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HIV in the Caribbean: Importance of Awareness and Stigma for People and Populations
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“If there is one thing that we have learned in the past two decades of this epidemic, it is that in the world of AIDS, silence is death”

This is how the Secretary General of the United Nations, Mr. Kofi Annan spoke of the need for the media to play an active and aggressive role in the fight against HIV/AIDS as he launched the Global Media AIDS Initiative 2 years ago. We must thank the Kaiser Family Foundation for the critical role it is playing in giving substance to the initiative and engaging the media so that there should be no more silence about this epidemic.

I believe that the silence we must break is that related to people and also that related to populations or the environment in which people as individuals move and behave. When I speak to students about public health and its challenges, I often refer to what is for me one of the most critical papers published in the history of epidemiology and contains a concept that must rank in importance with that of the great discoveries of modern medicine. It is a classic paper by Geoffrey Rose who illuminated clearly the difference in approaches to the health or illness of individuals and the needed changes at the social level that are necessary if one seeks to address the problems in a society or population that lead to individual illness. This is a fundamental concept that is seminal and applicable to the situation of HIV/AIDS in the Caribbean and very germane to the role of the media in controlling this epidemic.

The Caribbean Heads of Government have accorded the media the role of social partner, along with the public and private sectors, civil society and the trade unions. They did not spell out precisely the role of these partners and left us to intuit them, perhaps in relation to the different problems with which the society has to deal at a particular time. But I believe that the essential role of a partner is to share and in this case, share in the measures needed to improve society. These are several, but in essence they all boil down to the ways to improve the human condition and clearly I believe that health is one of these.

I have been an enthusiastic advocate for closer links between the Caribbean media and public health for many years and I recall with pleasure their active participation in developing The Caribbean Charter on Health Promotion which I launched in Port-of Spain

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some 13 years ago. Much has changed since that time. We are much more sensitive to the magnitude and gravity of the HIV/AIDS epidemic and certainly more conscious of the urgency to come to grips with it. We have seen the Heads of Government assume strong leadership, we have witnessed the emergence of another partnership to address the epidemic—the Pan Caribbean Partnership against HIV/AIDS and we are now even more conscious of the nature and essential components of the response needed.

All the social partners can play a role in the response, but the media have a special role that most of the other social partners cannot play. By your very nature you have the capacity to facilitate the sharing of information that the other partners do not possess. Indeed, without you the other partners cannot function optimally as they will not be able to disseminate the data which they produce or the views they hold. The broadcast media is even more special in that they have a greater reach and by their very nature can transmit the kinds of images that make the issues more personal and alive.

How does this translate into a role in HIV/AIDS? It implies both internal and external responsibilities. This internal responsibility was addressed very well in the recent inaugural meeting of the Caribbean Business Coalition against HIV/AIDS where it was pointed out that all businesses had the responsibility to ensure that they adopted good workplace practices with regard to HIV. But it is the external role that I wish to address in more detail-how do you use your installed capacity and expertise to help to break the silence and control the epidemic.

I understand that the leadership of the Global Media AIDS Initiative has identified four priorities-global engagement, maximizing impact, connecting resources and deepening commitment. I cannot speak to all of these and the extent to which they are all being developed, but the one that struck me most forcibly is that of maximizing impact. How can the media use its capacities to maximize the impact of the programs we have in place and how can it serve through its external role to remove some of the barriers that prevent us from realizing the most from our efforts?

The information that the media disseminate and share is essentially about the nature of the problem and its solution. Several studies show that the media are the prime source of information on AIDS. But there is still lack of awareness at high levels about the size of the problem. I was intrigued to find from a survey done of some key business executives for DFID a few years ago that many of them had very vague notions about the epidemic and the prospects for the control. They knew that the epidemic was serious, but they had rather imprecise ideas about its size, sometimes overestimating the numbers affected by an order of magnitude. While it may be said that it is better to overestimate than to underestimate the problem, both are dangerous. Overestimation for one thing makes it difficult to show progress since the basis for comparison is inaccurate.

My greater concern in the context of maximizing impact is related to optimizing the solutions available. I believe that the first of these approaches is to popularize the concept of the three ones that has been agreed upon by all the major actors in HIV/AIDS and articulated so well by Peter Piot-that there should be one national action framework, one

national coordinating authority and one system of monitoring and evaluation. The media can and should inform the public as to the status of these at the national level and Barbados is a shining example of the success in addressing the epidemic when these are in place.

But the major role that our media can play is in helping to remove those social barriers that impede the optimal delivery of the programs and jeopardize any success. And here I refer again to Geoffrey Rose's distinction between the individual approach and the attention to the population aspect of the epidemic which by definition affects groups of people. Considerable attention has been given to the individual in the efforts to control the epidemic. These are all laudable and highly desirable. HIV/AIDS has been placed among those diseases that are related to individual life style and tremendous effort has been expended in convincing individuals to modify their behavior. There is no doubt that if this were one hundred percent effective we would succeed in controlling the epidemic.

I sometimes draw the analogy with the cardiovascular diseases which together with HIV/AIDS represent the major health challenges for the Caribbean at this time. We know that the main risk factors for cardiovascular disease include blood pressure, blood lipids, smoking and overweight. As we have sought to develop measures to control these risk factors we appreciate we cannot depend only on individual will. There must be interventions at the population level as well. It is possible to engineer society so that it takes in less salt thus reducing the prevalence of high blood pressure and consumes diets that are lower in harmful fats. Society can be engineered to reduce the barriers to the intake of a healthy diet and facilitate an increase in physical activity. These are factors that must be modified at the societal or population level in order to control the epidemic. It is probably true that no epidemic has been controlled by paying attention solely and purely to the change of individual behavior. Epidemiologists always cite the example of cholera in mid nineteenth century London when the epidemic was controlled not by enjoining the worthy burghers to be cleaner, but by removing the handle of the pump of the well that was responsible for providing the infected water which spread the disease.

Thus I see a prime role for the media in the societal modification which must take place if we are going to control the epidemic. The first of the societal attitudes that we need to change is one related to the general perception that the disease is immediately fatal and is essentially a sudden kiss of death. The successful treatment of persons with HIV/AIDS and the restoration to productive life is a story that has to be told over and over. There is no media like the broadcast media in showing the transformation of the lives of persons with AIDS.

But the second and perhaps more important population level change we need is that related to the stigma and discrimination that are attached to HIV/AIDS. There is the stigma against persons who are HIV positive or are even thought to be HIV positive, with much of it related to the belief that AIDS is a disease of immoral and perverted "others" and not a problem that affects society as a whole. There is the stigma against the individuals and groups thought to be the ones responsible for spreading the disease. I need not dilate here on the consequences of the stigma and discrimination that attend HIV/AIDS-how they stop persons from being tested, less they discover that they are HIV positive-how they prevent

HIV positive persons from going for care and treatment-how they drive the epidemic underground and inhibit the establishment of an adequate public health response. The issue is how to address and change it.

As the declaration of Commitment on HIV/AIDS adopted at the United Nations five years ago stated

“Stigma, silence, discrimination and denial as well as lack of confidentiality, undermine prevention, care and treatment efforts and increase the impact of the epidemic on individuals, families, communities and nations”.

Apart from those who suffer from AIDS, the groups that are the object of most stigma and discrimination are homosexuals and commercial sex workers. Everyone here knows of the intensity of the homophobia which is present in our societies and the fact that persons have been persecuted to the point of being murdered because they were, or were thought to be homosexuals. It is no comfort that history is replete with examples of groups of persons who were persecuted because they were thought to be responsible for spreading disease. In the fourteenth century when the Black Death killed one quarter of the population of Europe, Jews were persecuted because it was believed that they were responsible for spreading the dreaded plague.

However, I believe that first, there has to be an understanding at the highest level in the media of the fundamental nature of stigma in general and that which attends HIV/AIDS in particular. It is the gatekeepers in the media that have to be convinced of the nature of stigma and discrimination, and the possibility of shaping rather than only following societal norms if they are going to commit their resources to achieving the impact that is one of the objectives of the Global Media AIDS Initiative. It is homophobia that prevents any attempt to modify the laws that still make homosexual behavior a criminal activity in almost all of the Caribbean countries and the chances of decriminalization or legislative change are slim as long as popular opinion runs so strongly in one direction.

What can the media, especially the broadcast media do to address the problem at the level of the population? First, there is the responsibility to provide accurate data in the format that your skills and knowledge of your craft dictate to be the most appropriate. I have read of programs as diverse as those presenting AIDS in a Sesame Street type of program and I have read of the need to mainstream HIV/AIDS into regular programming. I do not have the expertise to advise on the instrumental approach, or the kind of research to produce pilot programs suitable for the Caribbean audience. What I do urge on you however is to accept a role in changing the social norms that provide the environment which prevents control of the epidemic.

I am not so naïve as to believe that any suggestion of change in an area as sensitive as this will not draw vigorous opposition. I am not insensitive to the legitimate moral aspects of much of the debate swirling around the groups that bear the major brunt of

stigma. I would only ask that you facilitate the dialogue about the inappropriateness of conflating morality and criminality.

Finally, there is one aspect of the social environment that must be addressed vigorously if we wish to control the epidemic. I refer to gender discrimination-the power inequality between the sexes that makes women particularly vulnerable. This is not an issue that is ventilated adequately in our media.

Let me close by thanking the Kaiser Family Foundation for the tremendous effort it has made to give life to the Initiative. They have been the catalyst for the unprecedented global media response to break the silence. I have learnt of initiatives in Russia and the Ukraine, in India, Asia and the United states. I was particularly taken by the program in Africa in convening along with the Nelson Mandela Foundation and other sponsors the first African Broadcast Media Leaders Summit on HIV/AIDS which produced its own Declaration. One of the key outcomes of that Summit was the formation of the African Broadcast Media Partnership against HIV/AIDS to promote the objectives and commitments contained in the Declaration and to facilitate greater collaboration in HIV/AIDS communication and programming.

I trust that this Caribbean Summit will be equally productive in terms of the commitments and the partnerships needed to address the epidemic. I trust you powerful media executives will not be among those people in Simon and Garfunkel's famous "Sound of Silence".

People talking without speaking
People hearing without listening
People writing songs that voices never share
And no one dared
Disturb the sound of silence.

I thank you.