so or they are "pressured" against doing so because of the consequences of violation of (TRIPS)... Most recently, Uganda entered into an agreement with Cipla, an Indian generic manufacturer of ARV drugs to open a drug plant in Uganda. Because such opportunities for South-South cooperation abound in contemporary global AIDS diplomacy, developing countries should ingeniously exploit them in ways that do not violate TRIPS. The impediments to this framework would include circumventing the hurdles posed by TRIPS as well as the pressure by global pharmaceutical corporate giants against such initiatives.¹⁸⁷

Country experiences: Indonesia

In 2004, Indonesia issued a compulsory license to import two ARVs used as part of 'first line' treatment for HIV.¹⁸⁸ The compulsory license stated that it was issued "in line with the urgent need in the effort to control HIV/AIDS epidemic in Indonesia... to provide access to antiretroviral drugs that are still protected under patent." On the basis of the license the Government of Indonesia commenced producing generic ARVs at government owned pharmaceutical companies.¹⁸⁹ In 2012, the Government of Indonesia issued a compulsory license that lifts a patent restriction on generic production of seven drugs used to treat HIV and hepatitis B.¹⁹⁰ The Presidential Decree allows for local generic production of the medicines, which will open up competition and could significantly reduce prices.

Country experiences: Thailand

In 2006–2007, Thailand issued compulsory licenses for government use of drugs for the treatment of HIV, heart disease and cancer. The use of compulsory licenses occurred in Thailand after a history of successful consumer legal challenges against ARV patents.¹⁹¹ These victories allowed the Thai government's national treatment programme to scale-up using generic medicines. Thailand's subsidized ARV programme was extended nationwide through production of generic ARVs by the Government Pharmaceutical Organization for the public sector.

185 Momenghalibaf A. (2013). *Indian Court Limits Frivolous Drug Patenting, Clearing Path to Affordable Medicines*, 21 January 2013, Open Society Foundations.

186 Cipla cuts cancer drug prices by 76%, *Times of India*, 4 May 2012.

187 Aginam O. (2010). Global Health Governance, Intellectual Property and Access to Essential Medicines: Opportunities and Impediments for South-South Cooperation, *Global Health Governance*, Vol. IV, No.1.

188 Nevirapine and lamivudine.

189 Asawat V. (2012). *Existing Provisions on Compulsory Licensing in Countries of Asia-Pacific* (28 December 2012). Available at SSRN: <http://ssrn.com/abstract=2194321> or <http://dx.doi.org/10.2139/ssrn.2194321>

190 Drugs subject to licensing include efavirenz, abacavir, tenofovir, lopinavir/ritonavir, didanosine, and fixed-dose combinations tenofovir/emtricitabine and tenofovir/emtricitabine/efavirenz.

191 Ford, N., Wilson, D., Bunjumong, O., Angerer, T. (2004). The role of civil society in protecting public health over commercial interests; lessons from Thailand. *Lancet*, 363, 560–563, p.560.

Thailand issued a number of compulsory licenses for antiretroviral drugs in 2006-2007, and extended some licenses in 2010.¹⁹² The history of community mobilization to challenge patents and advocacy by people living with HIV for expanded access to generic ARVs have been key factors that contributed to Thailand's preparedness to issue compulsory licenses.¹⁹³ The Government's actions reportedly led to reductions in the price of one ARV (Kaletra) by half in 40 low and middle-income countries globally.¹⁹⁴

4.5.2 'TRIPS-Plus' measures in trade agreements

Trade agreements containing provisions beyond those required in the TRIPS Agreement can have the effect of restricting access to medicines. These are referred to as 'TRIPS-plus' requirements. Examples of 'TRIPS-plus' restrictions on access to medicines include, among others:

- i. limitations on the circumstances under which compulsory licenses may be issued;
- ii. extension of the minimum period of patent protection beyond the 20 years required by TRIPS;
- iii. data exclusivity requirements; and
- iv. requirements restricting parallel imports of drugs, which may prevent developing countries from sourcing drugs from the cheapest global supplier.

Concerns about TRIPS-plus provisions have been raised by HIV treatment activists in campaigns opposing proposals for a European Union (EU)-India Free Trade Agreement, an EU-Thailand Free Trade Agreement and an Asia Pacific regional trade agreement known as the Trans-Pacific Partnership (TPP).¹⁹⁵ TPP is a proposed regional trade agreement between Australia, Brunei, Canada, Chile, Malaysia, Mexico, New Zealand, Japan, Peru, Singapore, USA and Viet Nam. Thailand has expressed an interest and other countries may join in the future. The TPP appears to propose stronger intellectual property rights than those provided by previous trade agreements. High levels of intellectual property protection would have the effect of delaying the introduction of affordable generic drugs.

4.6 Lessons for the post-2015 development agenda

Legal and policy environments

The HIV response has illustrated how a focus on law and human rights can support the attainment of public health objectives. More broadly, sustainable development as a whole requires a focus on human rights and social justice. The MDGs did not include a strong focus on equity and human rights. The post-2015 development agenda requires a clear focus on the human rights of the most marginalized and the equitable distribution of the benefits of development.

The right to health goes beyond access to health care. As HIV has demonstrated, achievement of health goals is strongly affected by underlying social, economic, cultural and political determinants and structural barriers. A human rights-based approach provides a practical way to address the social determinants of health, including poverty, gender equality, ethnicity, economic exclusion, non-discrimination and other socially determined barriers.

It is insufficient to enact laws and develop policies without also considering the social and cultural context that affects implementation. For example, child and maternal health responses can be supported by a strong focus on laws and policies that address gender inequalities (see Chapter 7). Even in countries with gender equality

192 Including Merck & Co's Sustiva® (efavirenz) in 2006 and Abbott's Kaletra® (a combination of lopinavir & ritonavir) in 2007.

193 Krikorian G., Kapczynski A. eds (2010). *Access to Knowledge in the age of intellectual property*, New York: Zone Books, pp.440-441.

194 Abbott to Reduce Cost of Kaletra in Thailand, Other Developing Countries, *Medical News Today*, 13 April 2007.

195 Frommer M. (2012). Unjust treatment: Trans-Pacific Partnership Agreement, *HIV Australia* 10(2). October 2012; Civic groups warn against pact with EU, Bangkok Post, 1 March 2013; Lakshmi R. (2012) India-E.U. trade pact could boost AIDS treatment costs, health workers say, *Washington Post*, 10 February 2012; Sex workers, HIV-infected hold rally against FTA with EU, Indian Express, 10 February 2012.

laws, cultural factors often severely constrain women's enjoyment of rights of access to services. Gender equality considerations need to be integrated into governance arrangements, such as in approaches to community participation and representation. Gender equality plays a key role in accelerating equitable progress on health and all other key areas of development.

Human rights-based approaches

HIV has demonstrated the range of available mechanisms to ensure that human rights obligations are met. These include use of human rights conventions and reporting bodies at the global level, national mechanisms such as enforcement of laws and constitutionally guaranteed human rights, parliamentary oversight, national human rights institutions, NGO advocacy and community-based monitoring. Advocacy for the rights of people living with HIV, sex workers, people who use drugs, sexual minorities and transgender people is pioneering new approaches.

Principles of human rights, social equity and justice should guide the allocation of resources, the measurement of outcomes and impact, the framing of policies and strategies, and the planning and implementation of interventions. Applying these principles requires asking whether an approach is informed by an examination of issues of power, exclusion and structural injustice, and whether the approach has the effect of removing injustices and inequalities or whether it perpetuates the status quo.¹⁹⁶ Human rights-based approaches are critical to the success of all development issues affecting the most marginalized populations including persons with disabilities, people living with HIV, indigenous people, refugees and internally displaced populations, prisoners, and ethnic and religious minorities.

Legal empowerment

Legal empowerment, including human rights education and community legal services, can help disadvantaged populations to actively assert and claim their rights, and thereby participate in shaping rights-based development efforts. In the context of HIV, legal empowerment efforts have focused on marginalized populations that are highly stigmatized and criminalized. Legal empowerment strategies such as community legal education and strategic litigation can be beneficial across a range of development issues, including for example to advocate environmental rights, gender equality rights, rights to education and social protection, and rights to access clean water and sanitation.

Alignment of trade policy with development objectives

A key lesson from HIV has been that health objectives must not be given lesser priority than trade objectives when countries are defining national policy on issues such as pharmaceutical patents and the regulation of tobacco and food.¹⁹⁷ Intellectual property laws have a direct impact on health, education and access to knowledge, food security and rural livelihoods, international competitiveness and economic diversification. The international community should support local production of generic medicines in low and middle-income countries. All countries should carefully assess the potential adverse impacts of 'TRIPS-plus' provisions on access to medicines and other key development issues. Governments should advocate a pro-development interpretation of TRIPS requirements, and refuse to agree to TRIPS-plus requirements.

Trade and investment agreements can restrict the ability of countries to make effective use of intellectual property rules as a tool of development and to protect the rights of the most marginalized. Trade agreements should not impede the capacity of countries to adopt the system of intellectual property protection that best suits their development needs. For example, with appropriately flexible intellectual property laws and policies in place, people with disabilities can have affordable access to latest assistive devices, technologies and educational materials that can significantly improve their quality of life and participation in society.¹⁹⁸

196 See: Thanenthiran S., Ando M. (2010). The MDGs: A Critical Look and Some Proposals for the Post-2015 Development Framework, *Arrows for Change*, 16:1, 1-3.

197 See, for example, Moodie R., Stuckler D., Monteiro C. et al. (2013). Profits and pandemics: prevention of harmful effects of tobacco, alcohol, and ultra-processed food and drink industries, *The Lancet*, 23:381(9867): 670-9.

198 See, for example, issues related to a treaty for the blind: Love J. (2013). Disney, Viacom and Other MPAA Members Join Book Publishers to Weaken a Treaty for the Blind, *Huffington Post*, 23 April 2013.

Of particular concern are trade and investment agreements negotiated between countries with unequal political and economic power:

Often the weaker party in such bilateral and regional agreements ends up surrendering certain prerogatives that were granted at the multilateral level (the so-called WTO-plus and minus rules). By expanding their scope into services, investment, intellectual property and public procurement, trade rules encroach on the development policy space of developing countries.¹⁹⁹

Trade agreements can have significant environmental impacts including resource depletion, pollution and increased carbon emissions associated with rapid expansion in trade and industry. For example, an analysis of the impacts of the ASEAN-China Free Trade Agreement on the Greater Mekong Sub-Region (GMS) found as follows:

Within the GMS there is considerable trade in natural resources such as minerals, agricultural commodities and wood... Unregulated trade expansion in wood and wood products can result in forest decline, which leads to other environmental problems, such as loss of biodiversity, land erosion, flooding, landslides and climate change. Agricultural expansion and mining can further exacerbate pressures on natural forests. In the absence of fisheries management systems, increased trade in fish products is likely to contribute to overfishing with adverse effects on fish stocks and negative impacts on local livelihoods, especially those of the people who are directly dependent on fishing... An increase in trade in natural resource-based products within this context is likely to lead to further decrease in environmental quality...environmental issues must be considered and included in trade negotiations and agreements...²⁰⁰

199 Committee for Development Policy (2012). *The United Nations Development Strategy Beyond 2015*, New York: UN, p.47.

200 Vutha H., Jalilian H. (2008). *Environmental Impacts of the ASEAN-China Free Trade Agreement on the Greater Mekong Sub-Region*, Phnom Penh: Cambodia Development Resource Institute.

Participatory governance approaches

KEY POINTS

- HIV responses have been characterized by community participation and strong civil society leadership including the central role of people living with HIV and key populations in activism, policy development, service delivery, monitoring and acting as a watchdog for progress.
 - Participatory governance approaches have strengthened the HIV response and built the capacity of marginalized communities to contribute to broader development efforts.
 - Community participation needs to be adequately resourced to ensure that marginalized communities participate meaningfully in governance mechanisms. Inclusive development requires participatory approaches that actively involve marginalized communities. Across all fields of development, governance models are required that are participatory, responsive and inclusive to the needs of all communities, rather than only political and economic elites.
-

5.1 Community participation and the GIPA principle

Community participation in policies and programmes has been a key element of success of the rights-based response to HIV. Participatory governance approaches have strengthened HIV responses and built the capacity of marginalized communities to contribute to broader development efforts. The urgency of the early years of the HIV response provided the impetus for many communities of sex workers, people who use drugs, MSM and transgender people to mobilize around a political agenda to advocate their own health and human rights agendas.

Donors also actively promoted participatory HIV responses. For example, this has been a precondition of Global Fund country grants.

National HIV responses have applied the principle of the 'greater involvement of people living with and affected by HIV and AIDS' (known as the 'GIPA principle'). GIPA has been a guiding principle of the global HIV response since the Paris AIDS Summit in 1994. The principle calls for the meaningful participation of people living with and affected by HIV in the inception, development, implementation, monitoring and evaluation of policies and programs.²⁰¹ The GIPA principle extends to the involvement of populations that are at risk of acquiring HIV, and families of those living with HIV.

The GIPA Principle has been recognized by civil society in Asia and the Pacific through the *Bangkok Declaration by People living with HIV/AIDS in Asia Pacific* (2004) and the *Vientiane Statement of Commitment on the Greater Involvement and Empowerment of People Living with HIV* (2008).²⁰² Application of GIPA has improved the quality

201 UNAIDS (2007). *Policy Brief: Greater involvement of people living with HIV*, Geneva: UNAIDS. http://data.unaids.org/pub/briefingnote/2007/jc1299_policy_brief_GIPA.pdf

202 2nd Asia Pacific PLWHA Conference & APN+ (2004). *Bangkok Declaration by People living with HIV/AIDS in Asia Pacific*; ASEAN Task Force on AIDS and People Living with HIV (2008). *Vientiane Statement of Commitment on the Greater Involvement and Empowerment of People Living with HIV*.

and focus of HIV responses and has energized governance bodies such as NACs and CCMs.²⁰³ An empowered civil society with the necessary skills and resources for advocacy has demanded transparency and accountability from governments, while also establishing structures to ensure the accountability of civil society organizations to the communities they represent.²⁰⁴

To operate effectively, GIPA requires a pluralistic governance system with broad civil society involvement, involvement and support of local government actors and traditional leaders, low levels of stigma and discrimination, involvement of both people living with HIV and key populations (including women and young people from key populations), and access to HIV treatments so people living with HIV are well enough to participate.²⁰⁵

Across the region, as HIV stigma has reduced and treatments have become available, people living with HIV have played an increasingly active public role in HIV responses. People living with HIV rallied around a treatment access agenda, as articulated at the regional level in the *Colombo Declaration on Universal Access to Affordable HIV Medicines* (2007).²⁰⁶

Sidibé and colleagues describe this aspect of governance as “expanded political space for affected people, communities and civil society in the governance of a health-related development challenge.”²⁰⁷ They observe:

The global HIV pandemic initiated a massive mobilization of affected communities. AIDS activists, service organizations, support groups and networks of treatment activists stimulated public awareness and support, financial commitment, scientific investment, progressive dialogues on stigma, discrimination and rights and the formation of new local, national, and global institutions to respond to the disease. Beyond their activism, the meaningful participation of affected people in global and national decision-making forums has galvanized strong political support and improved accountability in meeting financial commitments and delivering more equitable and effective services.²⁰⁸

A key lesson has been the importance of ensuring that CBOs are given a role not just in providing services but also in policy development, planning and decision making regarding funding. CBOs have been active in empowering people living with HIV and key populations, advocating for law and policy reform and actively holding governments to account for their commitments. Community development approaches have required provision of support to CBOs to build and strengthen community networks, encouraging communities to take ownership and assume leadership in peer-based health promotion, care, support and advocacy.

Effective national HIV programmes are supported through community mobilization down to grass roots levels:

HIV prevention highlights the governance challenge of coordinating HIV programs with community sources of authority, combining formal and informal, national and local, sources of governance... a constituency governance model where national programs need to build on community sources of authority as a basic unit of governance.²⁰⁹

Participatory governance enables HIV programmes to mobilize the resources for HIV responses that reside in social networks as ‘social capital’. Social capital is defined as “features of social organization, such as trust, norms and networks that can improve the efficiency of society by facilitating coordinated actions.”²¹⁰ Community participation can help shape norms that enable and support behavior change. Building social capital through participatory

203 UNAIDS (2013). *AIDS, health and human rights: Toward the end of AIDS in the Post-2015 Development Era*, UNAIDS contribution to the Post-2015 Global Thematic Consultation on Health, Geneva: UNAIDS, p.9.

204 Piot P., Timberlake S., Sigurdson J. (2009). Op cit.

205 Paxton S., Jannsen P. (2009). *AusAID GIPA Scoping Report*, Canberra: AusAID, p.11.

206 APN+ (2007). *Colombo Declaration on Universal Access to Affordable HIV Medicines issued at the 8th International Congress on AIDS in Asia and the Pacific, Colombo, Sri Lanka*.

207 Sidibé M., Tanaka S., Buse K. (2010). People, Passion & Politics: Looking Back and Moving Forward in the Governance of the AIDS Response, *Global Health Governance*, Vol. IV, No.1, 1-17, p.4.

208 Ibid.

209 Low-Beer D., Sempala M., (2010). Social Capital and Effective HIV Prevention, *Global Health Governance*, Volume IV, No. 1 (Fall 2010). p.15.

210 Putnam R., Leonardi R., Nanetti R. (1993). *Making Democracy Work: Civic Traditions in Modern Italy*, Princeton: Princeton University Press, p.167; Low-Beer D., Sempala M. (2010). Social Capital and Effective HIV Prevention, *Global Health Governance*, Volume IV, No. 1 (Fall 2010).

approaches that generate social cohesion supports HIV prevention outcomes.²¹¹ HIV prevention successes have been underpinned by grass roots community mobilization.

5.2 Examples of participatory HIV initiatives

5.2.1 Community networks

The establishment of community networks as formalized organizations at the regional, national and sub-national levels has enabled a vibrant civil society movement active in HIV-related policy and advocacy. Civil society organizations established in response to the HIV epidemic include networks representing people living with HIV, sex workers, people who use drugs, MSM and transgender people.²¹² These networks include HIV within their mandate, but most also address other health, welfare and human rights issues affecting their constituencies and associated law and policy reform issues, rather than a narrow focus on disease-specific medical factors.

At the regional level, these organizations generally function as peak bodies representing national organizations. For example, the Asia Pacific Network of People Living with HIV (APN+) is a peer-based organization representing people living with HIV from 30 countries. With the legitimacy of this membership base, APN+ is able to play a representative role at regional meetings convened by UN agencies on HIV and related issues.

5.2.2 Country examples of participatory governance

Bangladesh

Durjoy is a sex worker-led CBO that provides HIV prevention and anti-violence programmes for more than 14,000 sex workers. Durjoy established community-level governance mechanisms comprising a violence committee, a watchdog committee and a support committee. The violence committee provided outreach and education to sex workers to enable them to access legal, health and social services, responding to incidents of violence. The watchdog committees were comprised of men whose role was to monitor and protect sex workers from violence, and to conduct social mobilization campaigns. These committees enlisted support from influential local men, such as religious leaders. Support committee members included people from the health sector and the police force, NGOs, lawyers and officials.

Mobilization of service providers, government institutions and the sex worker community led to improved mechanisms for reporting violence to police, increased access to school enrolment for children of sex workers, and improved community perceptions of sex workers. Building sex workers' capacity to become agents of change, claim rights and solve problems improved their ability to respond effectively to violence.²¹³

Cambodia

People living with HIV and key populations participate actively in the HIV response at all levels, from national strategic planning to grass roots service delivery. Civil society organizations participated in formulating the National

211 Samuels F, Pelto P, Verma R, George C. (2006). Social capital and HIV risk behavior among female sex workers and men who have sex with men in Andhra Pradesh: Insights from quantitative and qualitative data. *Horizons Research Update*. Washington, DC: Population Council.

212 Asia Pacific Network of People Living with HIV/AIDS (APN+); Asian Harm Reduction Network; Asian Network of People who use Drugs; Asia Pacific Council of AIDS Service Organizations; Asia Pacific Network of Sex Workers; Asia Pacific Coalition for Male Sexual Health; Purple Sky Network (PSN), a network of organizations of men who have sex with men (MSM) in the Mekong countries; Insular South East Asia Network on HIV and MSM (Indonesia, Malaysia, Philippines, Timor Leste); Pacific Sexual Diversity Network; Asia Pacific Transgender Network; YouthLEAD: Asia Pacific Network of Young Key Affected Populations; Seven Sisters network of regional HIV networks.

213 UNFPA, UNAIDS, Asia Pacific Network of Sex Workers (2012). *The HIV and Sex Work Collection: Innovative responses in Asia Pacific*, Bangkok: UNFPA, UNAIDS, APNSW, p.96.

Strategic Plan on HIV/AIDS, and in advocacy on law and policy reform, for example efforts to amend drug control laws to enable syringe distribution programmes and dialogue on how to integrate HIV services with other health and social protection services. The Cambodia Network of People Living with HIV/AIDS (CPN+) provides an advocacy voice to people living with HIV and has helped to develop home-based care models and the 'Continuum of Prevention to Care and Treatment' model of integrated service delivery. The National AIDS Authority has developed a framework for community networks that defines a systematic approach to capacity development. The national MSM network used the framework to develop a plan addressing the governance, leadership, representation, human resources financial management needs of the network.²¹⁴

Fiji

The Fiji Network of People Living with HIV participates in HIV policy and service planning and decision making processes.²¹⁵ Community representation in the national HIV coordinating authority (the HIV/AIDS Board) is guaranteed by the *HIV/AIDS Decree 2011*.²¹⁶ The Decree defines membership of the Board to include a representative of up to two civil society organizations concerned with the protection of the human rights of people living with or affected by HIV, with at least one of those appointed being a person who publicly identifies as a person living with HIV.

India

GIPA and State AIDS Control Societies

State AIDS Control Societies (SACS) coordinate responses and implement policies and programmes. SACS are encouraged by government policy to integrate GIPA into their work. CBOs of MSM, transgender people and sex workers implement peer-based prevention programmes and conduct advocacy campaigns to address human rights priorities.

A study of how GIPA has been implemented in five states found that implementation by SACS is variable.²¹⁷ The study referred to a six-tier model of GIPA which ranks levels of involvement in ascending order: target audience/beneficiaries, contributors, speakers, implementers, experts, decision-makers. The study found that women living with HIV face unique challenges in participating in decision-making processes, including restrictions from families on participating in public forums, and limited leadership opportunities within the activist networks due to assumptions about women's potential.²¹⁸

The state of Kerala has developed a GIPA strategy that recognizes that participation of people living with HIV in governance has the potential to benefit the HIV response and other health and development priorities. The GIPA strategy encourages the state to draw on experiences of people living with HIV to provide lessons for responding to other chronic manageable health conditions such as heart disease, diabetes and cancer, alcohol use, and to address gender issues and women's empowerment.²¹⁹

Sex worker mobilization

Indian sex worker organizations have been at the forefront of advocacy efforts seeking to improve their working conditions, legal status and access to health services. Sex worker collectives and unions have worked in partnership

214 UNAIDS (2012). *Case Study: The Royal Government of Cambodia at the forefront in applying new investment approach*, UNAIDS/PCB (31)/12. CRP.1; NAA (2012). *Institutional core competency framework for people living with HIV and MARPs Community Networks*. National AIDS Authority, Kingdom of Cambodia and UNAIDS.

215 *FJN+ Newsletter*, Vol 1, No 1, February 2012.

216 People living with HIV and key populations were also represented in the previous structure (the National Advisory Committee on AIDS). FJN+ was a member of the National Advisory Committee on AIDS since 2004. The *HIV/AIDS Decree* enshrined people living with HIV participation into law.

217 Chakrapani V., Abraham K. (2010). *"If we involve, will they contribute?": Involvement of people living with HIV in policy and program decision-making. A Qualitative Situation Assessment of 'Greater Involvement of People living with and affected by HIV/AIDS' (GIPA) in five Indian states*. Indian Network for People living with HIV/AIDS (INP+).

218 UNAIDS (1999). *From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)*. Best Practice Key Material.

219 Kerala State AIDS Control Society (2010). *GIPA Strategy for Kerala: Strategic approach integrating potential skills & life experience of PLHIVs for the development needs of the state*. KSACS.

with local health authorities and police to address HIV and other health and welfare issues. Community-level governance mechanisms (self-regulatory boards) have been established by sex workers in several districts.²²⁰

For example, the Durbar Mahila Samanwaya Committee (DMSC) represents 65,000 sex workers in Kolkata. DMSC's self-regulatory boards help sex workers challenge police abuses by creating an opportunity for sex workers to negotiate with local officials.²²¹ They are also provided with access to welfare services and cooperative banking services. Through implementing peer-based empowerment interventions, DMSC has achieved a significant increase in condom use among sex workers and a reduction in police harassment and exploitation from local gangs. Sex workers report that they are better able to negotiate health and work conditions.²²²

Another example of effective sex worker mobilization is the Karnataka Health Promotion Trust (KHPT).²²³ KHPT supported the formation of sex worker community-based organizations and involved sex workers in all aspects of HIV programme design and implementation, gradually handing over management of programmes to elected sex worker representatives. Sex workers were trained to enable them to participate in District AIDS Committees and to co-facilitate sensitization workshops addressing issues of HIV, social justice, stigma and violence to heads of government departments, the police and journalists.²²⁴

Indonesia

Government leadership on GIPA is strong, particularly from the NAC. There are also provincial and district AIDS commissions and people living with HIV sit on some of these bodies. Partnerships with civil society have been extensive, including community networks, faith-based communities and a wide range of national and local advocacy and service organizations.

National networks of key populations are supported by the National AIDS Commission to have a voice in national policy dialogues and funding bodies. The Presidential Regulation on the National AIDS Commission of 2006 specifies that the membership of the Commission includes the chair of the national organization of people living with HIV.²²⁵

Five national networks have been formed (the network of people who use drugs, network of sex workers, network of gay, transgender and MSM, and network of people living with HIV and of women living with HIV). These national networks have been included in activities of the NAC, such as mapping, planning, resource mobilization, monitoring and evaluation. The national networks have received operational support from the national HIV programme and the UN.²²⁶ Community engagement in the governance of the national response has been facilitated by on-going dialogue of key populations represented in the executive team of the NAC, and NAC working groups. Increasingly, civil society organizations have also been hired as consultants to take part in programme development and evaluation.²²⁷

Myanmar

Community system strengthening is a cross cutting intervention of the Myanmar *National Strategic Plan for HIV and AIDS 2011-2015*. Although there are many challenges in establishment of CBOs due to the legal and political context, seven national networks have been formed: the Myanmar Positive Group, National NGO Network on AIDS, Sex Workers Network in Myanmar, National Drug User Network in Myanmar, Myanmar Positive Women

220 Rao S., Sluggett, C. (2009). *Who Stole the Tarts? Sex Work and Human Rights*, Center for Advocacy on Stigma and Marginalisation (CASAM).

221 APNSW, UNFPA, UNAIDS, (2011). *Op cit.*, p.37.

222 The Durbar Mahila Samanwaya Committee Theory and Action for Health Research Team (2007). *Meeting community needs for HIV prevention and more: intersectoral action for health in the Sonagachi red-light area of Kolkata*, WHO, p. 16.

223 KHPT was part of the *Avahan* AIDS Initiative funded by the Bill & Melinda Gates Foundation.

224 Gurnani V, Beattie T, Bhattacharjee P., et al. (2011). An integrated structural intervention to reduce vulnerability to HIV and sexually transmitted infections among female sex workers in Karnataka state, south India, *BMC Public Health*, 11:755.

225 Government of Indonesia, *Presidential Regulation No.75 of 2006*, Article 4.

226 National AIDS Commission (2011). *The response to HIV and AIDS in Indonesia 2006-2011: Report on 5 Years Implementation of Presidential Regulation No. 75/2006 on the National AIDS Commission*, Jakarta: NAC.

227 See: National AIDS Commission (2011) *Response to HIV and AIDS in Indonesia 2006-2011*, Jakarta: National AIDS commission.

Network, Myanmar Interfaith Network on AIDS and Myanmar MSM network. The Myanmar Positive Group has 156 member self-help groups with nearly 9,000 members. The Country Coordination Mechanism (CCM) is the highest-level coordination body and is chaired by the Ministry of Health. Since 2005, community representatives have participated in the CCM and National Technical Strategy groups and provided their views and opinions for decision making and implementation of the national AIDS response. In 2012 these networks engaged in advocacy meetings with parliamentarians to discuss legal and human rights priorities.

Nepal

The Blue Diamond Society is a CBO that has combined community-led HIV programming among MSM and transgender people with advocacy aiming to create a supportive legal, policy and social environment for health promotion programmes. A combination of advocacy, leadership development, legal education and test case litigation has contributed to increased social, legal and political recognition of key HIV-affected populations. For example, in 2013, transgender people were permitted to register as 'third gender' when completing their citizenship certificates required to open bank accounts, buy property or to apply for a job and a passport.²²⁸ The approach of Blue Diamond Society demonstrates how HIV prevention programming can be located within a community-led organization with a broad agenda for improving the health and human rights of its stakeholder communities.²²⁹

The Philippines

The Philippine National AIDS Council (PNAC) proactively engages with CBOs of people living with HIV and key populations. Pinoy Plus Association is a CBO of people living with HIV that offers services such as counseling, referrals and care and support programmes. A representative of Pinoy Plus Association sits on PNAC, advocates human rights priorities of people living with HIV and provides input to national strategic planning and reviewing policies and programmes. Pinoy Plus is also a member of the Global Fund CCM.²³⁰

TLF Sexuality, Health and Rights Educators Collective (TLF SHARE) is one of the NGO members of PNAC. TLF SHARE comprises peer educators who work with MSM and transgender communities. With UNDP support, TLF-SHARE has helped MSM and transgender groups form national networks and engage Local Government Units, facilitating greater understanding of needs and planning processes. Local anti-discrimination campaigns have been implemented through partnerships between Local Government Units and community groups of MSM and transgender people.²³¹

Thailand

The National AIDS Committee includes the Thai Network of People Living with HIV/AIDS and civil society organizations such as the Thai NGO Coalition on AIDS, Thai Red Cross Society, the Thailand Business Coalition on AIDS, key government ministries and parliamentarians, and has strong connections with health and human rights academics.

The Foundation for AIDS Rights has been an implementing partner for UNDP in policy and advocacy on prevention of stigma and discrimination. Activities include legal hotlines, mapping of laws, policies and practices, and a partnership with the Royal Thai Police to integrate training on stigma and discrimination into the human rights curriculum for police cadets.

The Population and Community Development Association (PDA) has engaged in a range of HIV prevention, condom promotion and community development activities. PDA's Positive Partnership Project provided micro-credit to people living with HIV to reduce stigma and discrimination. HIV positive and HIV negative pairs were provided loans for businesses. Pairs also collaborated to disseminate HIV knowledge to their community, with the objective of

228 'Nepal transgenders gain recognition on ID cards', *Dawn.com*, 23 January 2013.

229 UNFPA, UNAIDS, Asia Pacific Network of Sex Workers (2012). Op cit., p .

230 ISEAN CBO directory, <http://library.isean.asia/cbodirectory/view/44555004>.

231 UNDP (2011). Innovative approaches, UNDP Philippines: Strengthening Community Leadership among Men who have Sex with Men (MSM) and Transgender Persons, Bangkok: UNDP APRC.

reducing stigma and discrimination. The project contributed to improved quality of life and economic conditions for people living with HIV, raising their visibility and acceptance and reducing stigma in hundreds of communities.²³²

The Thai sex worker CBOs Empower and SWING have provided community leadership for sex workers by mobilizing support for HIV prevention and related health and social justice issues. These CBOs advocate legal recognition of sex work as legitimate employment, with equal labour rights and occupational health safeguards. Empower has advanced labour rights for sex workers by ensuring their access to the Thai National Social Security Scheme.

Viet Nam

The Government of Viet Nam, people living with HIV groups and development partners issued a joint 'Viet Nam call to action for GIPA' in 2007. People living with HIV and key populations are increasingly involved in service delivery. Early in the epidemic, people living with HIV and key populations were treated as passive recipients of services. A stronger emphasis on peer education has built greater trust of people living with HIV and key populations in health services. Peer educator programmes have helped services to reach hidden populations with prevention and treatment services.²³³ The Viet Nam Network of People Living with HIV (VNP+) has engaged in policy discussions with government regarding the impact of free trade agreements on access to medicines and conducted a survey of people living with HIV on stigma and discrimination in five provinces.²³⁴ VNP+ in partnership with the National Committee for HIV, Drugs and Prostitution Prevention and Control have organized candidates to represent people living with HIV in official government delegations to regional and global HIV-related UN meetings.

5.2.3 Participatory research to inform legal and policy reforms

Participatory approaches have informed research methods used to generate evidence for HIV-related policy development and law reform.

For example, a regional research initiative on stigma has been led and implemented by people living with HIV. The People Living With HIV Stigma Index is a tool that measures changing trends in stigma and discrimination. Networks of people living with HIV in 14 countries in Asia and the Pacific²³⁵ have helped to design and conduct research applying the Stigma Index in their communities. Research teams typically include people living with HIV organizations and partners from local academic institutions. The research aims to increase the evidence base for policies and programmes and ensure that the greater involvement of people living with HIV is embedded within national HIV responses.²³⁶ The research method empowers people living with HIV by facilitating their increased awareness of the nature and extent of stigma and discrimination, its adverse health impacts, and remedies to address it. The Stigma Index process has facilitated community partnerships with research agencies and government, and identification of priority areas for advocacy.

Another example of community-based research is a project conducted by drug user organizations in Yunnan Province, China. The research examined the national system by which former drug users were subject to life-long monitoring by the Ministry of Public Security. Drug users helped to design and conduct the research through the Yunnan Harm Reduction Network.

232 Viravaidya M., Wolf R., Guest P. (2008). An assessment of the positive partnership project in Thailand: key considerations for scaling-up microcredit loans for HIV-positive and negative pairs in other settings, *Glob Public Health*. 2008;3(2):115-36; Jain A., Nuankaew R., Oranop na Aythaya P., Richter K. (2012). *Success! Interventions that work to reduce HIV stigma and discrimination in communities: results of an evaluation study in Thailand*, XIX International AIDS Conference on AIDS, 22-27 July 2012, WEAD0501, Oral Abstract Session.

233 Fujita M., Poudel K., Do Thi N. (2012). A new analytical framework of 'continuum of prevention and care' to maximize HIV case detection and retention in care in Vietnam, *BMC Health Services Research*, 12:483.

234 Viet Nam Global AIDS Response Progress Report 2012, p.46.

235 Bangladesh, Cambodia, China, Fiji, India, Lao PDR, Malaysia, Myanmar, Nepal, Pakistan, Philippines, Sri Lanka, Thailand and Viet Nam.

236 The Stigma Index is a joint initiative of the Global Network of People Living with HIV/AIDS (GNP+), the International Community of Women Living with HIV/AIDS (ICW), the International Planned Parenthood Federation (IPPF) and UNAIDS. GNP+, ICW, IPPF, UNAIDS (2011). *People Living with HIV Stigma Index, Asia Pacific Regional Analysis 2011*, Geneva: UNAIDS.

The Yunnan Harm Reduction Network observed that registered former drug users were facing difficulties due to monitoring. The research indicated that former drug users were harassed when checking into hotels, applying for papers and documents, travelling, and renting apartments. The system negatively influenced their work, family life and mental health. Based on this evidence, advocacy to reverse this policy was undertaken by the Yunnan Harm Reduction Network targeting the Yunnan Narcotics Bureau, the National Narcotic Control Office and the media. In response, the government changed the national regulation on Narcotics Control. The new *Narcotics Control Law* allowed former drug users who had been abstinent or on methadone for three years to be removed from the system. As a result, 68,000 former drug users were removed from the system.²³⁷ Ultimately it would be desirable to completely remove the legal requirement that the Ministry of Public Security monitor former drug users.

5.3 Lessons for the post-2015 development agenda

Participatory governance lessons can be drawn from many fields of development, but the unprecedented attention that HIV has received has helped to bring certain experiences and lessons to prominence. HIV responses built on previous learning in the field of primary care, where a consensus emerged during the 1970s of the key role of community participation in health care. The *Alma Ata Declaration* of 1978 stated: “primary health care...requires and promotes maximum community and individual self-reliance and participation in the planning, organization, operation and control of primary health care, making fullest use of local, national and other available resources; and to this end develops through appropriate education the ability of communities to participate.”²³⁸

Participatory governance has been identified by the UN Committee for Development Policy as one of the key challenges for global development.²³⁹ Elitist and autocratic governance structures contribute to social tensions and conflict. Failure to generate inclusive growth that benefits all in society, including those who are socially excluded and most in need, is a source of discontent in many countries in the region. Across all fields of development, governance models are required that are participatory, responsive and inclusive to the needs of all communities, rather than only political and economic elites.

Development efforts need to draw from the commitment, experience, and mobilizing capacity of civil society. Civil society roles include: activism, advocacy, awareness, policy setting, programme design, service delivery, research, monitoring, evaluation and acting as a watchdog for progress.²⁴⁰ A clear role for civil society will be crucial to achievement of global development goals and targets.

Approaches to participation vary between countries and are influenced by cultural and political factors. Whereas no single model of participation is appropriate to every context, it is important that approaches conform to principles of equity and non-discrimination. Criminalized key populations are particularly vulnerable to exclusion from participation. The *United Nations Development Strategy Beyond 2015* observes:

Definitions of participation vary greatly, ranging from a narrow focus on nominal membership in a group to a much broader emphasis on interactive processes, in which the disadvantaged have voice and influence in decision-making.

Some see participation... in terms of its intrinsic worth in enhancing equity and empowerment for those economically and socially disadvantaged. Others see it narrowly in terms of its potential efficiency effects. Although participation is meant to operate on democratic principles and to involve and benefit all sections of the community, institutions which seem participatory and inclusive in formal terms can effectively exclude significant sections, especially the poor and women. These “participatory exclusions” can, in turn, unfavourably

237 Sharma M., Chatterjee A. (2012). Partnering with law enforcement to deliver good public health: the experience of the HIV/AIDS Asia regional program, *Harm Reduction Journal* 2012, 9:24.

238 *Declaration of Alma Ata*, International Conference on Primary Health Care, Alma-Ata, USSR, 6-12 September 1978.

239 UN Development Committee (2012). *The United Nations Development Strategy Beyond 2015, Policy Note*, New York: UN.

240 Task Team for the Global Thematic Consultation on Health in the Post-2015 Development Agenda (2013). *Health in the post-2015 agenda, Report of the Global Thematic Consultation on Health*, <http://www.worldwewant2015.org/health>.

affect both equity and institutional efficiency. Exclusion can be up front through the rules of entry, or subtle, such as through social norms.²⁴¹

Key lessons relating to participatory governance for the post-2015 development agenda include:

- Participation is effective when it allows a safe space for communities that have previously been excluded from power to debate, shape, monitor and hold to account the actions of governments and non-government actors that affect them.
- Civil society networks representing populations who are socially and legally marginalized can participate meaningfully in policy development and planning with capacity building support. Participation needs to be adequately resourced to ensure that marginalized communities can participate meaningfully.
- Development responses are strengthened by multi-level governance models integrating national programmes with the community response, recognizing communities as the basic unit of governance of national development programmes.
- Development interventions should value communities as change agents in development, rather than passive recipients of aid.
- Community-based participatory research can strengthen the evidence base for policies, programmes and services that are responsive to needs, and build the capacity of communities to influence and participate in decision-making. It can also ensure that the intended beneficiaries accept the findings and recommendations arising from research.
- The perspectives of marginalized groups should be central to planning, monitoring, and evaluating the post-2015 development agenda. Targets and indicators should be defined to enable measurement of progress in efforts to foster participation and community mobilization in support of development goals and to engage the most discriminated and marginalized populations.

241 UN Development Committee (2012). Op cit., p.41.

Applying governance lessons to chronic non-communicable disease (NCD) responses

KEY POINTS

NCD responses should be guided by the principles of universal access and social justice. A rights-based approach requires engaging at the structural level to address the social determinants of health, rather than a more limited, top-down medical approach. The commitment and mobilizing capacity of civil society should play a key role in advocacy and awareness, policy setting, service delivery and acting as a watchdog for progress.

NCD responses require national leadership and coordination mechanisms that are inclusive of multiple stakeholders, particularly key government ministries, affected communities, the private sector and a broad range of civil society organizations. While it is important to engage the legal, trade and education sectors in a coordinated response, the central role of the ministry of health should not be undermined. NCD strategies are required that address:

- i. the role of political, business and civil society leadership, including empowering communities to participate in NCD advocacy;
- ii. advocacy on the legal, regulatory, policy and the human rights environment, particularly in relation to trade policy, the regulation of harmful products and access to medicines;
- iii. coordination of government roles in health, law, trade and education sectors;
- iv. prevention strategies that address the role of the private sector and media;
- v. monitoring and reporting of progress towards commitments and targets; and
- vi. transparency and accountability to stakeholders.

NCD responses should focus on vulnerable populations who bear disproportionate socioeconomic and health burdens from NCDs, including the poor, women, girls, persons with disabilities and indigenous people. An enabling policy and legal environment for NCD responses requires:

- Taxation of tobacco and alcohol, regulation of their production and sales, and restriction of advertising and marketing.
 - Regulation of production and sale of food (including restrictions on labeling, marketing, advertising and sponsorship) and taxation measures, to reduce consumption of foods that contain high amounts of sugars, processed carbohydrates and saturated fats;
 - The role of intellectual property laws and treaties in relation to trade and investment in limiting or facilitating access to affordable lifesaving medicines for NCDs;
 - Assessment of the impact of trade and investment agreements on capacity to enforce laws and policies related to producing or selling food and drugs; and
 - Implementation of universal health insurance and other mechanisms to remove financial barriers to health care.
-

6.1 Lack of action on NCDs: a regional health emergency

In the last decade, there has been a growing movement to demand greater attention to NCDs, which in many countries now account for a greater disease burden than communicable diseases. NCDs were omitted from the MDGs, but are likely to feature in the targets of the post-2015 development agenda.

In the face of ageing populations, lifestyle changes and urbanization, many countries of the region now face a double burden of disease where the pre-existing disease burden from infectious diseases is compounded by the emerging epidemics of chronic NCDs – mainly cancer, cardiovascular diseases, diabetes and chronic respiratory diseases. Non-communicable diseases are the leading cause of mortality and morbidity in the Asia-Pacific region.²⁴² It is anticipated that a growing number of people will be affected by chronic NCDs in coming decades. For example, recent data indicate that NCDs are the top killers in the South-East Asia region, causing 7.9 million deaths, and the number of deaths is expected to increase by 21 percent over the next decade.²⁴³

The poor, particularly the urban poor, are exposed to greater NCD risk factors such as smoking and drinking and as a result are more likely to die earlier than other segments of the population.²⁴⁴ Alcohol abuse has been found to increase domestic violence against women,²⁴⁵ and NCDs constitute one of the leading causes of disability in the region.²⁴⁶ Like HIV-related key populations, people with disabilities face gross rights violations.²⁴⁷

The chronic nature of NCDs can have catastrophic financial impacts both at the household and macroeconomic levels. In India for example, the risk of catastrophic spending is 160 percent higher for hospitalization due to cancer, as compared with hospitalization due to a communicable disease.²⁴⁸ Economic loss in China due to stroke, heart disease and diabetes (not including cancer) was estimated to be USD\$18 billion in 2005.²⁴⁹ The total cost for China incurred by overweight and obesity among adults is projected to surpass 9 percent of GNP by 2025.²⁵⁰

In South Asia, over half of the disease burden is now attributable to NCDs – a larger share than communicable diseases, maternal and child health issues and nutritional causes combined. Lifestyle changes associated with urbanization and globalization are increasing the risk factors and disease onset at younger ages. As a result, South Asians are becoming more vulnerable to heart disease, cancers, diabetes, and obesity, which are creating significant new pressures on health systems.²⁵¹

In China, 80 percent of deaths are due to NCDs, and the public health response to NCDs is at a very early stage. Heart disease, strokes, diabetes and chronic lung disease account for more than 70 percent of China's health expenditures.²⁵²

NCDs are the leading cause of death in 12 Pacific island countries for which data is available, frequently accounting for 70 percent of all deaths. Cardiovascular disease is the leading cause of death in the Pacific. NCDs impose

242 WHO (2010). *Global Status Report on Non-Communicable Diseases*. Geneva: WHO.

243 Narain J., Garg R., Fric A. (2011). Non-communicable diseases in the South-East Asia region: burden, strategies and opportunities. *Natl Med J India*, 24(5):280-7, 280.

244 Yang, T. et al. (2009). Smoking patterns among Chinese rural-urban migrant workers. *Public Health*, 123, 743-749.

245 Burnet Institute (2010). *Situational analysis of drug and alcohol issues and responses in the Pacific 2008-9*. Melbourne: Burnet Institute.

246 WHO (2008). *Health in Asia and the Pacific*, Manila: WHO.

247 OHCHR (2002). *Human Rights and Disability: The current use and future potential of United Nations human rights instruments*, Geneva: OHCHR.

248 Mahal, A. et al. (2010). *The economic implications of non-communicable disease for India*. HNP Discussion Paper. Washington, DC, The World Bank.

249 WHO (2005). *Preventing chronic diseases: a vital investment*. Geneva: WHO.

250 Popkin, B. et al. (2006). Measuring the full economic costs of diet, physical activity and obesity-related chronic diseases. *Obesity Reviews*, 7:271-293.

251 Engelgau M., El-Saharty S., Kudesia P., Rajan V., Rosenhouse S., Okamoto K. (2011). *Capitalizing on the Demographic Transition Tackling Noncommunicable Diseases in South Asia*, World Bank, p.22.

252 WHO: 80% of China deaths from Non-communicable Diseases, *Wall Street Journal*, 7 December 2012.

significant and growing financial burdens on Ministries of Health and Ministries of Finance. This is particularly significant in the Pacific where governments already finance and provide the bulk of health services.²⁵³

In 2011, through the Honiara Communiqué, Pacific Health Ministers declared that the region is facing an NCD crisis. WHO and the Secretariat of the Pacific Community reported that of the estimated 63,900 adult deaths (from natural causes) that occurred in Pacific island countries and territories in 2010, approximately 75 percent were attributable to NCDs. The Pacific has the highest prevalence of obesity and diabetes in the world. Most NCD-related deaths in the Pacific region are due to cardiovascular disease, followed by cancer. Most Pacific island countries exhibit relatively high levels of tobacco use and alcohol consumption, poor dietary practices and low levels of physical activity, the main factors that contribute to NCDs.²⁵⁴

6.2 Political leadership and coordination

HIV responses have benefited greatly from political champions who have challenged stigma and mobilized public support and resources to the cause. NCD responses also require champions prepared to take a public stance and act as ambassadors to raise awareness, resources and support from across society.

Since 2011 the global community has taken a series of measures to generate political consensus on the need for escalated action to tackle NCDs. As occurred with HIV a decade earlier, the UN General Assembly agreed its first Political Declaration on NCDs in 2011.²⁵⁵ As with HIV, the Declaration positions NCDs as a development issue. A further milestone was the development of the *Global NCD Action Plan 2013-2020*, agreed by the World Health Assembly in 2013, which established overarching principles including a multi-sectoral approach, human rights and empowerment of people and communities.²⁵⁶

At the regional level, NCDs are addressed in general health frameworks such as the *ASEAN Strategic Framework on Health Development 2010-2015*. WHO has led regional health sector efforts.²⁵⁷ For example, the WHO Western Pacific Regional Office developed the *Western Pacific Regional Action Plan for Prevention and Control of Non-Communicable Diseases*, adopted in 2008. WHO is developing a new regional action plan for NCD prevention and control in its Western Pacific region for 2014-2018. Most Pacific countries now have national NCD strategies and plans in place, and there is a *WHO Pacific Framework for the Prevention and Control of Non-Communicable Diseases*. More could be done to engage the non-health sectors in these regional plans.

As has been effective in HIV, leadership and coordination mechanisms for NCDs should engage multiple stakeholders, including communities, CBOs and NGOs representing patient constituencies, the private sector and a broad range of civil society organizations. For HIV, economic arguments were used to highlight the potential for companies and industries to incur losses due to mounting HIV-related illnesses and deaths among people of working age. These arguments worked well to engage the private sector and sectors of government such as those responsible for industry and agriculture. NCD responses could also engage sectors beyond health by highlighting adverse economic impacts of ill health and deaths on specific industries and communities.

A comprehensive approach to NCDs requires coordination of multiple sectors, including health, finance, foreign affairs, law and justice, trade and education. NCD responses should link across sectors, ensuring health ministry programmes are supported and enabled by coordinated action from other relevant government agencies. The

253 Anderson I. (2012). *The economic costs of Non-Communicable Diseases in the Pacific Islands: a rapid stocktake of the situation in Samoa, Tonga and Vanuatu*, Washington DC & Sydney: World Bank.

254 Pacific Islands Forum Secretariat (2011). *MDG Tracking Report 2011*, Suva: PIFS, p.56.

255 UN General Assembly (2011). *Political Declaration of the High-Level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases*, Document A/66/L.1.

256 Sixty-Sixth World Health Assembly, *Provisional agenda item 13.2 Draft action plan for the prevention and control of noncommunicable diseases 2013–2020 Report by the Secretariat*.

257 WHO Regional Committee for the Western Pacific Region (2011). *Resolution WPR/RC62.R2 on Expanding and Intensifying Non Communicable Disease Prevention and Control in the Region*.

multisectoral HIV response has worked effectively when the health sector has reached out to other sectors and sought to understand the goals of these other sectors, so that sectors can coordinate their strategies, plans and activities to achieve mutual goals. Working across sectors and coming out of the comfort zones of the health sector is an important lesson for NCD programmes.

While it is important to engage these other sectors in a coordinated response, the central role of the ministry of health should not be undermined. Care needs to be exercised in establishing multisectoral coordinating bodies for NCDs that are fit for purpose, and able to prioritize resource allocations according to an identified strategy and attention to the specific local and national context. Accountability mechanisms have been of key importance to successful HIV responses, including monitoring and reporting of progress against specific commitments and time-bound targets at national and global levels.²⁵⁸ In 2012, the World Health Assembly approved a target of reducing mortality from NCDs by 25 percent by 2025. Appropriate country and regional level targets and accountability mechanisms are also required. For the HIV response, countries are required to submit annual 'global AIDS response progress reports', which report progress against global targets. These are an important resource for transparency and accountability, nationally and globally. A similar system would be beneficial for NCDs.

National and regional NCD strategies can address factors such as the role of political, business and civil society leadership; advocacy on the legal, regulatory, policy and the human rights environment for NCD responses; education and prevention strategies including the role of media; policy on access to medicines; empowering communities to participate in NCD advocacy; and collaborative and accountable national governance mechanisms.

The experiences of the Commission on AIDS in Asia and the Commission on AIDS in the Pacific demonstrate the value of independent expert panels in generating evidence for advocacy and leadership on sensitive policy issues. For NCDs, governments may also benefit from seeking advice from commissions of independent experts to assess the evidence base for potentially controversial policy actions (such as restrictions on the tobacco and alcohol industries). This may be helpful to secure political and community support for controversial policies.

6.3 Community mobilization and NCD activism

A participatory activist movement is required to build on the momentum generated by the NCD Political Declaration and to work cooperatively with global and national institutions, as has been the case with HIV activists.²⁵⁹ However, community mobilization around an activist agenda may be more challenging for NCDs than HIV. NCD advocacy tends to be led by medical specialists and disease-oriented NGOs and institutions, rather than affected communities. NCD responses would be strengthened by participation of affected communities. This aspiration is reflected in the WHO NCD Action Plan, which states:

People and communities should be empowered and involved in activities for the prevention and control of non-communicable diseases, including advocacy, policy, planning, legislation, service provision, monitoring, research and evaluation.²⁶⁰

A representative of the International Diabetes Foundation has observed that patient advocacy for NCDs is not as well developed as for HIV:

The HIV response has been successful because of the multi-stakeholder partnership. It has been a partnership between different donors, different organisations – but the most important thing has been the advocacy of the patient organisations. Unfortunately in a lot of developing countries the patient organisations for hypertension or diabetes are very weak structurally. They are not able to do advocacy, because they have yet to become

258 Piot P. (2012). 'Learning from AIDS: Responding to Non-Communicable Diseases', *Huffington Post*, 20 September 2012.

259 *Responding to the Asia Pacific NCD crisis*, http://www.menzieshealthpolicy.edu.au/other_tops/pdfs_events/beagleholeabstract.pdf

260 WHO (2013). *Draft action plan for the prevention and control of noncommunicable diseases 2013–2020*, 6 May 2013, 66/9, Paper for 66th World Health Assembly, para 18.

organised. And that seems to be the major shortfall why the NCD agenda is not going forward in developing countries.²⁶¹

HIV responses have been characterized by activism led by organized and politically mobilized communities of people living with HIV, sex workers, people who inject drugs, MSM and transgender people. Members of these populations often have a strong sense of identity related to membership of these communities, which is often absent in the case of people with specific NCDs. The impact of HIV on specific communities has meant that HIV activism and empowerment approaches have built on the existing community and political networks of these subpopulations. HIV funding has supported community networks to play an advocacy role at national, regional and global levels. For HIV, certain populations have been motivated by a broader rights agenda to become politically engaged. Importantly, progress in addressing HIV has been linked to progress in securing civil and political rights for marginalized populations, such as anti-discrimination protections and decriminalization.

Community-based advocacy movements focused on NCDs are rare, particularly in low and middle-income countries. NCDs include a diverse range of conditions, many of which impact across whole societies. It is often more difficult for NCDs than HIV to define specific political constituencies and networks motivated to take ownership of a comprehensive NCD agenda and participate in the governance of policies and programmes. Historically, the civil society advocacy response to NCDs was first associated with health-focused NGOs, such as the NCD Alliance organizations focusing on diseases such as cancer, lung diseases, heart disease and diabetes. As awareness of NCDs has grown, broader ownership of NCD advocacy agendas has occurred among mainstream consumer associations and environmental groups. Understanding of the links between NCDs and consumption-based growth models, and globalization of food and agricultural production models has enabled NCD advocacy to find support beyond groups with a single disease focus. Encouraging broader ownership of the advocacy agenda among consumer and environment groups may be key to growing a community-based NCD movement.

An example of an effective NGO advocacy initiative in the NCD field is the Southeast Asia Tobacco Control Alliance, which encourages regional collaboration, advocates for policy change, and provides technical assistance to tobacco control efforts in Cambodia, Indonesia, Lao PDR, the Philippines and Viet Nam. The Alliance aims to demonstrate the effectiveness of tobacco taxes and graphic warnings on cigarette packaging and to build support for more expansive policy change. The Alliance includes representatives from government, WHO and leading tobacco control NGOs.²⁶²

The NCD advocacy movement is in its early stages, and it may be possible over time to institutionalize greater community involvement. The International Development Law Organization (IDLO) has argued that community engagement must be measured within new NCD reporting frameworks:

The NCD indicators should also measure the participation of civil society in the national response. The HIV/AIDS reporting guidelines measure both process (e.g. inclusion of affected communities in decision making about the national response) as well as epidemiological and program indicators. NCDs, like HIV, are not casually transmitted. Therefore the focus must include voluntary behavior change within an enabling legal and policy environment. Civil society must be appropriately involved in every aspect of the response, including monitoring.²⁶³

6.4 Centrality of human rights and social justice to NCDs

Tackling NCDs calls for a paradigm shift, from addressing each NCD separately to collectively addressing a cluster of diseases in an integrated manner, and from using a biomedical approach to a public health and human rights-

261 Ramaiya, (2011). *Discussion on AIDS MAP Theo Smart, Coverage of meeting on HIV and Health Systems: Leveraging HIV scale-up to Strengthen Chronic Disease Services*, <http://www.aidsmap.com>

262 Southeast Asia Tobacco Control Alliance, See: <http://www.seatco.org>.

263 WHO Discussion Paper, *Global Monitoring Framework for NCDs* (dated 22 March 2012). Submission by the International Development Law Organization.

based approach guided by the principles of universal access and social justice.²⁶⁴ Like HIV, NCDs call for a 'social determinants of health' approach, given the need to address the socio-structural factors that contribute to NCDs, including the role of consumption-based growth in providing the context for unhealthy dietary and lifestyle changes linked to many NCDs. The NCD Alliance emphasizes how a human rights-based approach draws attention to the social determinants of health:

NCDs are affected by a number of underlying social, economic, cultural and political determinants of health and structural barriers. A human rights-based approach provides a practical way to address the social determinants of NCDs, including poverty, gender equality, ethnicity, economic exclusion, non-discrimination and other socially determined barriers.²⁶⁵

An editorial of the *Health and Human Rights Journal* describes the intersection of health and human rights in terms of the impact of poverty:

After the advent of effective antiretroviral medicines, HIV/AIDS became a paradigmatic example of access to care as a human rights issue because of the strongly patterned outcomes in poor and wealthy communities. Today, the burden of NCDs displays in sharp relief the social fissures that demarcate the rights of different populations. In countries that are deeply unequal, such as India, the poorest communities suffer from both infectious and non-infectious diseases driven by the same fundamental causes. For example, patients with tuberculosis and with diabetes among the poorest people are both likely to be undernourished. In fact, a patient with diabetes in a poor community may have more in common with a tuberculosis patient in that community than with another diabetes patient living in an urban area, in terms of determinants, manifestations, dilemmas in therapy, and in outcomes.²⁶⁶

Helena Nygren-Krug (Health and Human Rights Advisor for WHO) analyzed the application of a human rights framework to NCDs, and concluded:

Analysing and addressing NCDs from a human rights perspective brings to the forefront the most challenging and pressing issues in public health, such as how to ensure a more intersectoral and coherent response to address upstream determinants of health; how far the private sector can be held responsible and accountable; the nature and scope of state obligations under international law; the extent of the role of the state in protecting public health versus allowing individual freedom and choice; and how to empower people affected by ill-health to demand action from powerful actors to promote and protect health.²⁶⁷

Grover and Knaul have emphasized the importance of a focus on social justice and structural inequalities rather than only individual behaviours in addressing NCDs:

Advocates need to reframe the NCD debate into an equity imperative and a key lever for economic, social and human development ... To be successful we need to accept that the majority of people who suffer from NCDs have little choice when it comes to determining their health outcomes. The argument should not be about who is to blame – this only reduces our space of action to an endless debate about prevention versus treatment. Rather than pigeonholing global and national policies against NCDs into the all-or-nothing debate of focusing exclusively on behavioral change, our actions must be broad and respond to the basic right of all individuals everywhere to have the capabilities to live a healthy life.²⁶⁸

Like HIV, the health burdens of NCDs are often greatest on poor and marginalized communities. Globalization and increasing trade in processed food, sugary drinks, tobacco and alcohol can create conditions that increase health vulnerabilities of people, especially the poorest and most marginalized in society. Governance at the global, regional, national and subnational levels can play an important role in ensuring that the risk factors of

264 Narain J., Garg R., Fric A. (2011). Non-communicable diseases in the South-East Asia region: burden, strategies and opportunities. *Natl Med J India*, 24(5):280-7.

265 NCD Alliance (2011). *Non-Communicable Diseases (NCDs): The Human Rights Factor*.

266 Editors, *Health and Human Rights Journal* (2011). Intersection 2: Non-communicable diseases and global health equity, *Health and Human Rights*, 13(1).

267 Nygren-Krug H. (2011). A Human Rights-Based Approach to Non-Communicable Diseases, *Swiss Human Rights Book*, http://www.swisshumanrightsbook.com/SHRB/shrb_03_files/16_453_Nygren.pdf

268 Grover B., Knaul F. (2012). Closing the NCD Divide: A Matter of Equity and Social Justice, *The Huffington Post*, 19 September 2012.

NCDs are reduced, and that the health promoting actions are encouraged. For example, municipal authorities play an important role in providing local infrastructure and encouraging public transport facilities for a healthy environment. A social determinants of health approach also requires examination of the role of corporations involved in agriculture, pharmaceuticals, food, tobacco and other drug industries in influencing consumption patterns and the policy contexts in which these businesses operate.

Social determinants of NCDs are strongly associated with poverty and lack of development. Poorer people tend to have less access to education, health services and nutritious food. They also tend to consume more tobacco than wealthier people. Poorer people are less likely to seek out preventive services for NCDs. If they are diagnosed with an NCD they are less able to afford treatment.²⁶⁹

Parallels can be drawn between HIV and NCD-related physical disabilities and mental illnesses. Mental illnesses and disabilities are often stigmatized and misunderstood. As has been the case for HIV, disability programmes and mental health programmes benefit greatly from community mobilization, demand generation, engagement of civil society and establishment of peer educators or supporters.²⁷⁰

6.5 Priorities for an enabling legal and policy environment

Attention to the legal framework for addressing NCDs is critical for the success of NCD responses. A supportive and enabling policy and legal environment for NCD responses requires attention to the following:²⁷¹

- Taxation of tobacco and alcohol, regulation of their production and sales, and restriction of advertising and marketing. It has been argued that state regulation and market intervention are the only evidence-based mechanisms to prevent harm caused by sale and promotion of tobacco, alcohol and processed food and drink.²⁷² Subsidies for local production or healthier alternatives to hyper-processed foods can also play a role. Food-related strategies may include taxes, incentives and other measures to reduce consumption of foods that contain high amounts of sugars, salt, processed carbohydrates or saturated fats, and restrictions on marketing, labeling, advertising and sponsorship.
- Implementation of universal health insurance or other mechanisms to remove financial barriers to health care.
- Relevance of human rights law to NCDs. The human right to health guaranteed under international law and some domestic human rights laws is an important justification for government intervention to address NCDs with special attention to the most marginalized and vulnerable. However, arguments based on individual civil and political rights can also be used to justify limits on government intervention. Clarification of the appropriate role of government intervention under a human rights-based approach is an important aspect of the legislative response to NCDs.
- Assessment of the impact of trade and investment agreements on capacity to enforce laws and policies relating to selling food and drugs and limiting or facilitating access to affordable medicines for NCDs.

Trade policy is emerging as a key area of debate in efforts to strengthen policy responses to a range of health challenges including HIV and NCDs. At the international level, the 59th World Health Assembly recognized the need for governments to address this area of policy in 2006, when the Assembly passed a resolution on international trade and health.²⁷³ The Resolution identified the need for ministries of health, trade, commerce, finance and foreign affairs to work together constructively in order to ensure that the interests of trade and health are appropriately

269 De Cesare et al. (2013). Inequalities in non-communicable diseases and effective responses, *The Lancet*, 23: 381, 9866, 585–597.

270 Rabkin M., Wafaa M. (2011). Why reinvent the wheel? Leveraging the lessons of HIV scale-up to confront non-communicable diseases, *Global Public Health*, 6:3, 247–156.

271 Magnusson R., Patterson D. (2011). Role of law in global response to non-communicable diseases, *The Lancet* 378, 859–860.

272 Moodie R., Stuckler D., Monteiro C. et al. (2013). Profits and pandemics: prevention of harmful effects of tobacco, alcohol, and ultra-processed food and drink industries, *The Lancet* 23:381(9867):670–9.

273 World Health Assembly (2006). *Resolution 59.26 on international trade and health*. Geneva.

balanced and coordinated. In 2011, the Political Declaration of the UN High-Level Meeting on NCDs identified trade as one of the key areas influencing the social determinants of NCDs.²⁷⁴

Several trade agreements being negotiated by Pacific island governments are likely to impact their ability to address NCDs, including the Pacific Agreement on Closer Economic Relations (PACER Plus) being negotiated between the Pacific Island Forum countries including Australia and New Zealand, and the Economic Partnership Agreements with the European Union. For example, reductions in import taxes on unhealthy products such as fatty foods, tobacco and alcohol could lower the prices of these products, contributing to obesity, diabetes and heart disease. To examine the linkages between trade, trade agreements and NCDs, a Pacific regional workshop was convened in 2013.²⁷⁵

Low and middle-income countries need to be able to access generic medicines for NCDs rather than more expensive branded versions.²⁷⁶ The NCD Political Declaration recognizes the rights of countries to exercise the flexibilities permitted by the TRIPS Agreement that allow compulsory licensing and importation of lifesaving generic drugs. It is also essential to ensure supportive trade agreements that offer similar flexibilities and are sensitive to public health and development needs of the country.

An example of coordinated activism is the Indonesian national stakeholder consultation on the use of TRIPS flexibilities and access to affordable medicines held in 2013, which engaged a national association of cancer survivors, to create a broad coalition and social momentum to pursue better access to affordable medicines beyond HIV.²⁷⁷

International trade and investment agreements can constrain the capacity of countries to use domestic laws to regulate commodities to address health, limiting their policy space. For example, tobacco producing countries and a tobacco company are relying on trade and investment agreements to mount legal challenges to Australia's plain packaging regulation of tobacco products at the WTO and in other legal forums for resolution of trade and investment disputes (based on the Hong Kong-Australia Bilateral Investment Treaty).²⁷⁸

The Trans-Pacific Partnership (TPP) is an example of a multilateral trade agreement that could restrict the ability of governments to regulate industries that produce goods that contribute to NCDs, such as tobacco, alcohol and processed foods. Governments need to ensure that public health factors are considered when trade agreements are negotiated. Friel and colleagues summarize these concerns:

There is concern the TPP will invoke the same risks to nutrition and health as existing multilateral and free trade agreements – through tariff reductions, encouragement of foreign investment and enhanced intellectual property rights for corporations.

On the face of it, reductions in barriers to trade should increase consumer food choices and improve supply for net-food importing countries. But trade liberalisation through multilateral and free-trade agreements has traditionally resulted in disproportionately large increases in imports and domestic production of foods that are high in saturated fat, highly processed, calorie-rich and nutrient-poor. In a number of the Pacific Island nations, for instance, multilateral and regional trade agreements have undermined domestic agriculture and created a strong reliance on imports. This has led to high levels of fat consumption through cheap imports of margarine, butter, meat, chickens and canned meat.²⁷⁹

274 UN General Assembly (2011). Op cit., para 36.

275 C-POND, SPC, UNDP and WHO (2013). *Trade, Trade Agreements and Non-Communicable Diseases in the Pacific Islands*, Suva: UNDP.

276 De Cesare et al. (2013). Op cit.

277 UNDP Indonesia (2013). *National Stakeholder Consultation to Discuss Intellectual Property and the Right to Affordable life-saving Medicines*, UNDP Asia-Pacific Weekly Highlights, <http://www.snap-undp.org/WeeklyHighlights/Lists/Posts/Post.aspx?ID=277>

278 Rimmer M. (2013). Cigarettes will kill you: The High Court of Australia & plain packaging of tobacco products, *WIPO Magazine*, February 2013.

279 Friel S., Glesson D., Hattersley L. (2013). Trans Pacific Partnership puts member countries' health at risk, *The Conversation*, <http://theconversation.com/trans-pacific-partnership-puts-member-countries-health-at-risk-13711>

To respond to NCDs, governments need to be able to enforce measures on pricing, marketing, labeling, advertising, sale and distribution of unhealthy goods. The TPP has the potential to constrain the ability of governments to implement policies and laws that safeguard health and the environment.²⁸⁰

280 Gleeson D., Friel S. (2013). Emerging threats to public health from regional trade agreements, *The Lancet*, early online publication, 1 March 2013.

Applying governance lessons to child and maternal health responses

KEY MESSAGES

Child and maternal health responses require an enabling legal and policy environment for a human rights-based approach and participatory governance mechanisms that support community engagement in policy and programme development. Responses should be founded on principles of transparency, accountability, participation, non-discrimination, equity and gender equality.

Legal measures to address the social determinants of health include:

- Ratification and implementation of the *Convention on the Rights of the Child* and the *Convention on the Elimination of all forms of Discrimination Against Women*.
- National laws that place an obligation on the State to provide the services, human resources and infrastructure needed to realize the right to health of all women and children, including universal health coverage and with attention to the most vulnerable and marginalized.
- Child protection laws and laws providing rights of access to family planning, sexual health and reproductive health services.
- Legal protections from violence against women and girls.
- Laws on marketing and promotion of breast milk substitutes to prevent health harms.
- Laws and policies guaranteeing gender equality and the rights of women and girls to non-discrimination in access to health services, education and employment and that address gender discrimination affecting health outcomes, including female infanticide, discriminatory child feeding practices, gender stereotyping and restricted access to services for women and girls.
- Laws and policies that support legal and safe abortion services that are available, accessible and of good quality. Remove legal restrictions that make safe abortions and post-abortion care inaccessible especially to poor, displaced and young.

Child and maternal health would benefit from national governance mechanisms that mobilize resources, ensure a coordinated response, and facilitate cooperation between government ministries and with civil society stakeholders. Child and maternal health requires transparent and participatory governance mechanisms for policy development and planning, and country-led health plans supported by predictable and sustained investments to support functioning health systems.

Mechanisms are required to respond to human rights violations against women and children that affect their access to health services. Governments should actively engage with women and girls to ensure their participation in designing, implementing and evaluating maternal health and violence protection policies and programmes. Health data should be disaggregated by sex and age to detect underlying inequality. National human rights institutions and consumer organizations can play important roles in ensuring transparent and accountable responses.

7.1 Slow progress towards child and maternal health MDGs

MDG 4 aims to reduce child deaths by two-thirds between 1990 and 2015. MDG 5 has the target of reducing maternal deaths by three-quarters over the same period. Many countries in Asia and Pacific will not achieve these goals and targets by 2015. Of the countries in Asia and the Pacific for which data are available, most are 'off track' in reaching child and maternal health MDG targets (see Tables 3 and 4).

For the region as a whole, there has been progress. During the period 1990-2011, the under-five mortality rate decreased by 50 percent, from 83 deaths per 1,000 live births in 1990 to 42 deaths per 1,000 live births in 2011. The infant mortality rate dropped from 61 deaths per 1,000 live births in 1990 to 33 deaths per 1,000 live births in 2011. Yet in 2011, 2.4 million infants and 3.0 million children under five died in the Asia-Pacific region.

As of 2011, Afghanistan still had the highest under-five mortality rate (101), followed by Pakistan (72) and Myanmar (62).²⁸¹ In the Pacific, although most countries recorded a decline in child mortality, progress on child health is variable and uneven across the Pacific island countries. Most Pacific Island Forum countries are below the global developing country child mortality target.²⁸²

The maternal mortality ratio in the Asia-Pacific region declined by more than 50 percent during the past two decades, from 379 deaths per 100,000 live births in 1990 to 146 deaths per 100,000 live births in 2010. Nevertheless, over 100,000 maternal deaths in the region occurred in 2012. The difference in the maternal mortality ratios between low-income and high-income countries was extreme: 260 maternal deaths per 100,000 live births in low-income countries; 8 maternal deaths per 100,000 live births in high-income countries.²⁸³

Maternal mortality is closely linked with antenatal care. In 2010, approximately 14 million women in the region did not have a single pregnancy-related antenatal care visit, and 22 million births were not attended by skilled health personnel (19 million of these births occurred in South and South-West Asia).²⁸⁴ High levels of maternal mortality occur because too few births take place in the presence of skilled attendants. With the exception of Bhutan and Indonesia, there has been relatively little progress. This situation is of particular concern in Bangladesh and Afghanistan. Although these countries have been making progress, skilled professionals attend less than one birth in four.²⁸⁵ Maternal mortality could be substantially reduced if all mothers had access to antenatal care. The region as a whole, however, has been slow to achieve universal access.

Maternal and child health indicators for the Pacific have begun to plateau in many countries since 2000. Women continue to die of preventable and treatable complications in pregnancy and childbirth, often because of delays in receiving care. Lack of regular antenatal care is a contributing factor. In some Pacific island countries, such as Fiji and Kiribati, maternal mortality rates have increased in recent years. Most of the child deaths in the Pacific occur at less than one year old and the most common causes of child mortality (diarrhoeal disease and pneumonia) are preventable. In many countries, child mortality rates have not improved since 2000. In some cases, they have deteriorated (Fiji, Tonga and Tuvalu).²⁸⁶

281 UNESCAP (2012). *Statistical Yearbook for Asia and the Pacific 2012*. Bangkok: UNESCAP, p.viii.

282 Pacific Islands Forum (2011). *MDG Pacific Regional Tracking Report*, Suva: Pacific Islands Forum.

283 UNESCAP (2012). Op cit., p.viii.

284 Ibid.

285 UNESCAP, ADB, UNDP (2012). Op cit., p.15.

286 AusAID (2011), *Supporting health in the Pacific, A Guidance note for AusAID staff*, Canberra: AusAID.

Table 3: Progress toward the MDG 4 target for under-5 mortality rate (2012)

Early achievers	
Bangladesh	Maldives
China, People's Rep. of	Mongolia
Lao PDR	Timor-Leste
On track	
Armenia	Nepal
Bhutan	Thailand
Indonesia	Vanuatu
Slow progress	
Afghanistan	Myanmar
Azerbaijan	Pakistan
Brunei Darussalam	Palau
Cambodia	Papua New Guinea
Cook Islands	Philippines
Fiji	Samoa
Georgia	Solomon Islands
India	Sri Lanka
Kazakhstan	Tajikistan
Kiribati	Tonga
Korea, Rep. of	Turkmenistan
Kyrgyz Rep.	Tuvalu
Marshall Islands	Uzbekistan
Micronesia, Fed. States of	Viet Nam
No progress/regressing	
Nauru	

Source: ADB (2013). *Key indicators for Asia and the Pacific*. Manila: ADB.**Table 4: Progress towards the MDG 5 target to reduce the maternal mortality ratio (2012)**

Early achievers	
Bhutan	Nepal
Maldives	Viet Nam
On track	
Bangladesh	Lao PDR
Cambodia	Taipei, China
China, People's Rep. of	Timor-Leste
Slow progress	
Afghanistan	Myanmar
Armenia	Pakistan
Azerbaijan	Papua New Guinea
Brunei Darussalam	Philippines
Fiji	Samoa
Georgia	Singapore
India	Solomon Islands
Indonesia	Sri Lanka
Kazakhstan	Tajikistan
Korea, Rep. of	Thailand
Kyrgyz Rep.	Turkmenistan
Malaysia	Uzbekistan
Micronesia, Fed. States of	Vanuatu
Mongolia	
No progress/regressing	
Tonga	

Source: ADB (2013). *Key indicators for Asia and the Pacific*. Manila: ADB.

The Asia-Pacific Regional MDG Report 2011/12 recommended the following approaches to improve child and maternal health:

A robust health system focuses on the needs of various groups along the continuum of care. Health systems can, for example, reduce inequities in maternal and under-5 mortality by adopting a lifecycle approach – improving access and addressing the vulnerabilities and risks that women, adolescents and children face throughout their lives. If mothers face emergencies during pregnancy and birth, for example, it is vital that they have timely support from skilled attendants, and if necessary from doctors who can treat obstetric complications. Other simple and cost-effective measures could reduce child deaths by around two thirds. These include implementing comprehensive breastfeeding programmes (early initiation of breastfeeding and exclusive breastfeeding in particular), controlling vector-borne diseases, and strengthening immunization programmes.

Governments also need to take a rights-based approach to the laws, policies, social norms, customs and practices that impoverish and disempower women. This should involve specific action against gender-based violence.²⁸⁷

7.2 Human rights-based approaches

An approach to child and maternal health informed by principles of democratic governance requires an enabling legal and policy environment for a human rights-based approach and participatory responses that support community engagement in policy and programme development. It requires policies and programmes to be founded on principles of equity and gender equality, transparency, accountability, participation and non-discrimination.

A human rights-based approach requires ensuring women and children (particularly those from vulnerable and marginalized groups) have access to free or affordable quality primary healthcare. An enabling legal and policy environment is critically important to support effective child and maternal health programmes. At the international level there is increasing recognition of child and maternal health as human rights issues, consistent with the *Convention of the Rights of the Child* (CRC)(1989) and the *Convention on the Elimination of All Forms of Discrimination Against Women* (CEDAW)(1979).

In 2009, the Human Rights Council adopted a *Resolution on Preventable maternal mortality and morbidity and human rights*. The Resolution recognizes that:

...preventable maternal mortality and morbidity is a health, development and human rights challenge that also requires the effective promotion and protection of the human rights of women and girls, in particular their rights to life, to be equal in dignity, to education, to be free to seek, receive and impart information, to enjoy the benefits of scientific progress, to freedom from discrimination, and to enjoy the highest attainable standard of physical and mental health, including sexual and reproductive health.²⁸⁸

General comment No. 15 (2013) of the Committee on the Rights of the Child provides detailed guidance on a human rights-based approach to child and maternal health.²⁸⁹ For example, the Committee recommends the following legislative action for fulfillment of children's right to health:

National laws should place a statutory obligation on the State to provide the services, programmes, human resources and infrastructure needed to realize children's right to health and provide a statutory entitlement to essential, child sensitive, quality health and related services for pregnant women and children irrespective of their ability to pay. Laws should be reviewed to assess any potential discriminatory effect or impediment to

287 UNESCAP, ADB, UNDP (2012). Op cit., p.4.

288 Human Rights Council (2009). *Resolution 11/8. Preventable maternal mortality and morbidity and human rights*. Human Rights Council, 11th Session. 16 June 2009, A/HRC/11/37.

289 Committee on the Rights of the Child (2013). *General comment No. 15 (2013) of the Committee on the Rights of the Child on the right of the child to the enjoyment of the highest attainable standard of health (art. 24)*. 17 April 2013, CRC/C/GC/15.

realizing children's right to health and repealed where required. Where necessary, international agencies and donors should provide development aid and technical assistance for such legal reforms.

Legislation should fulfil a number of additional functions in the realization of children's right to health by defining the scope of the right and recognizing children as rights-holders; clarifying the roles and responsibilities of all duty bearers; clarifying what services children, pregnant women and mothers are entitled to claim; and regulating services and medications to ensure that they are of good quality and cause no harm. States must ensure that adequate legislative and other safeguards exist to protect and promote the work of human rights defenders working on children's right to health.²⁹⁰

Social protection interventions are also important including ensuring health insurance or other measures to support universal health coverage, paid parental leave and other social security benefits. Given the high rates of pregnancy among adolescents and the associated risks of morbidity and mortality, services should address the specific sexual and reproductive health needs of adolescents, including family planning and safe abortion services. Discrimination based on adolescent pregnancy, such as expulsion from schools, should be prohibited, and opportunities for continuous education should be ensured.²⁹¹

An agenda for human rights-based approach to maternal and child health requires actions by governments to tackle the underlying social determinants of health through legal and policy measures. These should include:

- Ratification of key human rights treaties such as the *Convention on the Rights of the Child* and the *Convention on the Elimination of all forms of Discrimination Against Women*, and implementation of these treaties through domestic health and human rights legislation.
- Introduction of comprehensive child protection laws and laws providing rights of access to family planning, sexual health and reproductive health services.
- Comprehensive legal and policy responses to violence against women, including sexual assault laws and domestic or personal violence laws.
- Attention to food and drug laws (such as those governing marketing, promotion and labeling of breast milk substitutes) to prevent health harms caused by inappropriate use of products.
- Actions to address gender-based discrimination affecting a wide range of health outcomes, from female infanticide to discriminatory infant and young child feeding practices, gender stereotyping and access to services through introduction of laws and policies guaranteeing gender equality and rights to non-discrimination on the grounds of gender in provision of health services, and other areas such as education and employment.
- Introduction of laws and policies to support legal and safe abortion services that are available, accessible and of good quality, and removal of legal restrictions that contribute to making safe abortions and post-abortion care inaccessible especially to poor, displaced and young women and reinforce the stigma that abortion is an objectionable practice. Examples of restrictive laws include:²⁹²
 - Conscientious objection laws that permit health-care providers and ancillary personnel to refuse to provide abortion services, information about procedures and referrals to alternative facilities and providers.
 - Requirements of counselling and mandatory waiting periods for women seeking to terminate a pregnancy;
 - Requirements that abortions be approved by more than one health-care provider;
 - Parental and spousal consent requirements; and
 - Laws that require health-care providers to report suspected cases of illegal abortion when women present for post-abortion care, including miscarriages.

290 Committee on the Rights of the Child (2013). Op cit., p.16.

291 Ibid, p.13.

292 See: UN General Assembly (2011). *Interim report of the Special Rapporteur on the right to everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/66/254.

Hunt and De Mequita have identified three interrelated ways in which principles of equality and non-discrimination can support efforts to reduce maternal mortality:²⁹³

- a. First, these principles support prioritization of interventions that can guarantee women's enjoyment of the right to health on the basis of non-discrimination and equality. Guaranteeing the right to health on the basis of gender equality demands that States undertake measures to reduce preventable death from pregnancy and childbirth;
- b. Second, they require action to prioritise efforts towards those at risk of maternal mortality, such as women living in poverty and in rural areas or belonging to indigenous groups, and adolescent girls. They underpin efforts to assess and address why these women are particularly vulnerable to maternal mortality, such as a lack of access to necessary health services, and political and social marginalisation;
- c. Third, policies which promote non-discrimination and equality (as well as dignity, cultural sensitivity, privacy and confidentiality) in the clinical setting can improve patient-provider relationships and encourage women to seek health care.

Just as HIV activists have advocated for health rights to be accorded a higher priority than private sector profits in the context of access to medicine, health advocacy must ensure that health rights of women and children are accorded a higher priority than corporate profits in arguing for rights of universal health coverage and access to primary care. User fees and other free market approaches to health care services can undermine a rights-based approach. Priority should be given to health systems strengthening, rather than vertical programmes associated with user fees. Macroeconomic policies that reduce public spending on health services while expanding the role for the private sector in health care can further disadvantage already poor and marginalized women.²⁹⁴

7.3 Participatory national planning and coordination mechanisms

Child and maternal health would benefit from national governance mechanisms that mobilize resources and ensure a coordinated response, as has been effective in the context of HIV. For example, a national strategic plan to address child and maternal mortality could include scaling-up access to basic emergency obstetric care through strengthening of the overall health system, aligning health worker training, infrastructure development, procurement of drugs and supplies and attention to improved referral and communication systems, as well as attention to gender-based discrimination, violence protection, and the legal and policy environment.²⁹⁵

General Comment 15 of the Committee on the Rights of the Child describes national governance arrangements that would facilitate national coordination and community participation:

The Committee recommends that States establish and make use of a comprehensive and cohesive national coordinating framework on children's health, built upon the principles of the Convention, to facilitate cooperation between government ministries and different levels of government as well as interaction with civil society stakeholders, including children. Given the high number of government agencies, legislative branches and ministries working on children's health-related policies and services at different levels, the Committee recommends that the roles and responsibilities of each be clarified in the legal and regulatory framework.

...A "child health in all policies" strategy should be used, highlighting the links between children's health and its underlying determinants. Every effort should be made to remove bottlenecks that obstruct transparency, coordination, partnership and accountability in the provision of services affecting children's health.

293 Hunt P., De Mesquita J. (2007). *Reducing maternal mortality: The contribution of the right to the highest attainable standard of health*, Colchester: University of Essex.

294 de Pinho, H. (2009). On the 'rights' track: the importance of a rights-based approach to reducing maternal deaths. In A. Clapham, M. Robinson, C. Mahon & S. Jerbi (Eds.), *Realizing the right to health* (pp. 111-119). Zurich: Ruffer & Rubb, p.117.

295 Ibid.

...States should engage all sectors of society, including children, in implementation of children's right to health. The Committee recommends that such engagement include: the creation of conditions conducive to the continual growth, development and sustainability of civil society organizations, including grass-roots and community-level groups; active facilitation of their involvement in the development, implementation and evaluation of children's health policy and services; and provision of appropriate financial support or assistance in obtaining financial support.²⁹⁶

National planning for child and maternal health requires participatory governance mechanisms and country-led health plans supported by predictable and sustained investments for functioning health systems. Civil society organizations including women's and children's groups and organizations that advocate for women's and children's health should be supported to participate in policy development.

A rights-based approach (to maternal health) should be evident in the coherent workings of government, development partners, international agencies and civil society... Development of constructive accountability mechanisms that create an effective dynamic of entitlement and obligation between people and their government...requires not only the creation of spaces, both internal and external to government, for participation and engagement to occur, but also requires government to make more transparent its planning processes and priority setting criteria, and civil society to work together to translate available data into information that communities can use to hold government accountable.²⁹⁷

A rights-based approach requires formal mechanisms to hold governments accountable. It requires mechanisms that can monitor and respond to human rights violations affecting women and children's access to health services. Bodies responsible for programme development and implementation should actively engage with women and girls to ensure their participation in designing, implementing and evaluating violence protection and health policies and programmes at local, district and national levels. Health data should be disaggregated by sex and age to detect underlying discrimination and inequality. National human rights institutions and health consumer advocacy organizations can play important roles in ensuring transparent and accountable responses.

²⁹⁶ Ibid, p.20.

²⁹⁷ de Pinho, H. (2009). Op cit., p.117.

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