

## CASE STUDY ON 'POSITIVE VOICES 2.0 (POSITIVE STIMMEN 2.0)'

### Context

The PLHIV Stigma Index was developed by the global network of people living with HIV (GNP+), together with the International Community of Women living with HIV (ICW), the International Planned Parenthood Federation (IPPF) and UNAIDS. Since 2008, it has been implemented using a standardised questionnaire in more than 100 countries across the globe. In Germany, the PLHIV Stigma Index 2010–2012 was carried out by Deutsche Aidshilfe under the title 'positive stimmen' (*positive voice*).

Based on the results of the first PLHIV Stigma Index, the revised version 'PLHIV Stigma Index 2.0' was launched at the World AIDS Conference in Amsterdam in 2018. This questionnaire includes new areas of investigation regarding stigmatisation and discrimination of different population subgroups among people living with HIV, an extended section on the healthcare system, and reflects changes to the HIV epidemic and the global response.

The PLHIV Stigma Index 2.0 was implemented as part of 'positive stimmen 2.0'.

### Introduction

'positive stimmen 2.0' is a community based and participatory research project. The first part of the 'positive stimmen' project started ten years ago, with people living with HIV asking other people living with HIV about their experiences with stigmatisation and discrimination. This approach has now been continued with around 500 interviewees, and as a joint project of Deutsche Aidshilfe (DAH, German AIDS service organisation) and the Institut für Demokratie und Zivilgesellschaft (IDZ, Institute for Democracy and Civil Society).

### Aims

A central goal of 'positive stimmen 2.0' and the 'PLHIV Stigma Index' is for results identified to have an impact, and to empower people living with HIV.

The project is also intended to help break down structural discrimination and marginalisation. For this purpose, 'demands' and 'recommendations for action' were developed based on the results.

### Method

The study consists of two modules:

- A peer survey based on the global 'People Living with HIV (PLHIV) Stigma Index', coordinated internationally by GNP+, the ICW and UNAIDS (Module A), comprising of 450 peer interviews, standardised questionnaire, quantitative analysis and data collection from May 2020 to January 2021.
- A complementary online survey (Module B), comprising of an online survey with 935 participants, and the establishment of four focus groups and subgroups working on different topics.

#### INITIATIVE PARTNERS



#### OBSERVER MEMBERS

- European AIDS Clinical Society (EACS)
- European Center for Disease Prevention and Control (ECDC)
- Fast Track Cities
- UNAIDS
- UNITE

## Results

The two modules enabled to gather additional insights related to healthcare quality of life of people living with HIV. This includes:

- 9 out of 10 people living with HIV declared that they are “living well” with their HIV infection.
- However, 1 out of 2 people living with HIV mentioned that prejudices towards people living with HIV are impacting their lives, while 1 out of 4 declared feeling “ashamed” or “guilty” for being HIV positive. Furthermore, 6 out of 10 people living with HIV answered yes when being asked whether they faced negative experiences in the healthcare system due to their HIV status.
- 3 out of 4 people living with HIV said that in “many parts” of their lives, their HIV infection is not known.

## Recommendations

Recommendations include:

- Doctors, nurses and other health care personnel should be better trained regarding HIV, both as part of their vocational education and through regular professional development.
- AIDS service organisations should establish or expand services for newly diagnosed people that are easy to access, and ensure their geographic coverage, as well as link their psychosocial services better with HIV medical care.
- To ensure that media professionals depict people living with HIV and live with HIV in a sensitive, well-informed way, free from stigma and discrimination.
- The DAH’s Contact Point for HIV-related Discrimination should be extended and made better known, so that more people living with HIV can defend themselves against discrimination and can be assisted when discrimination occurs.
- Anti-discrimination agencies should have better networks and exchange their knowledge, with the Federal Anti-discrimination Agency taking on a coordinating role.
- Deutsche Aidshilfe, local AIDS service organisations, and funding bodies should expand measures for the empowerment of people living with HIV.

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