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New Study Reveals Varying Acceptance by CCMs of People Living with HIV/AIDS

The Global Fund's official guidelines on the composition and purpose of Country Coordinating Mechanisms (CCMs) make clear that the role of a CCM is to build partnerships between *all* the relevant players in a country. The guidelines, likely to be strengthened soon, state that each CCM should "strive to include ... people living with HIV/AIDS, TB and/or Malaria." The guidelines also expect CCMs to be involved at every stage of a Global Fund project, from drafting the proposal to selecting a Principal Recipient to monitoring implementation of the grant.

A new study from GNP+, the Global Network of People Living with HIV/AIDS, available in English, French, Spanish, and Russian at www.gnpplus.net, offers a fascinating window into whether people with AIDS are truly playing the participatory role that the Fund envisioned.

The Global Fund's own data have shown that during Rounds 1 through 3, between 25 and 29 percent of CCMs lacked any representation by people living with one of the three diseases. The GNP+ report offers a glimpse behind the data for 13 countries – 12 of which have at least one member who is a person living with HIV/AIDS (PLWHA) – through interviews with CCM leadership, PLWHA representatives, NGO representatives, and others. Stuart Flavell, the project supervisor on the report and the international coordinator of GNP+, points out that the study is based on interviews conducted last summer and fall, and that CCMs have matured a tremendous amount in the intervening months.

The GNP+ report, "A Multi-Country Study of the Involvement of People Living with HIV/AIDS (PLWHA) in the Country Coordinating Mechanisms (CCM)," found that merely having a seat at the table didn't always count for much. On some CCMs, PLWHAs play an active role in proposal writing or review, selecting Principal Recipients, designing disbursement plans, engaging in AIDS-related project implementation, and

doing monitoring and evaluation. But on others, PLWHAs are excluded from these significant roles, and their signatures appear on proposals only as a “rubber stamp.”

On six of the 13 CCMs featured in the study, PLWHAs report experiencing open bias or paternalism; on some others, the opinions of PLWHAs are simply disregarded. Only four CCMs have PLWHA participation at the subcommittee level – Boliva, El Salvador, Nigeria, and Ukraine. In most countries, the PLWHA representative was simply appointed; only in Bolivia, El Salvador, and Peru did the PLWHA community manage to elect their own representatives based on clear, public criteria. In these countries, this process produced a high level of confidence that the PLWHA representatives were really bringing the views of their community to the table; on many other CCMs, such confidence was lacking.

“The most exciting thing for me is that in these countries, the national AIDS groups have really embraced the notion of community representation on the board,” said Flavell in a conversation with GFO. “The community representatives on the board have a real constituency and a real system for communication and accountability. They’ve gone above and beyond what was expected.”

Despite this mixed track record on PLWHA participation, the report conveys a strong vision for the role PLWHAs could play on CCMs in the future, in challenging discrimination, using their first-hand knowledge to shape proposals and strategies for treatment access, and bringing transparency to the CCM.

The report identifies a number of obstacles to meaningful involvement by PLWHA: many speak only the local language, and yet meetings in some countries are conducted in English to accommodate representatives from international bodies; there is often poor communication from CCM chairs to CCM members; there is a lack of clarity about the PLWHA role on the CCM; and many PLWHA representatives lack equipment and training to access email or the web, as well as experience with proposal writing and project implementation. “There’s no technical support for CCMs,” says Flavell, “or for people living with HIV.”

The report recommends a number of forms of technical assistance that would foster deeper engagement by PLWHAs in their CCMs: instruction in basic literacy and in the English language; email training and access; and training on proposal writing, budgets, project development, and evaluation. The report also tackles the question of financial support, recommending that CCM secretariats be staffed, that communications between CCM representatives and their constituencies be subsidized, and that CCM members receive pay or at least transportation stipends to facilitate their involvement; it suggests, too, that PLWHA organizations themselves need financial support and office space to better function as representative bodies. (Half of the CCMs in the GNP+ study already do cover transportation costs to enable PLWHA representatives to attend meetings, and one provides a subsidy for Internet access.) Finally, the report suggests a change in tone – that PLWHAs be invited to play a more fully participatory role, and that CCMs themselves engage in combating stigma.

Building meaningful representation from PWLHAs is clearly unfinished business, but the report found broad goodwill toward the CCM structure and the multi-sectoral approach it has encouraged. And the report identifies some challenges for CCMs that extend far beyond the role of people living with AIDS. The report exposes an enormous lack of clarity about the role of the CCM, and in many cases, a lack of transparency. According to the report, “luck and word of mouth” are the main means of CCM communication with the broader public in five countries. Only half of the CCMs are engaged in monitoring and evaluation of grants; six of the CCMs don’t even report having plans to put such a system in place. “What’s missing is any thought that CCMs are going to be here for a while, that this is more than a one-shot deal,” says Flavell. “I’d like to see people look to building their CCMs as ongoing institutions, and talking more about evaluation and ongoing needs assessment.” While most of the CCMs function democratically, through votes or consensus, participants in two CCMs report the chair making unilateral decisions, and two others report that the government or large international NGOs dominate decision-making. As one respondent from Nepal said, the CCM is a very powerful structure that needs to be awakened.

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