Setting the agenda of promoting acceptance of people living with HIV/AIDS in Hong Kong

- a strategy paper

Committee on Promoting Acceptance of People Living with HIV/AIDS, Advisory Council on AIDS, Hong Kong SAR Jan 2001 Setting the agenda of promoting acceptance of people living with HIV/AIDS in Hong Kong a strategy paper

Background

- The reasons behind the global spread of human immunodeficiency virus (HIV) infection are complex. However it is clear that nonacceptance of people living with HIV/AIDS (PLHA) hinders attempts of controlling the epidemic by exacerbating existing forms of marginalisation, discouraging individuals from testing, and engendering complacency in groups untargeted yet at risk for HIV infection¹.
- 2. The Committee on Promoting Acceptance of People Living with HIV/AIDS (CPA) was formed in late 1999 by the Hong Kong Advisory Council on AIDS in response to an external consultancy review of the local AIDS prevention and care programme². Among its terms of reference was "to recommend and coordinate strategies in enhancing understanding of HIV/AIDS and acceptance of people living with HIV/AIDS".
- 3. The CPA reviewed the situation of discrimination against PLHA and convened discussion forums for local stakeholders and experts before making its recommendations on the strategies of promoting acceptance of PLHA. It is expected that these strategies will serve three purposes: to stimulate interest and debate in the community regarding discrimination against PLHA, to catalyse the formation of a concerted effort in promoting acceptance of PLHA, and to form a

framework upon which future refinement of strategies will be based.

- 4. As a working definition, the CPA reckons that acceptance of PLHA is their being 'considered as ordinary members of the community who are accorded equality, compassion and mutual respect'. The CPA further adopts the definition of discrimination as 'any measure entailing an arbitrary distinction among persons depending on their confirmed or suspected HIV serostatus or state of health'.
- 5.Although no systematic analysis has been done in Hong Kong, isolated yet fairly regular incidents of discrimination against PLHA³ testify to its existence. The scope of such incidents also indicates that nonacceptance is pervasive in our society. As such, it calls for a multidisciplinary strategy to promote acceptance.

Avenues of advancing acceptance

6. Four avenues are identified to advance acceptance: education, legal provision, involvement of care professionals and certain stakeholders. They are deemed priority areas for action. Failing this will risk aggravation of nonacceptance toward PLHA. Sizeable overlap exists between these avenues but unique emphasis is given to each as explained below.

Education

7. There is an apparent confusion between HIV as a dreadful disease and PLHA as its sufferer deserving of compassion. This confusion is not alleviated by the low prevalence setting of HIV in Hong Kong. Human psychology also has it that risk

groups do not generally interpret themselves as such. Certain defense mechanisms are probably at play to resolve the conflict and justify continued risky behaviour.

8. Education in the context of promoting acceptance should therefore transcend the confines of medical knowledge, transmission routes, or safer sex. It entails refocussing on nondiscrimination against and acceptance of PLHA. This is not a luxury but necessity as real acceptance involves a fundamental change of cultural values, which is not achievable by laws alone.

Legal provisions

- 9. In Hong Kong, a legal infrastructure apparently protective of PLHA is in place. It is also the governmental policy to 'cultivate a sympathetic social environment which is vital to ... the humane care of affected individuals'. This infrastructure remains to be seriously tested. The Kowloon Bay Health Centre incident, frustrating as it was, did expose one major inadequacy: the Equal Opportunities Commission (EOC) was limited in its power to proceedings by aggrieved persons against named persons. The fear of public identification thus seriously inhibited aggrieved persons from lodging any complaint at all.
- 10. 'Legality' also matters in people with risk behaviours as well as those already infected with HIV. The law currently prohibits carriage of needles with drugs and therefore indirectly forbid needle exchange. This intolerance to drug users hampers efforts on effective prevention.

Involvement of care professionals

- 11. Arbitrarily defined as those involved in the provision of health care and social service to the PLHA, care professionals guard the first phase of interaction between PLHA and the community. Their attitude directly influences the welfare of PLHA, and indirectly sets an example for societal behaviour.
- 12. While exceptionalism in the provision of service to PLHA may have helped safeguard their basic rights, it has also engendered misunderstanding and aggravated nonacceptance. In its report, external consultants identified and condemned the two-tier system of infection control in hospitals, where extra precautions were practised with known HIV-infected individuals⁵.
- 13. Similarly mainstream nongovernmental organisations (NGO) have been passive in the provision of social service to of PLHA. Although it may be argued that this role is adequately played by AIDS-specific NGOs, the segregation of care is not conducive to a community-wide receptive attitude towards PLHA.

Involvement of stakeholders

- 14. Four stakeholders are identified as key contributors towards acceptance: PLHA, the media, the employer, and insurance industry.
- (a) The marginalised PLHA shy away from interaction with the community, wary of discrimination. Yet the lack of mutual understanding further nurtures nonacceptance toward them.
- (b) Beyond its role as a reflector of public attitude, the media are also powerful stakeholders in public education. They can be allies in the shaping of a new culture accepting of PLHA.

- (c) The improved life expectancy as a result of modern medicine will have to be complemented by good quality. To a large extent this is determined by access to gainful employment. Nondiscrimination in hiring policy and confidentiality is the minimum goal.
- (d) As the health care system of Hong Kong reforms itself, the insurance industry is expected to play an increasingly important role. Their attitude towards PLHA is largely unknown.

Core principles of promoting acceptance of PLHA

- 15. Four core principles shall underpin strategies toward promoting acceptance of PLHA.
- (a) The promotion of acceptance is congruent and complementary with that of human rights⁶. The very definition of acceptance includes equality which is one basic human right. Emphasis on human rights in turn enhances acceptance of people with HIV/AIDS by virtue of their empowerment.
- (b) Nondiscrimination of PLHA is necessary but not sufficient for acceptance. By the same token, efforts to this end should not be limited to anti-discrimination.
 Acceptance with the positive qualities of equality, compassion and mutual respect shall be the ultimate goal.
- (c) Acceptance of PLHA entails a change of attitude, which is a long term process.

 All efforts on acceptance should therefore be designed with sustainability as one priority. Furthermore, societal efforts should be of sufficient breadth in order to bring about what is essentially a change of cultural values and norms.
- (d) To overcome fear and misunderstanding of the public, the greater involvement of

people living with or affected by HIV/AIDS (GIPA)⁸ is essential. There are two elements in this approach: firstly, recognising the important contribution PLHA can make in the response to the epidemic, and secondly, creating space within society for their involvement and active participation in all aspects of that response

Recommended strategies

- 16. Education on HIV/AIDS should begin with the very concept of acceptance of PLHA. The effort should be broad-based, including professional training, school and civic education. It should start with a focus on the young but ultimately should involve all members of society. It should also extend beyond the conventional health partners to avoid exceptionalism.
- 17. Education with a focus on acceptance is complemented by that on human rights.
 This is especially pertinent in the education of PLHA themselves, as their empowerment will work against the forces of marginalisation.
- 18. Alliance ought to be built with various sectors of the community, including but not limited to social service and education. To jumpstart the process, discussion forums may be initiated between AIDS-specific interest groups and mainstream NGOs to not only promote mutual understanding and future cooperation, but also to provide a model upon which such alliance could be built.
- 19. The establishment of a central repository of education materials on promoting

- acceptance of PLHA is cost-effective, at least in the initial phase. Thereafter this 'backbone' may be supplemented by parallel efforts of other interested parties.
- 20. HIV/AIDS related facilities are a sensitive issue in society. Good liaison in the early planning stage of such facilities will be the key to acceptance. Nevertheless, there should be zero tolerance to discrimination.
- 21. To protect the confidentiality of PLHA, the Committee is of the view that the EOC should be able to "seek declaratory and/or injunctive relief in its own name, in respect of all unlawful acts under the antidiscrimination laws". The Committee also recommends that alternative means of dispute resolution such as the involvement of mediators should be explored in matters related to PLHA.
- 22. Laws relevant to HIV and PLHA have to be continually reviewed, with a view to timely response to the epidemic and needs of PLHA. In this context laws governing the possession of illicit drugs are in conflict with the harm reduction approach in general and the needle exchange programme in particular. It is advisable that these laws be reexamined. The Committee reiterates its support of the harm reduction approach which is conducive not only to HIV control but acceptance of PLHA and some marginalised groups.
- 23. Acceptance of PLHA among care professionals shall begin with a regulatory framework. In the case of the medical profession, the Hong Kong Medical Council, Hospital Authority/Hong Kong Medical Association, and individual medical institutions shall establish appropriate ethical codes, guidelines and protocols respectively. The same hierarchy will apply to other professions,

including but not limited to social service workers, nurses and other allied health disciplines.

- 24. It is important to bring home to the business community that acceptance of PLHA is in line with their interests. In fact recruitment of employers in the prevention and care of HIV will constitute a potent force for change¹⁰.
- 25. The effective but costly health care of HIV/AIDS highlights the importance of assuring access. In light of impending health care reforms, it is therefore important that acceptance of PLHA among the insurance industry should be studied to contribute to future strategies towards the equitable treatment of PLHA.
- 26. Acceptance of PLHA is facilitated by implementation of the principle of GIPA in which PLHA shall be involved in all levels, from being a target, through contributor, implementer, to ultimately decision maker. Successful GIPA will be one testimony to acceptance of PLHA in a community. To this end, it is important to develop effective means toward their empowerment in terms of communication skills, knowledge in HIV, job-specific training, and skills for organising and conducting policy dialogue¹¹.
- 27. The media are important stakeholders because of their significant impact on public opinion. It is proposed that a three-pronged strategy of networking, education and persuasion be adopted to inculcate a sense of responsibility as a short term goal.

28. The level of acceptance should be monitored by a process of benchmarking and periodic assessment. In this connection, sustainability and consistency are most important. Indicators that are amenable to measurement include legal rights of PLHA, the placement of HIV/AIDS in a relative scale of acceptance, and the social distance accorded to PLHA. The Committee itself shall also contribute to this monitoring process by examining and responding in a timely fashion to individual events in the community that are damaging to acceptance of PLHA.

References

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² External Review Team for the Advisory Council on AIDS (1998). Moving ahead together - expanding Hong Kong's response to AIDS.

³ Mak H (2000). Gaining community acceptance of HIV/ADS treatment facilities. XIII International AIDS Conference. Abstract MoPeE2925

⁴ Secretary for Health and Welfare Bureau in the Adjournment Debate of the Legislative Council on 10 Feb 1993

⁵ External Review Team for the Advisory Council on AIDS (1998). Moving ahead together - expanding Hong Kong's response to AIDS. P 13

⁶ UNAIDS & United Nations High Office Commissioner (1999). HIV/AIDS and Human Rights International Guidelines. Second International Consultation on HIV/AIDS and Human Rights.

⁷ The Synergy Project, United States Agency for International Development (1998). Discussion papers on HIV/AIDS care and support – human rights and HIV/AIDS.

⁸ Declaration of the Paris AIDS Summit (Section IV, Paragraph 1), available at http://www.unaids.org/whatsnew/conferences/summit

⁹ Equal Opportunities Commission (1999). Report on case study of Kowloon bay Health Centre.

¹⁰ The Conference Board (1997). Corporate response to HIV/AIDS. A research report. Report no. 1186-97-RR.

¹¹ UNAIDS Best Practice Collection (1999). From principle to practice, greater involvement of people living with or affected by HIV/AIDS (GIPA).

About the Committee on Promoting Acceptance of People Living with HIV/AIDS

The Committee on Promoting Acceptance of People Living with HIV/AIDS (CPA) is a new committee formed under the fourth term of ACA. It is responsible for coordinating and recommending strategies for enhancing acceptance for people living with HIV/AIDS. It also works towards creating an environment of acceptance through community mobilization, conducting studies and making recommendations accordingly.

CPA has the following terms of reference:

- (a) To recommend and coordinate strategies towards promoting understanding of HIV/AIDS and acceptance of people living with HIV/AIDS;
- (b) To recommend to policy makers measures conducive to acceptance of people living with HIV/AIDS;
- (c) To mobilize the wider community in creating an environment of acceptance for people living with HIV/AIDS;
- (d) To examine legal and ethical issues of HIV/AIDS and their impacts on societal acceptance and make recommendations to the Advisory Council on AIDS; and
- (e) To review steps taken pursuant to recommendations made by the Committee and to carry out functions that ACA may delegate to the Committee.

Membership

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