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Empowering People with HIV to better access and take advantage of health services : Estonia

What was the issue?

The results of the People Living with HIV Stigma Index Survey and a study on “Late testing/ late treatment” (both available at (<http://www.stigmaindex.org/estonia>) identified that HIV related stigma and discrimination is ongoing and acts as a barrier for people living with HIV to access HIV prevention, treatment and care services.

Internalised stigma amongst the respondents due to their being HIV+ was reported in the following ways:

- over 60% felt guilt
- 57% blamed themselves
- 42% felt ashamed
- more than over 33% reported low self esteem
- 10% reported having felt suicidal, these feelings – with women more often reporting suicidal thoughts (15% to 7%).
- Only 8% of respondents overall were not afraid to disclose their status to anyone, with many people not even informing their close family or medical staff.

Why was change needed?

Participants in the research had identified that a lack of ‘empowered disclosure’ and internalised stigma was resulting in not accessing clinic and hospital appointments- as well as not considering or taking part in on other activities related to general health improvement. Participants also identified these feelings of self and internalised stigma as limiting their participation in everyday society, increase isolation and damaging their ability to live well with HIV.

What could be done to improve matters?

This demonstration project took two cohorts of individuals living with HIV who were afraid of disclosing their status. They were offered a series of workshops and interventions to inform them about their rights, help build their confidence and evaluate their attitudinal change.

What were the barriers to change?

The main barrier was the low self-esteem and self-motivation of participants in the training. However, as the training progressed, their motivation grew and most participants completed the full training to the end. Some participants were not able to attend all ten sessions, which reduced their effectiveness for those participants. There was also a reluctance to do “homework” outside the actual sessions, possibly due to time constraints

or personal living situations, which meant that all work had to be done within the formal sessions.

How long did change take and who was involved?

Each course consists of ten two-hour sessions with a qualified and experienced psychologist, over a period of several weeks. PLHIV participating were sometimes accompanied by partners or close relatives

How was change made?

In all, ten training sessions were conducted in Narva. The group set its own goals and objectives, which were achieved with varying degrees of success, depending on the complexity of the problems tackled. The training was holistic and topics were organised in a logical progression, building on and reinforcing the results of earlier sessions. Sessions were based on previously identified problems expressed by PLHIV in that particular area of Estonia.

Summing up the results, all the participants achieved some change for the better, but these changes were more marked when participants were able to attend the full course. Results and changes reported by the participants in feedback included:

- More freedom from others opinions and resultingly, less tension in relationships with others
- Reduced impact of stigmatising labelling
- Motivation for personal changes; many reported their lives had changed for the better
- Reduction of intrapersonal anxiety levels
- A more robust response to external stigmatisation and rejection, including from within their families
- A more positive general attitude toward life, due to replacing fear of new situations with acceptance of potentially positive experiences

Are there any ongoing issues?

As a result of involvement in the course, PLHIV have gone on to undertake further projects to challenge stigma and discrimination against HIV-positive people in Estonia: a video, further training in psychology and an exhibition of Estonian PLHIV art with challenging and innovative installations. However, there is a need for an ongoing programme of groupwork with support from a psychologist because external stigma from medical services and in family contexts continues to be a challenge to PLHIV self-belief. Funding is an underlying problem in achieving this.

What lessons have been learnt?

It is possible to challenge people's internalised self-stigma through groupwork, but support is needed to ensure that people are able to benefit fully from a full course of sessions. It may not be feasible to expect people to work on these issues in isolation between sessions due to personal pressures. Challenging internalised self-stigma can also lead to successful engagement in challenging external stigma and discriminatory attitudes.

“It is very important, when you have the opportunity, to come and share your problems with others and work on them with a specialist. It's important to know that you are not alone and that you have support, a circle of people who have coped with similar problems or are trying to do so. I'm sad that the training is coming to an end... it's very difficult to keep everything within myself” (participant)

More information

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