



## HIV EUROPE

A network of organisations predominantly committed to the GIPA Principles

### **Response to Draft UNAIDS Policy Brief, November 2006 The Greater Involvement of People Living with HIV (GIPA)**

This issue was debated at length at a meeting of HIV Europe held in Warsaw over the weekend of 17<sup>th</sup> to 19<sup>th</sup> November 2006.

#### **The following country organisations of PLWHA were present:**

Denmark, Sweden, Finland, Norway, Iceland, UK, Albania, Greece, Portugal, Croatia, Ukraine, Italy and Poland; plus AIDS Hilfe Switzerland and a collaborative representative of the Eastern and Central Asia Network (ECUO).

#### **Response to UNAIDS**

This was viewed as a very thorough and useful draft paper which was very welcome.

Priority should be given to stressing the inclusion of GIPA in national plans.

The following additional comments are forwarded

**Positive Prevention** is missing – no acknowledgement that PLWHA who know their status who are probably contributed more to HIV prevention than any other group – evidenced by a number of research projects that show knowledge of HIV status results in behaviour change by the vast majority of PLWHA.

**Vulnerable Groups** under action for international partners, point 2

particularly mentioning the rights of women, young people and vulnerable populations may lead to ignoring the other PLWHA not only those listed as vulnerable as all PLWHA are vulnerable.

However, HIV Europe was wary of taking out mention of groups who are specifically marginalised in some countries (e.g., gay men in Uzbekistan and other countries are criminalised; Moslem countries attach little value to the rights of women or, particularly,

young girls; IVDUs are frequently criminalised and lack access to health care or harm reduction services).

**Consideration should be given to publishing the whole list,** interesting to measure the effect of some of these words as they did not get into the UNGASS political declaration.

**How to monitor GIPA.** The document mentions challenges to achieving GIPA, but offers no solutions – PLWHA are the potential solution.

Whenever a government sets up a programme on any issue related to HIV, we as organisations should aim for meaningful involvement under GIPA, and we should aim to include a GIPA goal in any programme.

There was a long discussion on tokenistic engagements with unrepresentative organisations and small numbers of token individuals in countries where this is espoused as “involvement” when it is mere employment in many cases, not involvement with the wider communities.

Monitoring of programmes should include an assessment of the GIPA component in any national plan dealing with prevention, care, treatment, etc. In developing countries, is there data collection on UNGASS indicators as one of them is involvement of PLWHA? Evidence from recent Moscow meeting that in the East that there are no important indicators in some countries. Impossible to enforce or grade these indicators – you cannot ask multi laterals like UNAIDS or the EU to come and help: GIPA indicators can only be accomplished on a national level, there is no way to put in measurements from outside, and it is up to us to do this locally. Monitoring can only be done by local people. Example measurements might be that local and regional networks should be involved in policy development, the measure being were they meaningfully involved and this can only be measured by people in country, in region.

How would a country like Croatia be persuaded to take on some of the actions proposed for local organisations, governments, when there is no support for NGOs either by government or external funder agencies?

**Young people** - Nothing really mentioned, how do we get young people participating – one of their barriers to participation is fear of disclosure / stigma, so how do we (or anyone else) pull them in? Young people are not interested in sitting in boring meetings, so

how do we change things to make them more accessible to young people?

**Organisational development and support** to some extent the Positive Development book from GNP+ (available on line in various languages at [http://www.gnpplus.net/cms/article.php/Positive\\_Development](http://www.gnpplus.net/cms/article.php/Positive_Development)) describes how at different levels you can start up and strengthen an organisation; this concept is missing from the paper

**PLWHA as drivers of research** is not included amongst the areas of involvement, yet traditionally one of the first things PLWHA did was pressure for access to new treatments, for research and break in to FDA, etc., and this is an area where there is great involvement with scientists, industry, etc.

**What works?** On page 7 – suggest deleting “what works” as this is likely to be interpreted as only including the issues mentioned, but not many are included and perhaps these should not be within a short policy briefing.

**The ladder of involvement** shown in other GIPA documentation could be repeated somewhere.