Moving from anecdote to evidence: PLHIV using the PLHIV Stigma Index to create a partnership that can properly gather the evidence to document the Stigma faced by PLHIV in Poland and generate advocacy and action

The first case of an HIV infection was recorded in Poland in 1985, and the first AIDS case was diagnosed in 1986. In those first years the main routes of transmission in Poland were: intravenous psychoactive substance use and sexual contacts between men. From 1985 until the end of October 2009, 12,627 new HIV infections were recorded in Poland. However, the number of HIV infections estimated by experts is 20,000 to 30,000. Accumulated data shows that 48% of all infections were related to intravenous psychoactive substance use.

In Poland there is ‘officially’ no problem with HIV stigmatisation. People Living with HIV (PLHIV) are afraid of fighting for human rights because of possible disclosure to families and friends. Prior research (2008) of 150 PLHIV discovered 64% felt they had been discriminated against by medical staff, some had lost employment or found it unable to get access to sanatoriums; HIV infected children are still being excluded from schooling due to HIV status.

In 2009 Polish PLHIV National Network organised “Round Tables” and other activities for NGO working with PLHIV to generate interest, form a partnership and develop an action plan to systematically research the situation of PLHIV Stigma in Poland, using the PLHIV Stigma Index (www.stigmaindex.org) as our model. This was part of a process made possible by a seed grant from the International PLHIV Stigma Index partnership administered by GNP+. It laid solid foundations for a plan for national ‘roll-out’ of the Index.

THE PLHIV STIGMA INDEX IN POLAND

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Lessons Learnt:

We learnt that it was possible to form a partnership and get community members involved if

1) The researchers who would be interviewing them were also PLHIV
2) If they believed that by telling their stories things could be made better
3) That using a tool (the PLHIV Stigma index) that had been developed by and for other PLHIV made the forming of partnerships (with other PLHIV organisations, with research institutes, with medical and government institutes) much easier and helped in gaining the necessary resource mobilization for national roll out.

Next steps:

A consortium of all Polish PLHIV organisations, assisted by a research institute and other NGO’s are training PLHIV community researchers to interview 500-700 PLHIV across Poland between May and October 2010, to generate robust data, formulate community driven action plans, and provide a base-line for future research of the community by the community.

In June 2010, during the XIV Polish National Meeting for PLHIV, a pilot research programme was organized; 5 interviewers were trained to be able to conduct the interviews; 50 interviewees completed the Polish version of Stigma Index questionnaires; interest was generated amongst the wider PLHIV community. Additionally we have partnered with GNP+ and HIV in Europe who are supporting the full implementation of the Stigma Index. Results will be fully available by December 2010 – including results of additional questions we are asking to look at the barriers to earlier testing and accessing care caused by stigma.

For the Polish implementation of the Stigma Index we have gained an honorary patronage of the National AIDS Centre – Agenda of the Ministry of Health and the Polish AIDS Research Society. We have also established a partnership from the Open Society Institute – Global Drug Policy Program.

The PLHIV Stigma Index is a Global Partnership Initiative being coordinated by The Global network of People Living with HIV (GNP+), the International Community of Women Living with HIV (ICW), the International Planned Parenthood Federation (IPPF) and The UN Joint Programme on HIV/AIDS (UNAIDS). The People Living with HIV Stigma Index is a participative research tool (questionnaire) intended to be administered by trained PLHIV researchers to members of their community. It has several sections dealing with different aspects of stigma; Experience of stigma & discrimination from others, Access to work and services, Internal stigma and fears, Rights, laws and policies, Effecting change, Testing & diagnosis, Disclosure & confidentiality, Treatment; Having children, Self-assessment of stigma & discrimination.

For more information and to be kept informed of the work and results please leave your information and we will be in contact with you.

Authors: M. Ankiersztejn-Bartczak, W.J. Tomczyński, J. Hows, D. Michalak