

## Care and Support: Effective advocacy in action

The UK NGO Consortium on AIDS and International Development, Care and Support Working Group has worked over the last two years to raise the profile of HIV-related care and support. In recent years with an ever increasing focus on access to treatment and improving combination prevention, care and support has received less attention. However, two thirds of people living with HIV eligible for treatment - an estimated 10 million people - are unable to access it. Under these circumstances, care and support services are as essential as ever. The majority of these services are provided by families and communities, often struggling to access adequate resources. To call attention to this neglected area, the Care and Support Working Group has systematically constructed its case and taken it into the international arena. The results of this advocacy are so far strong. UNAIDS has included care and support in the Outcome Framework priority action area on Social Protection; the UNGASS indicator set has been reviewed and strengthened, a Global Care Givers Action Network has been launched; and a bilateral donor has agreed to host a consultation to develop a road map for future action and investment.

The first step of this advocacy in action was to define the five main domains of care and support in collaboration with South based civil society partners and a bilateral donor from the North<sup>1</sup>. Based on the premise that what is not measured does not get done, the next step was to identify all the indicators that related to the five domains in the UNGASS set and complementary sets such as indicators used by PEPFAR and the Global Fund. Having identified the relevant indicators, they were evaluated against the indicator standards tool developed by the UNAIDS Monitoring and Evaluation Reference Group (MERG) Technical Working Group (TWG) on Indicator Standards and Development.

In 2009 the Care and Support Group made a presentation to the TWG including recommendations on possible additions to the UNGASS Indicator set that might fill the gaps identified by this process - recognizing that not all five domains could easily or appropriately be assessed by the UNGASS set or process. As a result of this solid ground work the group was asked to co-chair the UNGASS review process for the care and support indicator set currently underway and have had the opportunity to test out this work with a broader group of stakeholders to refine the recommendations and strengthen the case.

Two parallel processes have added to the evidence base. An intern volunteer with VSO, using key words linked to the five domains, analysed the UNGASS country reports from 2008 to assess the level and quality of reporting. Many countries from Africa in particular were reporting considerable activity in these areas, but this information rarely makes it into the larger publications. In 2010 UNAIDS is conducting a similar analysis of it's own to inform global reporting. Finally, the group used the opportunity of the International AIDS Conference in Vienna to convene and launch a global care givers action network and in collaboration with this network- of mostly home based care providers, the working group

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1. <http://www.aidsportal.org/repos/HIVCare.pdf>



researched and costed the contributions of home based care workers in six countries and released the report at the International AIDS Conference in Vienna.

### **Effective civil society partnership: giving each other space**

Promoting the engagement of civil society and people living with HIV in AIDS responses is a UNAIDS corporate principle. UNAIDS creates physical and political space for people living with HIV to help ensure they are at the heart of AIDS responses. UNAIDS provides direct support for networks and organizations with several UNAIDS offices also hosting organizations of people living with HIV.

When Jane Wilson, UNAIDS staff member since 2001, talks about partners 'giving each other space' as being central to fruitful relations with the community of people living with HIV, she means it - literally. UNAIDS Country Coordinator for Indonesia between 2001-2007, Jane and her team introduced new partnership concepts, which not only meant increasing collaboration and interaction with people living with HIV, but also literally making space within the UNAIDS office, to work side by side on a daily basis.

"When I started as UCC I was wondering how to put the GIPA principle into action," Wilson explains. "We offered office space to a new nongovernmental organization called PITA that supported parents of drug users living with HIV. Together, we decided to dedicate a community room within the shared office for the use of people living with or affected by HIV."

Bucking the trend for white-walled, corporate style offices, Jane requested multicolored interiors and comfortable surroundings, to give the UN offices a "heart and soul". Members of the community began to see this space as a safe haven: soon, there were back-to-back bookings for counseling and discussions on HIV-related matters. "One morning I arrived at the office to see a group of fathers of injecting drug users around the table sharing their concerns. The room was taking on a life of its own!" she says.

It is a concept that reaped rewards. Not only did the partnership create a safe space for the community to discuss and work with the UN on issues affecting them, but it gave UNAIDS access to the community that led to increased input and collaboration benefitting not only the UNAIDS Secretariat but also many cosponsors and other partners for whom working with the community was vital. Some of those involved with this work became UNAIDS volunteers and staff members, demonstrating UNAIDS' recognition of their extraordinary experience and how much they could contribute to UN work.

### **Expanding the space: enhanced partnership with APN +**

Fast forward three years, to Bangkok, Thailand and the regional support team (RST) where Jane now works as Regional Advisor on Gender and Human Rights and where the shared space partnership concept is ongoing.

Strong relations between the regional support team in Bangkok and community networks – particularly the Asia Pacific Network of People Living With HIV/AIDS (APN+) is often heralded as one of the most effective examples of solid, mutually beneficial partnerships within UNAIDS. The RST and the Network consistently come together on key issues to help ensure collaboration and coordination, and to ensure all perspectives are considered within different debates. The RST has provided core funding for the support of the Network since 2008.

It is a partnership that has grown and blossomed over time – and one that is grounded in the principle of mutual respect, knowledge sharing and giving each other space. Here, the space-sharing element is led by the network itself, who make space in their own office in downtown Bangkok – a desk and resources for members of the UNAIDS RST, to work, spend time and share expertise, on their doorstep.

“We wanted to connect more immediately with the community. First of all we just started hanging around the APN+ offices for a few hours here and there, connecting where we could – even in the corridors!” explains Jane. “When the network moved into its new offices, they set aside some ‘space’ where UN colleagues can go and work on a regular basis, at the heart the community, working for and with them directly,” she added. “Now I or other colleagues go down to the APN+ offices at least once a week and work from there. This way we have a much better idea of what each other is doing and who we all are.”

According to APN+, this partnership style is one of the fundamental factors behind the consistently strong relations the network has with UNAIDS – and is driving results.

“When you have the regular, human, contact and information sharing with each other, this is when the concept of partnership takes on its real meaning,” said Shiba Phurailatpam, Regional Coordinator and Director. “And like any professional or personal partnership, there are sometimes challenges that have to be worked through, but this is easier to do because we have been able to build much stronger links, and accomplish much more through this kind of partnership. It is much more effective and deeper than just inviting each other to meetings.”

### **Sustainability is key**

Sustainability of such close relations is fundamental to their ongoing effectiveness and is a challenge recognized by both the network and UNAIDS regional office. Changes in staff are inevitable, but both organizations are adamant that the partnership will continue to grow. Handover and continuation is an absolute must, and the RST is dedicated to ensuring the ongoing support.

“We have gained so much from this knowledge sharing and cooperation – and we have to make sure that this successful model is able to continue, even if one person leaves, or if structures change,” said Kiren, Coordinator of the women’s programme at APN+. “That’s why we continue to identify new people within the RST who can pick up the partnership baton, keep the community link strong and let us give them some space!” she added.

### **In from the Margins: UNAIDS Partnering with the International Network of People who Use Drugs (INPUD)**

Two years ago, International Network of People who Use Drugs ([INPUD](http://www.inpud.net) link to: [www.inpud.net](http://www.inpud.net)) started a journey of organizational development against the backdrop of the financial crisis which the World Bank has estimated has led to a 40% drop in funding for NGOs in the HIV sector. People who use drugs have not previously sustained an international network and the drug users movement had in recent years organized alongside the harm reduction movement and its conferences. As such, INPUD was coming to the HIV policy arena with limited knowledge about the structures, few resources and a history of struggling to secure meaningful participation in the drug policy and practice sectors.

The Greater Involvement of People living with and affected by HIV and AIDS (GIPA) principles have been hard fought for by people living with HIV and advocates of key

populations at higher risk of HIV. These principles describe the meaningful participation of people living with HIV and more recently also of the key populations affected by HIV in global HIV policy and planning. INPUD therefore entered a policy environment that was welcoming and desiring to meaningfully engage people who use drugs.

INPUD started out on its development journey with a commitment in 2007 from the International Harm Reduction Association (IHRA) of £20,000 annual core funding under its programme of financial support for harm reduction networking, a programme made possible by a grant from the UK's Department for International Development (DfID).

INPUD's new leadership team met key partners at a donors conference on HIV hosted by the Dutch Government in January 2009. INPUD's Board Member, Vito Georgievski spoke on one of the panels at the event and Mat Southwell, INPUD's Project Manager was able to meet and sound out potential donors. One of the outcomes of the event was an agreement that INPUD needed to be properly resourced. However, when it came to the pledging stage of the meeting and the need to fund INPUD was raised, there was an expectant hush across the room and no donors came forward. Vito remembers "it was very disappointing after the positive atmosphere of the meeting but just as we were giving up hope, UNAIDS pledged support".

A small grant of US\$23,000 from UNAIDS allowed the INPUD Board to appoint a paid organizational consultant and INPUD member to lead the rest of the development period. This was critical in sustaining the hard fought for early development phase, which had been developed on a voluntary basis.

Since this time UNAIDS has offered INPUD four small grants that have carried the organization through a two year period of organizational development. This has given capacity to the organization and confidence to other donors. Jude Byrne, INPUD's Chair notes "the UNAIDS funding was a practical illustration that our contribution was valued. Importantly it allowed us to focus on developing our organization, strategy and communication systems rather than too quickly being expected to undertake project work." This strategy has been successful and INPUD is now recognized as a credible and effective advocacy organization by key global partners.

(<http://www.worldaidscampaign.org/en/Constituencies/People-who-use-drugs/Resources/World-AIDS-Campaign-Report-into-Progress-of-INPUD-launched-at-IHRC>)

INPUD has now produced a three year strategy and is entering a 6 month period of intensive resource mobilization. Importantly, given the backdrop of the financial crisis, INPUD is being actively backed by its existing donors, key global NGOs, and partners in the UN system.

The final part of INPUD's engagement with the UN system has been INPUD's successful application to join the UNAIDS Programme Coordinating Board NGO Delegation. Joining the delegation allowed INPUD to meet key players in the UN system and to develop relationships with UNAIDS, the co-sponsors, country missions, donors, and the wider NGO community. Mat Southwell, INPUD's delegate, states that "on one hand it has been a very demanding role that has called on our limited capacity. However, on the other hand it has been a rapid education about the UN system and given us the opportunity to illustrate how people who use drugs can be effective, positive and robust partners in intergovernmental policy fora." Importantly this has led to a decision point committing UNAIDS and the co-sponsors specifically to the meaningful participation of people who use drugs and their associations.

So two years on people who use drugs are better organized, actively engaged in the UN system, and poised ready to secure the resources required to be meaningful and sustained partners in international policy discussions relating to public health, drug treatment, drug policy and human rights.