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**The role of civil society in the prevention and control of
noncommunicable diseases (NCDs)**

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First let me thank you for the invitation to participate in this important conference and see at first hand the progress being made in this Region in relation to the prevention and control of NCDs. I wish to congratulate the Regional Director and my colleague and friend Dr. Gauden Galea for their dedication and leadership and also the Ministers for their keen attention to the need to address this problem. There are several examples of relevant approaches from this region which merit emulation.

The increase in numbers and influence of civil society is one of the most impressive social phenomena of our time and I believe that this growth of its organizations and movements is one of the manifestations of the heightened interest of the citizens in the many and varied affairs of state. Civil society is really an umbrella term and in essence can be thought of as the various modalities of organized citizen action. The association of citizens for special interests or to provide a service not provided by the state is a very old phenomenon. This latter function is still in evidence in many parts of the world and contributes significantly to health care for example, but citizen action through civil society has gained more prominence and visibility in about the last half century, in part because of impatience with formal government action and also the desire of citizens to influence public policy not necessarily through the traditional democratic process. This is sometimes seen as a threat to the traditional democratic process, but those civil society organizations with which I am familiar take the view that their focus is on exercising influence and not wielding power. Citizen action through civil society is many splendored, and as one organization put it:

"Citizen action is as multidimensional as the diversity of human endeavors. It may be local or global, small or massive, permanent or ephemeral, highly dramatic or almost invisible, confrontational or collaborative, spontaneous or organized, promoted by associations of likeminded individual or by large civic movements, or any combination of these, depending on the needs of the moment".

As we shall see, civil society involvement in NCDs bears some of the features of this description. There are many categorizations of civil society organizations such as for-profit

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and not for-profit, civil associations or members with common interests who interacted for preservation of one or other identity or privilege, such as the ancient guilds which predated the modern state and the social movement organizations which see themselves as being primarily, although not exclusively advocacy organizations. This last is the grouping that is most relevant to our discussion on civil society's role in prevention and control of NCDs.

For the purposes of this conference the role of civil society has to be seen against the background of the Ashgabat Declaration which relates directly to the principal objectives of Health 2020. The critical focus is on improving health For All, reducing inequalities, strengthening leadership and promoting participatory governance. The specific roles of civil society as regards the prevention and control of NCDs and especially in relation to the last two were given legitimacy in the Political Declaration of the 2011 High Level Meeting. That Declaration referred to multilateral action no less than 15 times and in a specific paragraph, spoke to;

“Engaging non-health sectors and key stakeholders, including civil society and the private sector in reducing risk factors for communicable diseases and promoting health care”.

In addition, the WHO Plan of Action for the Prevention and Control of NCDs specifically spells out an important role for civil society.

If civil society is to play a role in participatory governance, it cannot be viewed in isolation but also in relation to the other actors in the governance process. I use the word governance to mean the structures and processes that facilitate the interaction needed for the optimum functioning of society or a particular institution of it. Governance at the whole of government level is exercised through the multisectoral cooperation that takes place among the various agencies of government. Civil society has no role here.

It is at the level of the state or the whole of society that I recognize the governance in which civil society plays a critical part. The actors at this level which interact intersectorally are the public sector essentially the government, the private sector and civil society. In my view civil society cannot function effectively in our democracies in the absence of government or the public sector. The presence and the conscience of civil society and the roles of the state are complementary. Although there are different categorizations of civil society which bear on their origins or orientation I will often use here the common acronym NGO as being coterminous with civil society.

I am proposing that there are three most important roles for civil society organizations dealing with NCDs. These are advocacy, the role of watchdog or ensuring accountability and that of the direct provision of NCD services. These roles are facilitated by capacity building and forming strategic alliances.

My more intimate experience with civil society performing these roles includes global, regional and national civil society organizations. The global organization I know best is the NCD Alliance which was founded in 2009 as a civil society network initially by three dominant

thematic NCD NGOs -the International Diabetes Federation, the World Heart Federation, the International Union against Cancer, with the aim of raising the priority given to NCDs on the global health and development agenda. The three were joined later by the International Union against Tuberculosis and Lung Disease. And here I must pay tribute to the heads of these individual organizations who recognized in a magnificent spirit of cooperative altruism that there was virtue in this collaborative structure which now embraces 4 regional NCD Alliances, 22 national NCD Alliances and incorporates over 2000 analogous organizations in over 170 countries committed to a similar cause.

The Regional Organization with which I am familiar is the Healthy Caribbean Coalition, of which I am the Patron, that brings together over 60 organizations in the Caribbean to address NCDs. It is comprised of organizations and institutions which embrace not only the thematic NGOs but also the related private sector organizations, the media, academia and faith-based organizations as the only sensible way of structuring a civil society response in a group of small states and territories that have a history of cooperative action in health.

I must stress that civil society will perform best when there is a functioning public sector. The government's approach to the prevention and control of NCDs through addressing the dominant risk factors is essentially thorough the instruments of taxation, regulation and legislation. Obviously civil society does not have the power to utilize these instruments, but it can and does exert influence on governments and its agencies at several levels. It influences the commitments made, the policies to enact these commitments, on the use of the three instruments.

Advocacy at the global, regional and local levels stimulates public interest in NCDs and helps to galvanize government action in honoring the commitments made in local and global fora with regard to NCDs. The tools of advocacy are well described and have been adapted to each specific organization and its needs. There are numerous examples of advocacy tool kits to be used by NGOs in their efforts to focus light on NCDs, but what is clear is the concentration on specificity of audience, accuracy and relevance of information to be used, effective communication strategies and establishment of the monitoring, evaluation and feedback mechanisms ex-ante and not ex post. It is also impressive that one of the critical aspects of the NGO movement for NCDs is the decision to tie efforts to the internationally agreed goals and targets, of course with any local adaptation necessary. Thus all the NGOs regardless of their thematic specificity, seek to promote the goal of a 25% reduction in NCD mortality between the ages of 30 and 70 years by 2025. The national and regional advocacy strategy must be in tandem with the global strategy.

It has been recognized that the effectiveness of advocacy by civil society would be enhanced if there was some common template that all organizations could use, adapting it of course to the local situation. The NCD Alliance has produced an online Advocacy toolkit expressly for that purpose. I quote the headings from the three main sections of the document which are:

- Working in an Advocacy Alliance, providing a brief introduction to advocacy, and offering the rationale and guidance on how to build a NCD alliance to support advocacy efforts at national or regional levels.

- Influencing and Monitoring NCD Policy and Practice which provides advocacy tips and opportunities for NGOs and national or regional NCD alliances to influence and monitor global and national NCD policy development and implementation, and
- Holding Governments Accountable, setting out tips, tools and resources for holding government accountable on NCDs through use of a Civil Society NCD Status Report.

Advocacy here points up the steps need to address the dominant risk factors and supports the WHO global action plan. But the global advocacy goes beyond the immediacy of the requirements of the UN High Level Meeting and embraces the challenge of ensuring a proper place for NCDs in the post 2015 Human Development Agenda.

The enthusiasm for the effectiveness of focused advocacy is built on experience to date. It was the advocacy of the NCD Alliance as mentioned above that was instrumental in bringing about the High Level meeting. There was a recognizable global advocacy strategy that secured acceptance of the overarching goal of a reduction by 25% in mortality from NCDs in those between the ages of 30 and 70 years. This involved other civil society agencies such as the medical media. The Lancet NCD Action Group was a vocal and effective proponent for adoption of that target and it also contributed to the framing of many of the elements of the Political Declaration. I believe that the story of the global commitment to the prevention and treatment of HIV was as a result of a process similar to this. There was civil society pressure to recognize the seriousness and global reach of the epidemic; it was civil society that stimulated the governments to make specific commitments and it was civil society in large measure which promoted the development and use of score cards that enabled them to exercise the kind of watchdog role that ensured accountability.

The presentation of arguments for modifying positions in the global consultations which have now become such a common part of the intergovernmental landscape is a role that the NCD Alliance and other NGOs have played well recently. The provision of information on which evidence is constructed is one of the critical roles played by civil society. The preparation of accurate policy briefs on the various aspects of NCDs is a vital role for civil society. Advocacy obviously is not effective if it is based on false claims and the negative repercussions of such efforts may take years to be repaired.

The observance and tracking of commitments is a one of the critical watchdog or accountability roles played by civil society and it is expected that the Civil Society Status report will be a powerful instrument for this. This Report however will go beyond the statistics on mortality and morbidity and the prevalence of risk factors that are collected routinely and will try to address, sometimes qualitatively, the influence of other determinants of progress or lack of it in the prevention and control of NCDs. Civil society in addition to ensuring the global commitment, has assisted in crafting the mechanisms to ensure that these commitments were met. The accomplishment of these commitments, the observance of the goals targets and indicators established globally for example in the WHO Global Strategy for prevention and control of NCDs is facilitated by the technical cooperation at the local level by organizations

such as WHO, but is also assisted by the local NGOs with the support of the global and regional bodies bringing the appropriate pressure to bear on governments.

But it is not only the local pressure that sometimes stimulates governments to comply with the commitments. I have suggested that governments by meeting together with the glare of public scrutiny on their accomplishments are socialized into stronger efforts to comply. It is a basic function of the intergovernmental organizations to provide the fora in which this socialization can take place, but civil society in its watchdog role is one of the audiences to which the collective body plays as well. The Healthy Caribbean Coalition is currently participating with other civil society organizations in evaluating the degree of government compliance with the commitments made in the 2007 Summit of CARICOM Heads of Government on the prevention and control of NCDs.

This watchdog role is not directed only to governments. Civil society will monitor the interactions among their own organizations and the relationship between government and the private sector to ensure that there are no conflicts of interest and to agitate when private sector actions are inimical to the prevention and control of NCDs. The relationship between the private sector and the other two part of the state can be delicate and there is now considerable effort to develop the appropriate guidelines. The multiple interests in any society which bear on NCDs create the need for independent organizations to insist on transparency and accountability.

Finally, civil society organizations have been involved in providing direct NCD services for generations. There are literally hundreds of NGOs of varying sizes involved in these activities ranging from the care of the diabetic foot to palliative hospice care for chronic diseases. This care may be funded independently by the NGO, but in the countries which I know best it is provided as part of a principal agent arrangement with government.

In summary, I have presented some thoughts on the nature of today's civil society and the role that it can and does play in the prevention and control of NCDs especially in the context of the participatory governance that is emphasized in the Ashgabat Declaration. I have stressed three critical roles for civil society-advocacy-serving as a watchdog and ensuring accountability and finally providing direct services. I have used the example of the NCD Alliance globally and the healthy Caribbean Coalition regionally. The possibility of compliance with the commitments made by governments is enhanced by civil society's capacity to discharge its seminal functions.

So, we must be cognizant of the current reality of the power and reach of civil society and take advantage of them to make the world a better place by preventing and controlling NCDs.