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Being positive:

experiences from
Serbia and Montenegro

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To say that this research would not have been possible without the ongoing commitment of our participants is to attempt to master the understatement. Their contribution over three years to this research has been extraordinary. Many have participated at some risk to themselves but have been determined to contribute their voice to help bring HIV out of the shadows in Serbia and in Montenegro. As you will read from their words, they are courageous, eloquent, witty and thoughtful individuals. Countless times we have been humbled by their ability, in spite of their circumstances, to be inspired and thrilled by life and be forever hopeful.

To all those who have given their time and energy to tell us their stories, thank you. It's been a privilege to hear your stories and know you over the past three years.

We hope that this research can be part of changing public attitudes to individuals living with HIV and anyone who is discriminated against on account of difference.

Sarah Bernays, Katarina Janković Terzić and Tim Rhodes

Introduction

The research team, led by Professor Tim Rhodes and Sarah Bernays from the London School of Hygiene & Tropical Medicine, has been conducting research in Serbia and in Montenegro with people living with HIV/AIDS (PLHIV) since 2005 and has produced two studies. The first was a baseline study conducted during 2005–2006 in which we interviewed 42 PLHIV and 18 service providers in Serbia and Montenegro. This was funded by the UK's Department for International Development (DfID) and was part of the HIV Prevention for Vulnerable Populations Initiative (HPVPI). In the second study (2006–2007) we followed up 23 PLHIV from the original study with multiple interviews aiming to get a more in-depth understanding of their lives and to trace changes over time. The study was funded by the UK Economic and Social Research Council (ESRC).

Other publications from this research: We have produced a UN report which focuses on the HIV treatment situation (Bernays et al 2007) from the baseline study and a report on the need for regular funding for HIV treatment monitoring tests (Bernays et al 2008) from the prospective study. These both have a direct policy focus.

Though Montenegro is now independent from Serbia, the study was designed before and undertaken during this period of separation and the booklet draws on data from participants from both Serbia and from Montenegro. The data we collected demonstrates that the settings and experiences of stigma and discrimination are very similar in both countries. Whilst this research is locally grounded we hope that this booklet has relevance throughout the region in characterising the social consequences of HIV.

What does qualitative research do?

This booklet is based on qualitative research.

- *The principal focus of interest is people's experiences and opinions.*
- *The sample size in qualitative research is much smaller than in quantitative research, e.g. in a survey.*
- *For the second study, from which all the data in this booklet comes, we interviewed 23 participants (usually for an hour or so of informal conversation) and asked participants to keep written or tape recorded diaries. We interviewed people three times over 12 months.*
- *The results are not judged or presented in number format but in the words of the participants.*

This second study aimed to capture more in-depth information, sensitive to the nuances of realities and experiences. Whilst it does not purport to be generally applicable, we have encountered very similar stories amongst the participants and we can suggest with some confidence that it is likely the experience holds true beyond our sample. In presenting our research we will often use one case study or story to articulate an experience which is very similar to other people's.

We are interested in people's perspectives. So whilst some other PLHIV or service providers may disagree with their characterisation of the situation, it is valuable to hear what these people living with HIV think and to try and understand why they might think about it this way.

What can this booklet do?

For most PLHIV being open and public about their status is not an option. The perceived necessity of keeping silent means that their voices are rarely heard. This research offers a rare forum in which PLHIV can speak safely and freely about their experiences without compromising their identities.

As Sanja explains:

'It means the world to me that it's anonymous... I just don't know how I'd... live here [if I was open]. When I mentioned this [study] to a few other HIV positive they started at me: "You're crazy!". They won't [talk]... But I appeal to all HIV people here, they all have the same problems as I do, only some of them won't talk about it and I want to talk about it'.

This booklet aims to represent the views of those who have participated in this study, as much as possible through their own words. The data is taken entirely from interviews with the par-

ticipants and their study diaries between mid 2006 and late 2007. We hope that reading this booklet will help you understand the realities that PLHIV face everyday: the good and the difficult.

Who is the booklet for?

The booklet can be used by:

- People living with HIV, particularly those who have been recently diagnosed.
- Professionals working with people living with HIV/AIDS. It has been designed specifically to be used as an educational and training resource for healthcare professionals, social welfare personnel and teachers.
- Advocacy and human rights groups doing advocacy and campaigning work in the HIV area.
- Trainers and teachers involved in educating people on HIV.
- Policy makers in incorporating the needs of PLHIV into protective legislation.
- Researchers conducting and developing further research in this area.
- Anyone who would like to learn more about the realities faced by those affected by HIV.
- Anyone interested in and/or working in areas, outside HIV, similarly affected by discrimination on account of being different from the social 'norm'.

Who is in the booklet?

This booklet is based on the experiences of 23 HIV positive individuals living in Serbia and Montenegro.

This is to introduce to a few of them

*Hello! **My name is Marina** and I've been living with HIV for 16 years now. Knowing I am ill has only made my will stronger over the years in fighting such a strong rival. I've learnt to appreciate life, because it can be so fulfilled, good and exciting, especially because of the fact that it's only ONE life! Let HIV/AIDS be one more reason for you to live your life to the fullest, for YOU ARE DIFFERENT IN SO MUCH AS YOU NOW KNOW THIS RECIPE FOR A BETTER (QUALITY) LIFE!*

*Hello! **My name is Ana**. For many years I wondered when there would be a service organised to meet all our needs. Treatment, social support, self-help, dentist or PLHIV association. I didn't know how or when. Who would organise it? I knew there was need for it, but no one was seriously working on the issue. I decided to change all that myself. I shared the idea with some other patients and friends. That's how we started work. Today I can say with certainty that some things depend on ourselves. Working on problems you realise that it is because people don't understand, don't know... they make mistakes in treating PLHIV. Working in an organised way on problems everything can be changed and improved in time. I feel secure, safe*

and confident again. There is no more keeping quiet and serious uncertainty. The demystification process is in progress. HIV is getting a face and prejudice is disappearing. I am especially encouraged and proud that the Denver Declaration was passed that sent a message from all PLHIV... We condemn attempts to label us as "victims," which implies defeat, and we are only occasionally "patients" which implies passivity, helplessness and dependence upon the care of others. We are "people with AIDS."

My name is Tanja, and my age is not important. I've been living with HIV for almost half a century! There have been some difficult moments and different illnesses. Some of them affect everyone else too. In the beginning I expected death to come every day. It hasn't happened yet, thank God! However, I have met people who gave me hope that life was worth living, I started HAART treatment and I'm still here! People who know about my status say that now you can't tell by looking at me! I believe them and I'm grateful to them [for that]! Life is a special gift that shouldn't be rejected so lightly!

My name is Mašan. I am 43 years old. I live and work in Belgrade, the most beautiful city in the world, where there are a lot of positive people! Each day I work on giving psychosocial support to people living with HIV! :-) I used to be a professional model. Now I live alone and I have a large number of friends who love and understand me. Having this status in Serbia is not really a prestigious thing so... it's nice to be in love!!!

Hi, **I'm Sandra**. I am 30 years old and I live in Niš together with my unwedded husband. I have been HIV positive since September 2000. I used heroin, intravenously, since I was 17, and I tried heroin for the first time when I was 12. Since 2004 I have been on methadone. I am one of those patients who have never taken drugs afterwards and I'm proud of it. I am active in NGO Sunce, I am the president of the organization and I consider my engagement the most important reason for my better quality life with HIV. I am quite different from other PLHIV (although it wasn't my wish) because I appear publicly and speak openly about my positive HIV status, with the aim to get the public to realise the truth about PLHIV. All this sometimes means additional struggle with the environment, but this is the kind of struggle I gladly accept.

What do people think having HIV means here?

People think it means death. (Vesna)

People think it's still a topic for scandal. (Peđa)

People think that it means you are a whore. (Boba)

People think that it means that you are a junkie. (Marina)

It means...

'If I blow in your direction, you'll catch it'. (Vesna)

It means...

'Get away from me'. (Tanja)

It does not mean any of these things.

Having HIV does not = death.

HIV can = living.

It is not just about risk groups. It is about everyone being at risk. People refuse to think it can happen to them.

The people whose stories you will read about contracted HIV from:

Injecting drug use

Blood transfusions

Sexual relations- both same sex and heterosexual relationships, most of which were long term and exclusive.

The people that it has happened to are like you.

People think they can't get it or they think... it can only happen to junkies and prostitutes and so on, not us... everyone experiences it like that, like it can't happen to them, and actually the biggest infection is transmitted sexually so people are uninformed about that too or they won't get informed. (Dejan)

People don't get tested because they don't want to know

This is based on an outdated idea that HIV is a death sentence. Medical advances have changed this situation. Effective HIV treatment is available, which if consistently taken and monitored, alongside a healthy life style and early detection can aid people to live a long life with HIV.

People also don't want to get tested because they think that the stigma of HIV constitutes social death. By treating those living with HIV better and acting against stigma, we ourselves can change this.

The implication of not getting tested is that in Serbia and in Montenegro most new cases are late presenters (Jevtović, 2007) – this means that they are at an advanced stage of illness. It is more complicated for treatment to be effective if people have had HIV for a long time but only get tested when they become seriously ill (Sabin et al, 2004).

Most people are at risk.
It is important to get tested.

Can you live with HIV?

With access to consistent, regular treatment HIV is a chronic illness. Such treatment is provided universally by both the states of Serbia and of Montenegro.

The knowledge of it [my HIV diagnosis], it was like the end of the world and at that moment I completely closed up, I didn't want to and I didn't have energy to communicate with anyone let alone with HIV positive people. When I went to the Clinic for the first time, and when I saw all those people just sitting there and chatting, communicating, they behaved as if they were in an ordinary Health Centre. I was watching them, I went there with an NGO volunteer and I asked her: "Are these people ill?" she says: "Yes". I said, " I cannot understand how they are just like that..."

she says: “You don’t understand, they live an ordinary life and you will as soon as you recover”, I said: “Fine, let it be...”

The next visit was already better, the next more so and then I started communicating with them. I see them plan things, I don’t know, to go to Egypt for the summer, Tunisia, I don’t know... Living, an ordinary life. Then I wondered: “If they can, why am I different?” Well, I cannot go to Egypt or Tunisia but I can think in a positive way. Then I started to convince myself that it had simply happened, so what now? I am living with that while I’m alive. (Stefan)

If HIV is detected early, if HIV treatment is delivered by the system and taken by if the patient **consistently** then life expectancy with an HIV diagnosis can be long. Some of the people whose stories you are reading in this booklet have been living with HIV for 22 years already.

What does an HIV positive person look like?

Like anyone else.

‘Here, you see, I’m not a zombie, I’m not what people think – they don’t have a clue what an HIV person looks like. I say of the [HIV positive] people I’ve met, they look much better than those who are healthy, concerning their mental and physical health... [She said to me] “You’re so positive.”, and I said: “From head to toe.”, and she said: “What do you mean?” and I said: “I’m a positive person in the true sense!”, and she hugged me and kissed me and said: “I can’t believe someone can be like this, I thought you were an athlete!” (Milan)

I went there and saw these chubby people, you know – I could feel the energy, and I said: “You’re awfully chubby for an HIV person!” (laughs). (Ana)

Having HIV does not mean that your life, including your sex life, is over. Many PLHIV are active, living and loving. Some are happy in relationships. A few have had children since they have been HIV – and they have been healthy children – and some others are considering having them. These individuals show that there is so much life and living left after an HIV diagnosis.

I want to live. I want to have a quality life. I don’t want to stay at home. I want to feel well, I want to do this and also do something else. I fixed up the flat with my boyfriend. We renovated the whole thing, we renovated the garden, we did paint work... Like... I’m active still. I simply take care of myself and that’s it, I don’t have the thing: “Oh someday I’ll be all healthy!” I feel healthy, like all people! I have a disease I take care of and that’s it, I really can’t foresee my future, nor do I try to, I’m focused on the near future, not on the far future. (Ana)

What makes it difficult to live with HIV?

Things are much better than they were, but living with HIV is hard.

1 TREATING HIV

Maintaining your health if you are HIV positive can be difficult: some problems remain in treatment delivery in both Serbia and Montenegro.

The focus of this booklet is not on HIV treatment access and experience, but on stigma and discrimination in these settings. Serbia and Montenegro have different treatment settings, which reflect different political processes and circumstances in each country. Therefore separate country specific reports have been produced from this research and are being used in discussions with key stakeholders. In Serbia the report focuses on improving the regularity of access to monitoring tests for all patients in need (CD4 and PCR). Montenegro's report focuses on the challenges of establishing an independent care and delivery system and how this is experienced by PLHIV.

Although this booklet does not focus on the experience of HIV treatment (therapy and monitoring tests), it is crucial that the influence of treatment availability on PLHIV's physical and emotional ability to live positively with HIV is not underestimated. All the participants involved in this research are influenced daily by anxieties around treatment. Managing this uncertainty is particularly difficult given that it takes place within the broader context of the social insecurity of living in a transitional setting.

Treatment delivery is improving. But even when treatment is available constantly the demands of HIV treatment on the individual taking it are serious.

For further information on the treatment situation in Serbia and Montenegro for PLHIV see:

- Bernays, S., Janković Terzić, K, & Rhodes, T. 2008. The need for consistent access to treatment monitoring tests: findings from a qualitative prospective study in Serbia. LSHTM: London.
- Bernays, S., Rhodes, T. & Jankovic Terzić, K. 2007. Living with HIV in Montenegro. LSHTM: London.
- Bernays, S., Rhodes, T. & Prodanović, A. 2007. HIV treatment access, delivery and uncertainty: a qualitative study in Serbia and Montenegro. UNDP: Belgrade.

2 STIGMA of HIV: a key constraint on quality of life in Serbia and in Montenegro

Medical developments in HIV treatment have transformed HIV from a terrifying death sentence to a manageable chronic illness. Whilst there continue to be some difficulties here in relation to the continuous availability of appropriate treatment, this means that PLHIV can live full and active lives within mainstream society.

Medically this reality is possible: socially it remains very difficult. Sociologically HIV is a specific illness unlike other chronic diseases. The study has found that the responses of other people to HIV is the main constraint now on an individual's health and quality of life.

- a Loneliness can be a key characteristic in the lives of some PLHIV. One participant described it as the 'silent killer'. The tenacious stigma of HIV makes it so difficult to continue normal life that some feel forced to cut themselves off from their lives before.
- b Reduced quality of life is not only due to physical problems. It is a consequence of HIV being a social illness, with potentially devastating consequences.
- c This is the focus of this booklet:

What is it like living with HIV by those who are:

Why it's so hard to tell you that I'm HIV

Reactions of family, friends and communities

Access to healthcare

Discrimination in access to employment

Access to financial and psychosocial support

HIV happens everyday: diaries

Why it's so hard to tell you that I have HIV...

- ...because I am frightened of how you will react.
- ...because I risk so much by telling you.
 - ...because it is very painful for me.
 - ...and yet it is so hard to live with this 'secret'.
- ...and I think you would find it hard too.

...because I am frightened of how you will react.

The majority of PLHIV that we spoke to did not want to tell anyone they were HIV because they were frightened of their response. How will they react? Will they no longer be my friend? Will my family disown me or kick me out of the home? Will you shout at me and reject me?

Most PLHIV take great care to protect others from infection. For these individuals it is the people who are not HIV positive that represent the threat: what will you do to me when I tell you?

Who knows how many people went through abandonment: by the family, school, workplace, who knows what else. After someone else's experience that (telling someone) is always painful, because all of us have sometimes heard of someone else's painful experience, there's no one who's a member of the PLHIV community and hasn't heard of such an experience. So there's this fear...(Saša)

I do understand human fear. If I was to test it and I don't recommend it to anyone maybe out of them, I don't know, 23 would react normally and would not reject me but I'm convinced that 17 would because I had an opportunity, amongst everything else to talk to them about these issues and when you mention it people are appalled, name calling. Among them are medical workers and they do most of the name calling. (Stefan)

...because I risk so much by telling you.

There are many people whose fears have come true when telling people:

I told her everything. I thought I'd tell her first, then she could tell mother, but explain it all nice, because I thought being a health worker she might give mother a gentler [introduction]... Actually no, she said to mother like: "Hey, he's AIDS!" And my mother was in shock when she heard it. I mean, she didn't help at all, but she did me harm. Then the rumours started, like I don't know... like all sorts of things. (Ivan)

His 'friend' told many people about his condition. Afterwards his mother did not want him in the house. He had to leave home and his family.

When Branko told his family they made him move out of his home and live alone. He was fortunate to be given accommodation alongside them, but they would not share their lives with him.

My parents when they found out I had HIV, and we used to live as a family, my dad, mum, me and my younger brother, they separated me right away so that I don't live with them, so as not to live in the same flat – not to have the same bathroom, not to have the same toilet, not the same kitchen... It's [the situation's] still the same. Since 2001, and now it's 2007. (Branko)

There is also the risk that accidental disclosure will have negative social and employment consequences for the family. PLHIV often keep it a secret to protect those around them.

Look, my biggest problem is that people [would] point their fingers at my parents, my brothers. I knew from the start that I could not forgive myself if they suffered because of me. I would speak publicly about the problem, however here, no, no, no. I simply can't do this to my family. (Nikola)

Dragana, on her way to the hospital for treatment told the bus conductor that she was ill with HIV. The response of the passengers on the bus was to literally run away from her.

I didn't have enough money to buy the ticket for the public transport and the controller came in and I told him, "Sir, I'm sorry, but I really don't have the money, I'd buy the ticket if I did. I'm HIV positive and I'm on my way to get treatment in XXXX." He ran away from me to the farthest part of the bus, he didn't come back, and suddenly, 'cos I said it loudly the whole back of the bus was suddenly empty! I'm not saying I was alone, there were a few people left, but a lot of people either went out or went to the front, as far away from me as possible. Like: "Aah, she's AIDS! Look who we're on the bus with!" I hear people comment – "Buy a car and don't be on the bus!" (Dragana)

Ivan was in a pharmacy collecting a prescription when he disclosed that he was HIV positive:

Yesterday I went to the Health Centre in Novi Beograd to get some pills, I forgot to ask the doctor who gave it to me if there were any problems because I'm HIV positive and I have tuberculosis, and I asked the girl at the counter like: "I'm sorry, is there any problem if I'm taking TBC treatment and I'm HIV positive?" Like, everyone's looking at us as if we'd killed someone... (Ivan)

Telling people is seen as a huge risk. The response can be very unpredictable.

As Ivan says 'You're always scared... you never know the effect.'

The consequences can be devastating. Disclosure can result in losing your family, your home, your job and your dignity. 'In 90 percent of the cases they don't look at you anymore.' (Branko)

Even so almost everyone we spoke to still fears the response when they tell someone.

'They won't even sit and have coffee with me'. (Nina)

However quite a few of the participants were pleasantly surprised by the response of those close to them. The subsequent support they have received has been invaluable.

...because it is very painful for me.

In addition, to worrying about how disclosure may change someone's relationship and behaviour to you, telling someone else in itself can be very painful. Telling someone that you have HIV requires acknowledging your own loss and the losses for those you care about.

This is particularly so when they have been recently diagnosed, before someone has adjusted and come to understand that there can be a lot of living after being diagnosed.

It's something very personal. You know, it is up to you. For example, if you lose a child it's up to you if you want to tell to somebody who is very close to you about this loss. So it's the same, it's difficult to speak to you about my loss of normal physical and mental condition... You are not sure how you will react or they will react... so you can have this defence system, and you will be closed. (Mašan)

...and it is also so hard to live with this 'secret'

For a few the risks are too high, so they do not tell anyone. This is not because they want to deceive anyone but because they do not feel they have any choice. It is important not to underestimate how hard it is to live with such 'a secret'.

And they feel that- they have a secret. It's very, very... can you imagine that you have to live now with some secret, you know? For example you work somewhere, or you go... if you are outside in this world then this secret is in front of your eyes much more, you have to be careful about it, you know. For example, if I could work in a school and among parents and children and my colleagues and everything, you know, and living in this fear every day that... someone will somehow find out what is going on with me. I hate secrets, it doesn't matter what kind of secrets you know. I don't have connections with people who don't know about my illness, because I didn't want to tell, I couldn't tell everybody, I didn't want to tell everybody... Maybe it's cowardice or something like this, these are people which are very nice to me and I love them but it's a... Not that I'm not so close to them, they love me, you know, but I didn't want to complicate this situation which is complicated enough, you know'. (Neda)

What happens if I fall down in the street, why can't I tell anyone what's wrong?! Why do I need to hide, why?!... 'I want to say what's wrong with me, I want to say and I don't have the possibility to tell people what it is! I have the possibility, but I don't have the guts to be like that around people: "Hey, you know, I'm this! Now if you have the balls sit with me!" (Tanja)

...and I think you would find it hard too.

Imagine that you find out that you have a serious illness – and are dealing with your own reaction to that – then telling someone knowing that once you tell them they may reject or abuse you when you most need support.

When we have a workshop and training, I always tell all participants – go home, tell your husband and your children that you are HIV positive. Then you will start with one very hard period in your life and just feel maybe for a second what it's like... they are very scared about this. They become very serious and they are very sad when I tell them about it. (Mašan)

Reactions of friends, family and community

Well, I hadn't been [home] in a long time. I hadn't been for two and a half years I mean. But I didn't go out at all... out of... embarrassment, shame... I went down and all the relatives came to see me. By the way they all know, like: "Are you alive, how come you're living with it, how's this, how's that?" They all came to see, they were all looking at me like I'm unique. They're all looking at me from head to toe, assessing, what not... Horrible. I'm sitting at home and they're just coming over and sitting in the living room watching me. I sit in a chair at this... dining table, there. They all look at me like this, everyone's curious... They thought who knows, I'm falling apart, dying like there's no help... And Dad's like, "We eat and drink with him. So you can eat too; you won't get AIDS. Who won't have coffee or juice shouldn't even come to my house". (Ivan)

As he told us in Chapter 1, Ivan's friend had told many people that he was HIV. This not only had implications for him but also for his family. It was this in particular that he found devastating.

I mean dad's like well-known in town. He had a lot of friends, a lot... As dad says you didn't know how many people went through the house in a month, now he says only two or three people come over. The house has like died out. No one will come, everyone's afraid. Everyone's gossiping, you can see... Like dad says: "I'm sitting in the pub," he's sitting there somewhere with his friends every night and you can hear people talk, pointing at him, his son's this and that... So it's for dad also a bit... but he's used to this... He doesn't care anymore, whatever he hears he doesn't care anymore. I wanted to make a fuss [about it], but my dad asked me not to. (Ivan)

Sandra's extended family wanted to evict her from their shared home:

'They tried to kick me out through the court because they don't want a junkie and someone with AIDS in the house. Those were the words they used'.

Fortunately for many their families have supported them, to varying degrees. They see this support as critical in helping them to adapt to and manage their lives with HIV in the short and long term.

Nina echoes what many people said when she recalled: "Thank God I have my mother. I don't know what I'd do without her". (Nina)

For those who are not so fortunate the negative response of family and friends can be a significant loss. Many of them feel that it is not ill health that is necessarily limiting their quality of life but the reaction of those close to them to their illness.

Here Branko talks about how his friends stopped wanting to be around him once it got out that he was HIV positive.

I had an enormous number of friends, I... live in XXXXX [a small town], if it could be said about XXX as a town, and half of XXX knew me and know me to this day. I was friends with many people, but those friends suddenly vanished when I told them I had HIV. I have about ten friends now. [They] can be counted on the fingers of both

of my hands. The people I can go to, who can come to my place and talk regularly, go out for drinks... Although I don't hide that I have HIV from anyone, whoever I'm in contact with or communicate with and let alone something more. They're simply afraid. I don't know why. I can't pinpoint it, but if there's a girl, then they think at once that she's probably intimate with me; now, for her not to be discriminated against like me, she avoids me because of it. (Branko)

How people will react is unpredictable. Milan recounts how disappointed he was in a friend, who he considered to be highly educated, who when he found out, his friend couldn't bear to be around Milan.

I had this situation when my colleague wouldn't shake my hand and he graduated from two universities, he's a real intellectual, he's from such a family, both of his parents are medical workers. Unlike a lady that serves food at the hospital when during my surgery she hugged me and brought food from home for three days while I was in hospital, she said: "Well, I have a son too, how should I know, he has a daughter too, we could all have it!". And when you hear it from someone like that, anyone can help, and this man wouldn't shake my hand... You don't know exactly where and who you can... But I say: "Lucky children to have a mother like that." (Milan)

Many participants talked, like Milan, about their shock that so many educated professionals were discriminatory and abusive to PLHIV. Although educating someone about HIV, transmission risks and consequences are key to reducing stigma: it is also about an individual's empathy.

This is the story of Sandra's experience when she was sitting in the park feeding her kittens:

This man started shouting: "You threw cats out of your flat, from your home, that's what you do, you throw them out there and they become strays! I'll send you to jail now and I'll call the police!" And I, already being sorry to part from the kittens, and he upset me even more, my knees started shaking and I was really shaken up, and I cried a lot... I was speaking and sobbing with tears. I tried to explain how I wasn't doing anything bad, how I was also feeding dogs. But he was still shouting at me. And I was starting to feel unwell, my ears started buzzing with the stress. I told him: "Please don't shout at me, I am ill". He told me: "What can you young, 20-year-old people can be ill from?!", because he's retired. I told him: "Let me be, I have AIDS!", I didn't say HIV because he wouldn't know what it was, but I told him I had AIDS, to let me be because of it, so that I don't get stressed, not to pass out in front of him. And he told me like this: "You have AIDS?! Shame on you! And you tell me! You AIDS person! You're not ashamed of yourself!" And he's shouting, yelling! And there are buildings nearby, people came out on the terraces, watching. I told him: "I'm not ashamed, it's my illness, I even appear on television and speak

about having AIDS”, and he got even worse: “Shame on you, you even appear on television, it’s obvious you’re crazy if you’re doing that and you’re not ashamed to say it!” “How can you say something like that?! I’m polite to you and you tell me I’m...”, he started insulting me and then I started insulting him. And he’s like: “You’ll infect me! You’ll infect me! You AIDS woman, it’s a shame if someone has AIDS, you’re crazy!”, and he wanted to call the police. And I beat him to it and called them myself. While I was talking to the woman who answered the 92 number, she could hear how much he was shouting at me. I even said over the phone that I had AIDS, that he had attacked me and wanted to take my telephone. And he left when I finished talking to the police. I told him: “Where are you going now that I called them to come, when you insisted?!” He said: “I’ll be back!” And the police came, I explained everything and told them: “He’s gone, he left”. And there he was, he appeared leading some old woman with him and like: “She’ll testify that that AIDS woman attacked me and wanted to infect me with AIDS and threatened me”. I said it, and the police officer himself said it as well: “She can’t testify, that old woman wasn’t here. She didn’t see what happened”. However, the old woman said: “I know, the gentleman’s a very fine man”. And so I turned out to be the bad person even though I came there to do something good: to release animals into nature, to feed them, not only them but the puppy as well, I gave water to him too. But he the police officer reprimanded him, simple, like: “You cannot talk like that to her, it’s nothing shameful and ugly, it is a good thing she told you”. However, he persisted insulting me in front of the officer, he still talked of me – the AIDS woman who should be ashamed talking about herself like that. I still don’t get it... he’s a nicely dressed gentleman, he’s no vagrant, educated... how can someone educated, let’s even call him a gentleman, speak like that, that I’m an AIDS woman and that it’s shameful to be an AIDS woman.

Why was I getting upset when the man was nothing in my life, a mere passer-by, but, Sarah, I was really fed up suffering being told:

“You’re a junkie!” – I keep quiet.

“You’re scum!”, I still keep quiet.

“You have AIDS!”, I still keep quiet.

I always have to keep quiet before these people.

And I try so hard, I appear in public and in newspapers to explain to these people that we’re not going to bite them, that we’re not going to do I don’t know what to them, that we want to live normally beside them, like they do. And they keep at it... I would not be so confused if it was someone uneducated like that, but this man seemed like he had come out of an office. And seeing by that example, how he experienced my story, which I told him nicely, it means that most people in this town would react like that. Many would... and it is so. So it’s like, you can take it all but sometimes it can really hurt. (Sandra)

Tanja recounts the situation now that her neighbours know that she is HIV. The task of educating her neighbourhood seemed too large to overcome.

My neighbourhood knows, for example, and no one's talking to me. No one. Six floors, I live on the fifth, no one's talking to me. I don't have a neighbour. I mean, I don't have a neighbour. Apparently no one should communicate with me, because I can transmit it through the air, you see?.. So I put it up in the entrance hall, like... HIV this and that. Three ways of transmission, and all that. But I thought to myself "Come on, Tanja, what are you trying to do for one building, when further on three, five, ten buildings haven't a clue how HIV is transmitted. (Tanja)

Participants living in smaller towns and rural areas stressed in their accounts that they felt they were affected more profoundly by stigma and discrimination than if they lived in cities.

I know it sounds horrible, but it disgusts me! All these small towns are the same story: everyone knows everyone else and everyone tries to pin something on everyone else! It's horrible, horrible! That was the main reason why I went to XXXX (large town). (Nikola)

Although it does appear to depend in part on the individual, this next account illustrates that proactive steps to educate people about HIV and transmission risks can make a difference.

Sandra's friends would not believe her about the low risks of transmission from casual contact so she encouraged them to speak to a doctor about it. Once they had this information they were happy for her to spend time with them and their daughter. Being included and not feared made a positive difference to Sandra's life and self-esteem. She recalls the first time they let her look after their child and how good it felt.

I have a friend in XXXX who's 30 years older than me. He has a wife now and a little two year old girl... Only after he found out from a doctor that it can't be transmitted just like that, did he relax. But he told me honestly "I went and asked" and so we had an open conversation. I had also told him to make sure to ask a doctor when he's getting a check up, because he went there to ask about it. I told him "ask any doctor, I insist you ask, because I'm not going to try to convince you about anything any more". And then they let me walk the girl on my own about ten days ago through the centre, the park in XXXX, where everybody know me. And I was happy to walk her. And everybody looked at us, me and her, sort of with amazement. I gave her candy, I put it in her hand, so I'm touching her, everything. It was hot, so I was perspiring. But no problem. The shop assistant who sold us the candy acted normal, and everything was sort of quite OK. So I can see that, all the brochures I gave him to read, and he saw me on TV, so he knew if I said something in public I'm not going to lie. But until he talked to the doctor, he wasn't quite clear on it. (Sandra)

Knowledge is important, as is the willingness to learn about it.

For those who have the support of their family and friends, life is much easier. Even for those who encounter or fear hostility from their communities, if they have familial support they feel better able to deal with it. Importantly not everyone encounters discrimination, there are some exceptions:

Well, since I found out I naturally haven't told the whole town, but I told my closest circle of friends and I thought... that if any one of them had a problem with it then I don't need them, what do I need friends like that for who'll suddenly have a problem with it, we were friends and now we're not anymore because of it. Then ok, they shouldn't be my friends. My relatives accepted it the way they did. They all know, they all know what it is, how it's transmitted, how it develops, the course of the illness, how long you can live with it, they know everything and no one has any problems at all. (Vesna)

For those who don't have the support of their families or friends and/ or those who are fearful of the social consequences of HIV it can be very lonely. However much they are themselves not a risk.

I'm trying not to infect anyone, if I can give someone some advice, I don't know, in this sense whoever wants to listen to me I'm always prepared to talk to people... Well the disease isolates one a lot, you know... It's not all the same to people who don't have it... I can understand these people too, but what can you do... At the moment here the situation is that the disease is very isolating. (Dejan)

Company and support can be especially important when you are not feeling well. Even if this is from pets not people!

When I'm in a bad mood and I start crying... When I cry, I cry very quietly, I don't mean to but the tears just fall... There he is – coming over! Then he lies down somewhere, sniffs around... I kiss him all the time, and then he like touches me with his wet muzzle, touches me like, you know... It's a reason to live, to live for someone. (Dragana)

The participants we spoke to also said that the physical and social consequences make you more vulnerable to stress.

Being alone or with limited support makes all the rest of the difficulties, for example accessing healthcare, or trying to get a job or financial support so much harder.

Yes, you know, the sensation of stress, it becomes much stronger when you have lost your immunity. This is the general problem... It's more stressful, you know. It is maybe ten times stronger because you don't have your natural defence system any more. For example, some minor situations make you completely disordered. (Mašan)

Access to healthcare

Branko recently broke his jaw and needed medical attention.

He asked himself: should I tell the doctor or not?

He didn't want to. He was frightened they wouldn't treat him.

His friend, an activist within the HIV community, persuaded him that it was right to be honest and to disclose his status to the doctors. His friend argued that it would not jeopardise his chances of treatment because the doctors had a duty to treat him.

They refused to.

He could not get treatment.

So, this guy you don't know, recently last summer he had a situation, he got beaten up. He's HIV positive...

I always used to tell him it's a nice thing to tell doctors and dentists. It's nice to tell people straight out honestly "I have HIV," so they know right away what they're dealing with. So it's all honest.

And he always opposed this idea of mine. "I don't want to talk, I don't want to say anything to anyone. What do I care, it's their duty to protect themselves," and so on.

And he's right and to some extent I'm right.

But then it became a great need because now his jaw was broken. He decided after all to be honest and say he's HIV positive, it was at the Dentistry Faculty.

Back in 2000, when my jaw was also broken, I told them honestly. I was admitted but with difficulties. All the senior professors turned me down, but a young doctor accepted to simply tie up my jaw. I didn't need surgery.

But this friend had a worse time than me and this was in 2007.

None of them wanted to operate on his broken jaw, because he said he was HIV positive. They had a team meeting to make the decision on this patient; who would take him over and who would do the surgery. In the end they told me they couldn't operate on him. We were rather shocked. Our doctor XXX, because he's usually a rather phlegmatic person, and somehow flexible, he can understand everything, he is full of understanding, especially for his colleagues, for the first time he was I can say a bit angry, he'd had enough. Because this is happening now, in 2007. That's when it happened, some twenty days ago, a month at most, when he was rejected by the doctors. And we were all a little surprised, we didn't expect after so much talk and so many years of talking. So I didn't expect something like this to happen to him at all.

Can you imagine how his family is disappointed now too. But they are also [disappointed] in me too, because somehow it all turned out in the end like: "XXX, you advised me to tell them and when it comes to some critical medical procedures like an operation and something like that, be sure to tell them," and he did. And I'd always thought he'd be accepted like I had been. Now I just don't know.' (Sandra)

Although it is against the professional code of conduct and against the law, a number of medical workers still refuse to give medical care to PLHIV. As Branko's story shows. Barriers to access remain par-

ticularly severe in surgery, gynaecology and dentistry. Tired of this, many PLHIV, like Branko, Sandra and Jovana, struggle with the dilemma of whether to tell medical staff that they are HIV positive.

If I go here and say say [I have HIV], then I get: "Well, you know, we don't have sterilised equipment at the moment." or "There's no water." Then "I'm in a hurry." Then: "Come back another day, let me call you back." When he says "Let me call you back." I know immediately he won't see me... So you go and say my tooth aches [and not disclose status and they treat you]: but I don't think that's right because then we confirm some stereotype story that all of us who have HIV want to infect others. All the people I know, 100% I know none of them wish to infect someone else. But when something like this comes up... Then you say to yourself: "Alright then! Just go and get it done, don't say anything!" (Jovana)

All the participants in the study want to be honest with medical workers about their HIV status, but they also want to get treated, as any patient deserves to. So some PLHIV do ask: how can they demand that we are open and honest, if the doctors with all their education to care and capacity to protect themselves still refuse to treat us?

Explicit discrimination appears to have become less common over the course of the research. However as Jovana's experience illustrates indirect discrimination, where medical workers deny treatment in more subtle ways, persists.

Common excuses:

- **'There is not enough space for you;**
- **I don't have the knowledge;**
- **I can't disinfect the equipment'.**

Dejan lives outside of Belgrade. He has been turned away from each primary health centre in his area because he is HIV positive.

I try to do whatever they ask of me, but sometimes it's very hard 'cos really no one here in Yugoslavia, at least 90%, with exceptions, they don't give you the time of day, as soon as they hear you're positive, it's like you have the plague, right?! And you're simply so discriminated that... In a year, we have around 8 GPs in XXXX, I went through all of them, no one wanted to keep me as their patient. Either for this reason or that...

What reasons do they give?

Well... for example there are too many patients, one gave that as the reason; the other one: she doesn't know about these things, she has never been interested in them so she doesn't have a clue and she doesn't have the will to keep learning; and the third one also said the same thing. (Dejan)

Dejan has also been trying to see a dentist, as PLHIV commonly face problems with their teeth. He has not been able to see anyone locally. Instead he has to travel to Belgrade.

'They don't dare touch me in XXX because of my illness, that's why they wouldn't pull [my teeth out]...

What do they say, why won't they?

They say they can't disinfect the tools afterwards...' (Dejan)

Not my responsibility

Some PLHIV found that despite their concerns medical staff *appeared* willing to offer care. However their attitude changed when it came to actually conducting any intervention. Sandra's account echoes many of the other participants'.

At first contact they don't react, when you tell them "I'm HIV positive", they're not surprised but they have that... "alright, that's normal". They have it... but when it comes down to an intervention when they have to make contact, then they start passing the ball a bit more to a colleague and so on. That's what you notice. (Sandra).

Tanja needs surgery but she can not find someone who is willing to operate on her.

'My gall bladder started, the gall bladder started excreting bile, and I was as yellow as a canary. But no one would operate on me! We have a big problem, no one will operate on me, no one's interested in operating on me!...

My life's hanging on a thread because of this gall bladder which is full of stones! It's not 1, 2, 3 but a whole quarry! It hurts so much. It really hurts!... And they kept searching for a surgeon for me, no one came to see me, no one came! (Tanja)

DENTISTS

As with Dejan, both Tanja and Sandra also need a dentist.

Tanja was refused treatment.

I got referred to the chief in XXXXX, he reads it, folds it, gives it back and says: "You go to your Health Centre where you will be given adequate help". ... "Don't you pull teeth out here? Pull out, fix...?" I needed just a plain tooth filling! And he ditched me: "Go to your Health Centre!", the chief... I'll find out his name... If I had cash I'd sue all of them, I'd call on all of them, all who disappointed me. (Tanja)

Sandra hasn't even tried to go to see a dentist because she fears that she will be pushed around institutions, with no one accepting responsibility to treat her.

This time again I need a dentist. I have such pains in my teeth and a high temperature because of my teeth. That's what the doctor finally said that it was giving me headaches and now I need to find a dentist. I decided to go and do it on Monday, but I don't have the strength, because I actually don't have anywhere to go and look for a dentist... If I go to the Clinic, I know what they'll say to me there. They'll say what they've always told me,

that they have no material, they don't have enough equipment for protection. If I go to the Health Centre they'll tell me that I'm not their case, but I better go to the hospital, the Dentistry School. And again if I go there, they'll say "You can't come here, you have to go to your designated clinic. And around in circles'. (Sandra)

Healthy treatment: the same rights as other patients?

Amongst those who do get treated, some experience poorer treatment than other patients. PLHIV interpret this as further discrimination.

An acquaintance was supposed to do an ultrasound of the upper abdomen, with a referral from a doctor in Belgrade. He went to get it done and the doctor who was meant to do it, when she saw the code B20 (HIV), she was horrified and wouldn't do it; "Why don't they do it in Belgrade?" and things like that... He says... she started putting gloves on... like he had the plague... I am saying that medical workers who don't deal with this issue are very uneducated in this sense and very uninformed; they live in their own ideal world which doesn't allow for a person like that, it's something she doesn't know about, [we're a] marginalized population and she doesn't want to deal with it. (Stefan)

There are clear procedures on how doctors and nurses should protect themselves in dealing with any patient. Being professional means being obliged to follow these procedures and not acting on personal prejudices within the work environment. For the latest information, consult the WHO guidelines.

Many PLHIV reported that medical staff commonly treat PLHIV as though they are unworthy of the basic rights entitled to other patients. This following case illustrates how this includes not only access to medical care but also treating people with respect and educating them about the choices that are available.

Nemanja went to see a doctor and took a friend with him who was also HIV positive and knew the doctor.

She went into the office with me and she was a bit more protective towards me, you know like... And the doctor sensed it and said : "Don't you think about having sexual intercourse! Viruses mustn't be mixed..." She could have said it in a completely different way, for example: "You are people with HIV...", it's my opinion that patients should be talked to like that: "If you decide to have intercourse there are condoms for protection." And that's it! And not: "Don't do it under any circumstances'. (Nemanja)

An example of the distrust between some medical workers and PLHIV is illustrated by a recent request by another ward to the HIV clinic asking them to disclose all the names of HIV positive patients.

They're always asking for it, the list of HIV positive people. I suppose to know them by their names, if they had a patient like them come, to know that they were HIV positive. They think that perhaps they'll protect themselves better like that. They [the HIV clinic] always reply that, I know this because I was present at one of those situations, "You're obligated to protect yourselves, legally, from anyone, and we are legally forbidden to provide names for you". (Sandra)

I expect that you will treat me badly

In various ways PLHIV feel discriminated against in accessing healthcare and treatment. Trying to find or visiting a doctor can then become a scary experience. In particular if it involves accessing care for the first time or through a different doctor to normal.

PLHIV have become reluctant to access healthcare because they anticipate there will be stigma-related problems and this will be stressful and upsetting.

I haven't been to a gynaecologist for a check-up since 2003. But I think I should. I don't know. I have this... like I'm tired of it, like I'm already expecting some sort of a negative reaction from them. And then I try to find out or hear about someone who's OK, a doctor without such prejudice and when I find out about it I'll go for a regular check-up. (Sandra)

PLHIV may experience discrimination in multiple settings: their home, their neighbourhood, their workplace, on the street and also when they are unwell and need healthcare. These experiences are not felt in isolation but build upon one another accumulatively. As a consequence of previous experience some PLHIV anticipate that they will definitely encounter negative attitudes and behaviours in particular situations. This expectation can become a form of self-stigmatisation.

10 years ago I was told: "You'll be kicked out of here, you'll be kicked out of there!", blah, blah, blah. I went to the Institute for Oral Surgery in Doktora Subotića Street, 10 years ago, not today. I told the nurse what it's about, she just looks at me and says: "Alright." The doctor saw me without any problem, he processed me like any other patient and nothing. And I discriminated myself by putting a label on myself. (Saša)

This is not to say that experiences of discrimination are imagined by PLHIV. It is instead to illustrate how the difficult environment in which people are living their life means that, for some PLHIV, their encounters are interpreted through the context of previous or anticipated discrimination. Their assumption is an internalisation of what is happening around them.

Most PLHIV have a very real fear of being discriminated against and are frequently in vulnerable situations. Both in cases of discrimination and self-stigmatisation medical staff need to be sensitive to how their actions, attitudes and behaviours might be interpreted. Care needs to be taken to encourage PLHIV to believe that there is no prejudice in the way that they are being treated. Treatment needs to be fair.

Why are PLHIV more vulnerable in securing access to healthcare?

HIV weakens the immune system.

PLHIV are more likely to be vulnerable to poor health.

Therefore PLHIV are more likely to need to access healthcare.

Yet because of being HIV positive, PLHIV are likely to have less access to healthcare due to discrimination by health care workers.

And because they are HIV they are also likely to have lower incomes and therefore be more dependent on the public health services rather than private healthcare.

They are also less likely to be in a position to pursue anti-discrimination legislation to ensure that they receive fair access and treatment.

Because of previous discriminatory experiences, PLHIV are likely to anticipate further difficulties and be very anxious about accessing healthcare.

In this way they are both more dependent and more vulnerable.

Access to healthcare – getting healthier?

Access and treatment for PLHIV appears to be improving. Though not necessarily representative beyond our sample, there has been a decline in the number of incidents reported amongst our participants over the duration of the research (2005–2008).

There are also instances of positive experience of healthcare access and treatment. These examples show what a positive impact it can have on individuals when they are treated fairly and decently as patients.

It was at the Institute for Blood Transfusion and the nurse was supposed to take my blood out to determine the blood type. There was a very nice, calm old lady who wanted to: she sat down, rolled up my sleeve and said: "Give it to me, give the hand over! Be still.", and she put the needle in from the first try and she says: "Don't you worry, just sit there for a few minutes." And no problem, I was thrilled with her approach. (Tanja)

Marina recounts an experience she had:

The doctor who did that operation, he was very, very good to me, and I liked him very much because he's... giving you some hope that everything will be alright. Another person who he also operated on, they were all very satisfied with him. ... Some people are totally scared, they don't want to know anything about that and they just want to avoid any contact, presence, things like that. But other people are open to life to everything, and they just... you know they do their job, they like to do that and they're open and very communicative. (Marina)

Unacceptably, accessing fair treatment still depends very much on the individual as Sanja explains:

'I went to a dentist, one rejected me. It was hurtful, he turned me down; he wouldn't take a tooth out for me and then I heard about a young doctor who is quite a good man and I'd say: "I will call him now and I did and he says: "Come here, I'll do it for you." And he did (...) if I have any problems with my teeth I have a dentist now.' (Sanja)

The question- how will they react to me? – is a scary one for PLHIV. The response of medical staff, however unjust this may be, is unpredictable. Fair treatment for PLHIV is not yet common practice. PLHIV are not confident in the system and with the professionals. In light of medical knowledge about HIV transmission risks and general protective standards, it is inexcusable for PLHIV to be treated this way by healthcare professionals.

You know, because you come to the doctor, to somebody who you should trust, who gives you some hope. But if he receives you without respect, without [acknowledging] how important it is for you, then he gives the wrong picture of his profession. He is not professional anymore. (Mašan)

Employment

At the beginning, for example, I wanted to work; maybe you remember that I said that it was horrible for me that I couldn't work. I went to this doctor to this commission for pension and I told him "I want to work!" I wasn't clear in my mind what was going on with me and what is happening... He said: "Yes, I understand you, but this is the Balkans and you can't work." And he was very kind, very polite but... I've heard totally different stories [from other people], you know, "What! You want to work around children!" Because I'm a teacher... I taught before and I love my children, they love me, but now... now, it is so. And it starts this isolation you cannot fight this, when you must make your own shell and to try to exist the best way you can. (Neda)

A few months later Neda talks further about what not being able to do her job means to her.

But my work – this is something that I cannot – I even now cannot... I don't want to think about it, you have to put it very deep inside you... Because it hurts so much. So I don't want to think about this, how it would be like to work with children again or something like this. It is like an atmosphere around me, you know; for example some common things: you don't have money because you can't work; you don't know what to do with your spare time because you have too much of it; you cannot engage your intellect because you don't know what with; you don't have obligations to go somewhere, to do something, to be inspired with something, you know? Everything you have to do you must take from yourself. It's like you're your own garden. (Neda)

.....
The denial of ongoing employment in this case on the basis of an HIV status is a violation of the following legislation:
.....

in Serbia

- **The Law on Employment and Unemployment Insurance (2003)[3]** prescribes equal accessibility to employment and equality in the recruitment procedure for all persons seeking employment, regardless of their race, skin colour, nationality, ethnic background, language, religion, political or other beliefs and affiliations, social background or descent, financial status, marital or familial status, familial responsibilities, age, membership in trade unions, associations or political organisations, or any other factor that may constitute grounds for discrimination or unequal treatment of individuals among whom differences do exist, but irrelevant for the performance of tasks pertinent to the post.
- **Article 21 paragraph 3 of the new Constitution of Serbia** is also violated in this instance for discriminating on the grounds of HIV positive status (which, amongst others, is defined within mental or physical disability). The constitution stipulates that all citizens shall be equal before the Constitution and the law, that all citizens shall be entitled to equal legal protection, without discrimination, and that any discrimination, direct or indirect, on any grounds is prohibited.

- Other pertinent examples of protective legislation.
 - **The Health Care Law (2005), [1].**
 - **The Law on Higher Education (2005) [2]** stipulates, inter alia, that higher education is based on the principle of “respect of human rights and civil liberties, including the prohibition of all kinds of discrimination”.
- Whilst legislation exists it is the implementation that is a problem. Jurisprudence should be further developed by the general Anti-discrimination Act which is currently being drafted.

in Montenegro

- **The Labour Law, Article 3.** (1) Employees are equal in accessing labour related rights regardless of nationality, race, sex, language, religion, political or other beliefs, education, social background, financial status and other personal qualities.
 - (2) It is the employer’s duty to respect the rights and the equalities of employees in accessing rights, as well as the employee’s privacy and dignity.
- Article 8 of the Constitution of Montenegro, **Prohibition of Discrimination**, which states that any indirect or direct discrimination on any grounds is prohibited. Regulations and special measures aimed to create conditions for the establishment of national, gender and overall equality, and the protection of individuals that are in an unequal position on any grounds shall not be considered discrimination.



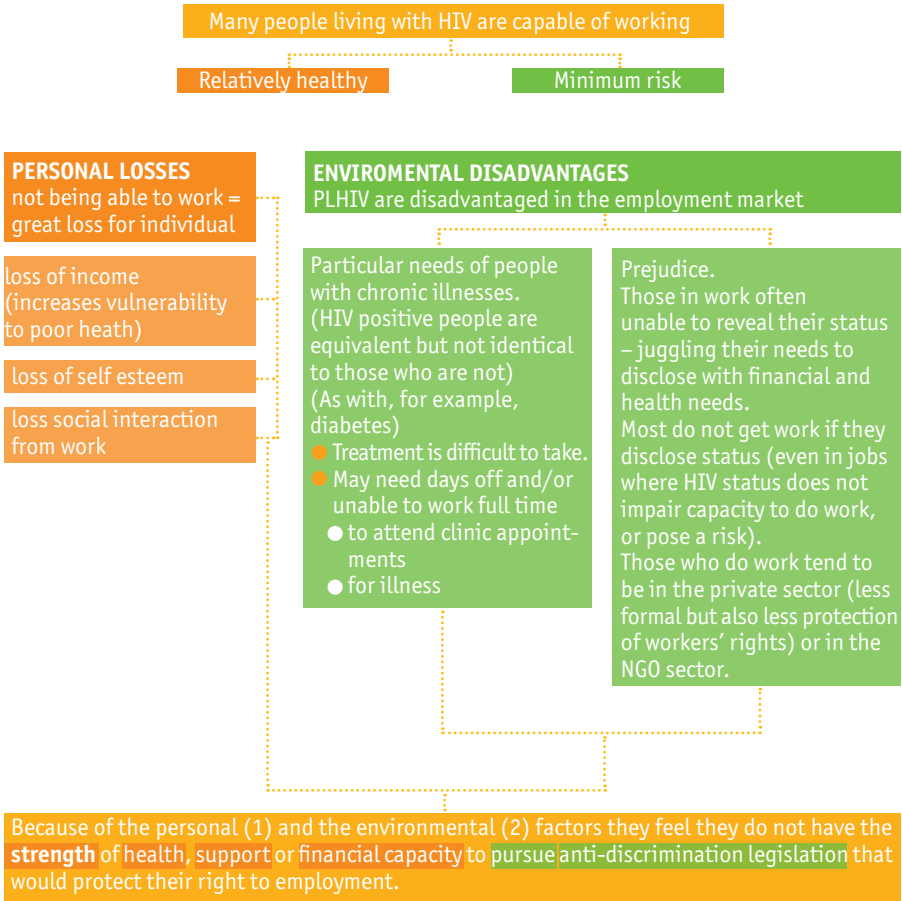
The changing and varied health of PLHIV

HIV is a virus that develops into AIDS. It is a complex disease that affects individuals differently. This means that PLHIV are all at different stages along the spectrum of health and illness. The low immunity caused by their disease means that most are more vulnerable to common infections and illnesses. On treatment some are almost as healthy as anyone else: others can be weaker and often ill. There is no one standard of health for all PLHIV. In two HIV positive people, even if infected around the same time, the virus can manifest itself very differently.

The health of one person can also fluctuate over time. Most of the time they may be well and fully functional but occasionally they may become ill and unable to work for short periods of time. This is common to many chronic illnesses.



Despite changes in the law to better protect PLHIV unfair recruitment, employment and dismissal practices are still commonplace.



No one deals with people’s life quality here, people just deal with seeing others alive and the like. Maybe there are some exceptions at some levels, but it’s very superficial, the quality of life is really important, because if it’s possible for me to live then we’re wondering what my quality of life is, if it’s something acceptable for me, or it’s like... Like when you put someone on machines like: “It’s great, he’s living!”, and he’s a vegetable! I mean, it’s questionable. On the other hand, when my life is of better quality then I’m more capable of working, then I have nothing to ask of the state of the social services, the social programmes. I mean, I can earn for myself. As in this case: at the moment I’m involved in volunteer work – I’m working, but maybe I could’ve been working somewhere for money, you see. And when I’m not capable of working, I think it’s much more expensive for the state. (Ana)

Dejan's story is indicative of the situation faced by many HIV positive individuals.

I'm still capable of working. Alright, I can't dig and break concrete and the like, but I can do anything else, not the hardest jobs, but like: paint, carpet or laminate flooring, parquet flooring. I can build, paint. Plus I work with tools, that's my trade... But what I don't understand, I went to the Municipality last week and the week before last, I had to go to the Vice-President of the Municipality and lay my problem out before them. And now, I explained to the President what the matter was, that I just couldn't understand: I didn't go anywhere to ask for help but the first thing I did was – I went to the Employment Office, I registered there, I went to the Health Centre – and I registered there. I told them immediately what I suffered from, it was all sorted. And then they put stamps, not stamps but they wrote it on my health card. I did some jobs then, how do you call it? Not regular jobs, but when you get something, someone calls when they need help, for two, three days. And when I was to go again to renew the Health Card then they saw it, right? And when he [man at employment office] saw it he said: "You won't get a job with it! With this disease there's no way anyone will hire you here!" And then he suggested I go to the Social Services and explain my situation and they would refer me on and they'd help me and so on. But that's also no good because you don't get any assistance from them, they just declare you as disabled afterwards and if you're lucky to find a regular job somewhere, they wouldn't take you full-time anywhere because you're declared disabled. And I chased around for a year, and I got all the papers and... I gave them everything they asked for! And then when I submitted it they said they'd decide and let me know. They turned me down... Because it was determined I was fit for work. But they told me I have the possibility to, [so] I sent the appeal, one day and two days later the decision from the council arrived that, since the papers are outdated and I haven't sent anything new, I'm still fit for work. They practically confirmed the first instance. And the second instance should be that they call you personally and they ask you questions and you answer. They didn't call me, nor anything but the paper just arrived and it said there was no more possibility to appeal, I should go to Social Services. And then the Social Services shut me up with 9 thousand dinars – if it were 9,000 at least, it's 2,900 a month...

And I'm supposed to use it for clothes, food, fags, everything, everything... Because unfortunately I have such a situation at home that I'm the blackest sheep there is in this world. Since that moment I've been a middle aged incompetent who can't wipe his own ass! And I've been living alone and taking care of myself for over 10 years, I never asked for anyone's help. I was a normal, ordinary man, born in the country, grew up on a farm partly, partly with my grandfather, I like nature and so on, agriculture and the like. And so on...

Actually, they say it costs them a lot and they won't employ me! All I ask actually is for them to employ me for as long as I can work, I'd like to work, only I can't do hard physical work, I don't mean leave me somewhere to sip coffee for 8 hours, of course, there are other jobs than digging or hauling and pushing rubbish bins and throwing them on tractor trailers...

I can't stand that someone won't help like that. I mean you won't give me a job but you won't give me this and you won't give me that. I have to do everything by myself, how can I? There's no other way for me, and I won't sit in this room of mine with my mother just waiting for the devil to take me. I'll just do it like this for as long as I can. (Dejan)

Support: financial and psychosocial

Financial support

The low employment market affects all people to varying degrees living in Serbia and in Montenegro. As we have heard, PLHIV also have to overcome the additional barrier of discrimination if they want to get or keep a job. This disadvantaged access to income means that many PLHIV are now living in poverty. Anyone with a chronic illness needs to take extra care with their health. As with any chronic illness PLHIV need to take extra care to maintain their health. Some PLHIV find that they do not have enough money to maintain a good diet, which is crucial in ensuring HIV treatment is effective and in keeping well (Paton, 2006).

Sandra, who does not have the support of her family, is currently on a very low income. She is aware her health is suffering, as her CD4 count is dropping, because she can only afford to eat sporadically.

But if I go on like this [poor diet], for example in spring I could expect it to be lower [CD4 count]. And if we're lucky enough to have something to do and find a job maybe... Then we could go on living normally... It's very burdening. 'Cos we're all alone, me and him, we have no relatives, no one... to turn to when we're in a crisis and it causes fear both with me and him. I worry because I'm ill and that's why I consider I should be a little better off financially. If I was healthy, if I didn't have HIV I wouldn't worry so much. (Sandra)

This echoes Mašan's remark in Chapter 3 that the consequences of HIV make PLHIV feel more vulnerable and makes everything much more stressful.

Not all PLHIV are well enough to work (even if jobs are available for them) and some financial pension support is available to those entitled to it. Like others though PLHIV often fail to access it because they are unable to navigate the complex bureaucratic systems.

However there are additional problems particular to PLHIV. Firstly, it is very difficult to find information which helps you understand what you are entitled to. Many PLHIV are missing out on support because they are unaware of the specific opportunities for assistance, for example either financial or legal support.

Secondly HIV is not a static illness. There can be long periods of time when you are well and then you can quickly become ill – for short or longer periods of time. There are difficulties in managing the financial support systems when your health status is changing. Ironically whilst sadly telling someone that you are HIV can still have explosive social consequences, physically it can be very hard to tell if someone is 'well' or 'ill'. So those who are too weak to work can fail to get assistance because they appear too 'well'. Physically 'AIDS doesn't make you dramatic'. (Ana)

Finally HIV positive individuals have to cope with the response they get from personnel working within the social welfare system. Some personnel are still 'afraid of me' (Milutin).

(Milan) describes how one centre reacts to him when he comes by:

"Don't come in, tell me what you want to know?" [while I stand] in the doorway, and: "Contact us on the phone." And then when you go out they wipe the door handles with alcohol and then it provokes sorrow with a lot of people and all... regardless that they too know that's not the way... (Milan)

Milan suggests that the issue is not education because they too know that it's wrong. It may instead be about prejudicial attitudes towards PLHIV. As we suggested in Chapter four, as with healthcare workers, there needs to be a greater appreciation for the difficulties that PLHIV may be facing in every aspect of their lives and within this context how upsetting their actions and approach can be for that individual.

Milan describes a more positive experience with a social worker and what a significant difference her reaction made to him and his life.

Here, for example, from three, four weeks ago, because I should have my teeth done and my social worker said: "Well, you have the right to this, because you haven't used this short-term assistance, because the amount is large for this...", because these medicines hurt our teeth a lot and I said I really don't have that much money, and then she said like: "We'll try and apply for this...". And she's new there, I saw her the first time now I was there, but my file had been there from before and she called me, she contacted me, and when I saw her knowledge about the disease itself and her interest even ... It thrilled me so much I said: "This is a wonder!" (Milan)

Psychosocial support

Other important forms of support that PLHIV need are psychosocial, advocacy and legislative support.

An analysis of the Non-Governmental Organisation (NGO) situation is available in our previous report (Bernays et al 2007). The stability of the NGO community is improving: although short term funding remains a concern for the stability of organisations.

Many PLHIV feel that it is important that they are included in NGO and support activities, not only as beneficiaries but also as service providers. For example in training conducted around HIV, PLHIV have considerable expertise from their experiences and this needs to be acknowledged and better utilised. Increasing their inclusion in community activities enhances the ability for others to understand the realities they face. It also counters the marginalisation brought about by the societal or anticipated prejudice towards PLHIV.

A few of the individuals included in this booklet are working in HIV NGOs. Here are a few accounts of what this means to them.

Really, it moves me and when you know... You tell someone there, they had a problem and they say: "You try.", then when you also resolve that problem then you're happy and they're happy and then it gives me even more potential that I can do something for myself too. (Milan)

But alright, these are some things that are very important for living with HIV. When someone who's been through it themselves tells you about this support, it's a bigger thing, than when you're reading about it in the newspapers, when you're sceptical. When you hear it live... It's not like it solves the problem for you, but you approach it differently. (Ana)

I think that by being active I'm fighting for human rights, my immune system's improving, but I'm involved and I live like normal people, and it's there I can see myself, that's my thing, I want to live as long as I live... (Stefan)

It feels good that I'm somehow equal to all these people who are professionals: there's a doctor infectologist, then another doctor who works with these younger children with an NGO, then there's the doctor who's chief of transfusion there, then there's... I consider them professionals involved in all this. I'm not saying I'm underestimating myself now, but it means a lot that you're being accepted, that they plan all these things with you. (Milena)

HIV happens everyday

Diaries

As Nikola says it can feel like 'the whole thing around HIV begins and ends on 1 December (World AIDS Day)'.

HIV affects people's lives everyday. Here are some extracts from HIV positive people's diaries over the year of the study.

4th January

I really don't expect anything else, just to be given the chance, the opportunity to fit in the society and live my own life, get a job, work, I'm not asking for anything else. But it seems to be too much, why I don't understand.

But alright I won't do anything and if I wanted just something – some help, take advantage wherever I can, if I were such a person I'd understand their stopping me so... I'm not such a person, I don't like asking other people for help... Simply because I've been on my own since a very young age...

I just don't understand the problem, what it's about here, why people are so bigoted here.

People are not informed, they don't know what it's all about, nor what it is, they just heard about HIV, that it's dangerous, that these are all criminals, junkies and insane people who have this disease and you should absolutely have no contact with them, isolate them, it's best if we bring back Hitler and the gas chambers and let's go for a shower! ... At least that's what I feel it's like here, and since your study's asking about feelings and experiences and events one's been through, there... That's what I've experienced in the last three years... Although if you remember when we met the first time I was really positive, I thought it would work out somehow: you're at home, in your country... What home, there is no home! Where's home?! Your country... People might understand me better here, I'm not a foreigner, I don't need a residence or working permit... No! Here they wouldn't let me go out of the house, let alone something else, only if they could! How it could come to that in this country, I don't know!

And finally, the most important thing for me in all this, and as I met people and as I saw the way they lived, what they're longing for and so on, no one is in that difficult a situation... No one's asking for something impossible, but just to let us live, fit in this society, accept us the way it is, to see the disease the way it is, it's not.. It's a dangerous disease and all, but you can't get infected so easily. Only people just don't do that, they don't get informed completely, they make the same mistakes I made, for example, with the disease. For a while, I mentioned it at the beginning, I just ignored the disease although it was before my eyes the whole time, I didn't avoid anyone, I was friends with everyone, whether they're ill, healthy, junkie or straight, it didn't matter, it mattered what the person was like and that's what people should understand here; it's people, and not be so strongly prejudiced... It's hard for me to understand... (Dejan)

17th February

Here, after 10 days of taking this new therapy, the first 5, 6 days like I felt horrible: I get up in the morning all sleepy, I can hardly wake up, half a day, until three, four in the afternoon it's the same

as with the last therapy, it was the same for the first 5, 6 days: like insomnia until 4, 5 in the afternoon, I can't sober up, come to all that easy. And then, now it's been some 5, 6 days the same thing happening. But now it's already since the 7th, 8th day I've been feeling much better. Like in the morning I have coffee, have a shower and come to. I feel some changes, I'm feeling better, I feel better, fewer health problems, the temperature's dropped, my temperature's dropped, glands a little, they can't disappear in 7 days, but I don't know... It's all there, the glands are the biggest problem suffocating me and all. Like this therapy is great for HIV, it's ok now, I function normally, I wake up in the morning great, whenever I get up, both if I get up two three hours earlier and two, three hours later like than the usual time I feel ok, I can work, I'm physically fit I guess, I don't know, I'll see what it will be like, I have to work... The only problem is that the winter is also very bad for me... (Ivan)

23rd March

1. Feelings related to XXXXX XXXXX in XXXX Street (treatment at a state medical facility) are feelings connected to humiliation, coercion, blackmail, incompetence and all that's bad in people is represented in XXXX and its staff.
2. With the gynaecologist at XXXX they were wonderful but still they're busy and you wait 8 hours at a time for examination! – crowded! Always the last – discriminated!!!
3. Taking blood at the local Dom zdravlja is frustrating because I have to tell all the staff I'm HIV+ and blah blah... It frustrates me that I'm like an alien! It's hard for me to visit [different] doctors all the time. It's best when I can have everything done at the Infective (HIV) Clinic.
4. Blood and urine analysis results (chemistry and biochemistry) it would be easier (physically, more comfortable) if I could do it like before at the HIV Clinic. (Ana)

28th March

I go to get ARV therapy at the Infective (HIV) Clinic. I find out from the doctors there is no combi-
vir and no reagents for PCR and CD4 analyses. I wonder how it will be in the future with medicines
and reagents? Will all the medicines be cancelled? We have been living with HIV for quite some time
– me for 20-22 years – quite some time says the society!?! Anxiety and uncertainty = fear always
present. They treat us and experts produce stress with HIV + people. (Ana)

12th May

But, I mean I'm alive, I can't stay at home, close up, and my circle of friends is getting smaller
every day. I told a few of them cos they can all see something's wrong with me, and I can't keep
quiet... They ask you every day what's going on with you. Where you're going, where you've been.
Like someone comes over, they're so free so they look into my drawer, open it and see a ton of pills,
strange ones. What can I tell them, it's for my head?! What? A mate who stayed over, he took the
liberty, I gave it to him, I left him alone in the flat, I wasn't in the flat, he was alone in the flat, he
was at the computer playing, before I got back he happened to go through my flat and he found HIV
pills, read the directions and saw what it was. I got back and he wasn't there, he wrote me a note
and that's it. No one wants to listen to explanations, I mean... They all give you the story: I'm look-

ing for an honest mate, friend, and when they find out the worst, the hardest, there are no mates or friends or brother or father or mother, there's no one. There's only, I don't know, a number to dial when it's the hardest for you and that's it. Like you have, you call the counselling service from time to time and they wash your brain like that, but they wash it in a positive sense, sort it out a little, it's always nice to let it out a little about HIV, to tell someone. In a way this too feels good now, talking... It's a little easier for me, as if I had a talk with someone... So that... It's good for my sleep, I'll go to bed now and I hope I'll fall asleep, I don't know... The temperature will drop by tomorrow so we'll see, I don't know... (Ivan)

2nd July

[I went to try to see a] Dentist, who wouldn't see me and wouldn't treat me. They sent me to the clinic in XXXX but I can't go there because I can't pay for treatment, my insurance doesn't cover it. [What are my feelings?] Unfortunately very bad! There are exceptions, but almost everywhere you're discriminated precisely because of your disease!!!

It makes me wonder really and I don't think it's sensible for experts to treat HIV+ patients like that. They simply ignore you everywhere, especially when it's well known that a positive person is not financially capable of surviving, they know we don't have the possibilities, we're asking for some understanding, tolerance! I mostly have the feeling I'm maybe really trash, because I'm being treated like it. (Dejan)

15th September

"I'm living one life, the most miserable way I can"

This is the sentence of the day, it won't leave me since I woke up, it saw me off to my dreams last night when I was falling asleep. It was born yesterday around noon.

I felt like crying there in the middle of XXXX [big shop] because I still have a big heart so I can feel sorry for myself... Although it's usually too late and futile feeling sorry for oneself because someone else has always come before me. So yesterday once more I reached bottom, and it was just after I'd got the money. Today the first sentence "I'm living one life, the most miserable way I can" got more sense. Today I'm hungry and full of dry food and too poor to buy something healthier. For me now new potatoes, greens and strawberries are a big luxury, there are no vitamins either for me this month.

Trying to get a job.

I'd get a job and I'll try to give reasons why I can't work somewhere in the column NO, and I'll write the reasons for finding a job in the column YES.

NO

1. I don't know anyone who'd hire me
2. No - because they run away from the HIV inside me.
3. No - because I can't stand the heat.
4. No - because I'm breaking the law if I get a job and I'm getting a pension as someone without a work card and work ability.
5. No - because how could I work in XXXX and in the NGO
6. No - café as an option, but they wouldn't take me because of HIV

7. No – non-stop [shop] because of AIDS and I don't know maths.
8. I don't know where I could work and be un-registered, undisclosed, unexposed to working with drink and food because of AIDS, unexposed to looks because I'd be reported and immediately I'd lose my pension.
9. No – because I will not break the law.
10. No – Can I physically take the work?

YES

1. I need the money (for food – for the bills – for hygiene [materials] – for clothes – for blinds and 300 dinar mirror – for the seaside).
2. For vitamins and medicines (that in particular).

The 10 No's were the first 10 reasons that crossed my mind, because of which I was given a pension and I don't have the work ability, but these are 10 realistic, real reasons, and not 10 excuses for me not to work.

The 2 Yes's are also realistic reasons, they are fewer than the No's, but they are worth more than this and infinite times more powerful than all the No's.

Will I be this miserable and helpless for the rest of my life? And I'm really trying to be cheerful, kind and smiling. "I'm living life in the most miserable way I can... and I'm dragging the AIDS virus with me because it's the only one that can understand me." (Sandra)

6th November

What needs to be done?

*More about the socio-legal aspect of HIV patients. **Visibility of the discrimination problem.** About the social inclusion of PLWH – reasons why PLHIV are so excluded, stigma and discrimination, and especially **SELF-DISCRIMINATION.***

The relations between patients and doctors need to be deepened!!! Medical support is not sufficient. Stronger connections need to be made – doctors' care (reproductive health, nutrition, sex life...), medical workers' for PLHIV. More possibilities to apply ARV better (more successfully).

More knowledge about ART gives more possibilities to the patient. If they know about something (have the knowledge) then they can ask for it from the doctor.

Self-help, support

Auto-stigma, stigma and discrimination

Unavailability of medicines – latest medicines, tests and the like

Legal rights

Reproductive health

Work ability

About what it's like being a patient with chronic illness HIV/AIDS

Lack of information about latest medicines for HIV/AIDS

Most general information from the HIV community in Europe

Help the patients to better understand their rights in the medical setting. They should know they have the right to the latest medicines and more medicines and tests, as well as the right to complain

- to rebel against the Ministry spending the citizens' money, but in what way? Teach them to ask for their rights. (Ana)

19th December

So, what I could give this study I did. As the study's coming to an end I can say I'm glad I've participated in it and... If the results of this study help future generations... and of course many other people to understand the disease and... people like me. If it helps this then I'm particularly pleased. (Tanja)

Recommendations and conclusion

HIV treatment:

In Serbia treatment availability has improved, but some problems remain.

The treatment situation has improved a good deal since 2004/2005, when we found that there were frequent interruptions or treatment changes due to treatment shortages. Whilst there are still sporadic shortages of particular drugs, treatment supplies in general have become much more stable. PLHIV still remain anxious about their supplies: as their lives directly depend upon consistent availability.

In Serbia irregular monitoring testing is a serious problem. This may undermine the effectiveness of treatment and is a cause for concern.

Not being able to monitor the efficacy of treatment and the condition of patients makes the effective treatment of PLHIV much more difficult. PLHIV almost universally find this a cause of stress and anxiety- as though they are feeling their way in the dark.

New clinics opening in Serbia

New clinics are opening in Novi Sad and Nis for PLHIV living in these areas. Our research shows that there is a great need for these clinics and not having to undertake the journey to Belgrade, with all the difficulties this can involve, is likely to be a very positive development for PLHIV in these regions. We hope that patients visiting these clinics will be treated with appropriate care and the necessary confidentiality.

The clinic in Belgrade continues to be regarded as a source of good care and support with committed staff working well given constraints of equipment etc.

Montenegro delivers treatment to patients post Independence

Significant progress has been made towards providing access to full HIV treatment and care for PLHIV since Montenegro became independent. There are some cases where patients receive all of the necessary treatment, however some patients have reported experiencing inconsistent availability of drugs in Montenegro. Monitoring tests are available regularly.

Recommendations:

- Implement data management software which enables more efficient management of treatment procurement, delivery and need to reduce incidence of shortages.
- Urgent action is needed to add reagents for monitoring tests to the positive list in Serbia.
- Ensure sufficient support is given to the training and development of the new HIV clinics/ wards to ensure appropriate levels of expertise, efficiency, confidentiality and trust. This also applies to local pharmacies who may be dispensing HIV treatment.

Access to healthcare:

Direct discrimination reduced.

Over the course of the study reports of direct discrimination of PLHIV by healthcare workers have reduced. Some individuals continue to encounter problems in accessing primary health care, dentistry, surgery and gynaecology. PLHIV reported finding it very difficult to demand their rights to be treated and are extremely upset by receiving such poor care from medical professionals.

Indirect discrimination is common.

Indirect discrimination was found to be very common in the experience of participants. Doctors and nurses often do not refuse treatment outright but make excuses about equipment or time availability; or refer them onto another colleague in order to avoid having to treat them; or in some way treating them more harshly than another patient without HIV. This was a source of immense frustration for some individuals as it is so much harder to explicitly address this more slippery form of discrimination.

Personal or recounted experience of discrimination have made some PLHIV very anxious about seeking healthcare outside of the HIV clinic. Many individuals anticipate a negative reaction. This may result in the behaviour of healthcare staff being interpreted as discriminatory when it may in fact be more to do with workload or manner. Medical staff therefore need to be sensitive to the context in which PLHIV are managing their illness and always act professionally. If they frequently encounter harsh responses, more effort may be needed to show that they are open to and considerate of the situations faced by PLHIV when they come to them for care and support.

Recommendations:

- Support training of healthcare workers on the situations faced by PLHIV to sensitise them to their behaviour and the needs of PLHIV. In particular emphasising the influence they have in providing a positive example to the rest of society about how to treat PLHIV.
- Medical personnel need to be made more accountable for their actions. Mechanisms for reporting cases of unprofessional behaviour by medical personnel need to be made clear, simple and confidential.
- Legislation to address indirect discrimination and for healthcare workers to take responsibility. If they are unable to treat PLHIV for legitimate reasons, to provide patients with a viable alternative.

Support: financial and psychosocial

Access to employment is severely hampered by an HIV diagnosis. For a minority this may be because they are not well enough to work. For the majority this is because of discrimination. Poverty is a significant problem for PLHIV.

The majority of participants were unemployed. Those who did work were employed in private firms or NGOs. Contrary to expectations this is rarely a result of poor health but reflects the difficulty of getting a job with an HIV positive status and also the demands of following treatment

and check-ups etc. Again whilst there are some incidents of direct discrimination in which people have been fired or refused a job on the basis of their status, more commonly it results in a fear of anticipated rejection. People do not feel able to put themselves through the upsetting scenario of potentially being abused and humiliated.

As treatment has improved so has life expectancy. 'Making ends meet' is a major concern for PLHIV. Their health is particularly vulnerable to poverty as effective treatment requires a good diet. Many PLHIV feel they need additional income to cover HIV treatment, monitoring testing when shortages occur as well as private healthcare in the face of limited access to public healthcare.

Social welfare and financial support is difficult to access and perceived discrimination common.

Participants reported encountering discrimination when accessing social welfare. Many participants find that the system is overly complicated and information about opportunities scant.

Recommendations:

- Support to make pursuing legal cases against employers needs to be made more accessible and affordable for PLHIV. In particular recognising the importance of financially and legally supporting initial cases.
- The changeable nature of HIV as an illness means that an HIV positive individual can be generally healthy but suffer infrequent bouts of illness. Employment terms and social welfare requirements need to be flexible in accommodating this reality.
- Providing more accessible information to PLHIV about their employment rights and access to social welfare support.
- Training amongst personnel working in the social welfare system about HIV and issues that PLHIV are facing needs to be made available, in order to overcome misunderstandings about HIV and to foster an increased sensitivity towards PLHIV.

NGOs need to be more transparent and inclusive.

Many NGOs are playing a vital role in supporting PLHIV. Some of our participants gain great satisfaction and self-esteem by being involved in helping other people cope with their illness. However many of them are concerned by a lack of transparency about the use of funds and have reported feeling under utilised by these organisations. Many PLHIV would like to get more involved in trainings etc undertaken by NGOs. Recognising the expertise of PLHIV on their experiences would add value to the authenticity and sensitisation objectives of the trainings. It would also contribute to further empowering PLHIV and countering their marginalisation.

Recommendations:

- More transparency on funding and activity by NGOs to foster trust with the HIV population
- More involvement of PLHIV at every level, in particular in trainings about HIV with service providers etc. Acknowledging their expertise.
- Capacity building for self-support groups.
- Supporting the sustainable development of networks amongst HIV NGOs so that organisations can work more effectively together at national and local levels.

- Protect activists from 'burn out'. Currently the HIV community is led by a few leading HIV positive individuals. It is critical for their health and the success of HIV community work that those taking on a significant proportion of work and responsibility are given adequate support and training by others working in the sector.

Family, friends and community

This booklet has illustrated the various and unpredictable responses people have when they hear that someone they know is HIV positive. The study has found that the consequences of accidental disclosure are most feared by those living in smaller towns or rural areas, where communities are more densely networked.

Understanding the transmission risks and protective measures that can be taken is critical in reducing the fear of HIV. In addition people need to be encouraged to think about HIV as an illness not as a person. Those that have HIV are still persons: a brother; a daughter; a best friend; a mother; a boyfriend; a wife. Support for PLHIV post-diagnosis and for those whom they choose to disclose to is important in facilitating understanding and care. This is already done informally by some doctors. This should be continued, better supported and expanded.

Recommendations:

- Offer accessible information and counselling for family members and friends of PLHIV.
- Establishing a support network for all those affected by HIV, for example a family support network.
- **Ensure that your reaction to learning of someone's HIV diagnosis is fair.**

You can change their stories

You have read the stories of individuals living with HIV here in Serbia and in Montenegro. Often they are active people, getting on with living a normal life as much as possible.

Everything about our illness is kept behind a veil of mystery [and] not reaching these masses of people, because the people don't want to see and they don't want to hear. So, you cannot begin from the end, you know, when you want to educate somebody you must begin at the beginning, you know. (Neda)

So this is what these individuals have tried to do by being part of this research: to bring the experiences of being HIV 'out of the shadows'.

What restricts the quality of life of those living with HIV is no longer so much their illness, as treatment has made a substantial difference to how long they can live with HIV. What impairs their quality of life is the social prejudice that clings to HIV.

They pull their sleeve: "Hey, don't stand with her, she has aids, you'll get it too!" that's that. I know I have to die – we'll all die, but with dignity, if it's like that – at least be civilised, be dignified, be human. I just want you to play fair with me, cos that's the way I behave, and I expect a normal attitude toward me regardless that I have HIV. (Milena)

Throughout the study participants have remained inspiringly hopeful that their situations will improve. There is a tangible sense of hope amongst these individuals that if others understood more about the illness, the transmission risks and the impact of unfair behaviour towards PLHIV- they would behave differently. This would mean that they could live positively with HIV as a manageable chronic illness.

And although we may not be able to discover new treatments for HIV:
**we can all make a significant difference to changing
the social consequences of being HIV positive.**

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