HIV and self-stigma
Core Beliefs Sheet

A practical tool for designing interventions to support people living with HIV and AIDS

Open Heart House & Trinity College Dublin
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This is a punishment • I can’t touch other people • I can’t use the same utensil in the house • I feel unclean • I am an ‘undesirable’ • I am done • I am ashamed • People can see straight through me • I am useless • I am dirty • I am not at ease with myself • I am angry • I have a burning rage inside that could burst at any minute • I’m dangerous I can’t handle it • I’m alone • I have no one to talk to • I have a low self-esteem • It was self-inflicted • I •

They won’t want to have anything to do with me • People will stay away from me • They look at me differently • People change the way they look at you • People look down on me • They would see me as
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This Guide is being made available so it can be used broadly by all those who want it. In its application please include the following citation: ‘An unspoken world of unspoken things’: A study identifying and exploring core beliefs underlying self-stigma among people living with HIV and AIDS in Ireland, Open Heart House & Trinity College Dublin, (Ferris France, 2012)
INTRODUCTION

This guide has been produced to assist those wishing to design and implement interventions aimed at supporting people living with HIV to address core beliefs associated with HIV and AIDS-related self-stigma.

Like everything else meaningful, unless the change starts within, with yourself, change is slow to happen and is not as powerful. Self-stigma comes from within, propelled by the negative, self-abasing beliefs deeply held by people living with HIV, reinforced then by society, of which people living with HIV are a part.

We have medication of the body - now we need medication of the mind. It is this combination that will ensure the quality of life all people deserve.

HOW WAS THIS GUIDE DEVELOPED?

This guide was a core output of a qualitative research study produced as part of a MSc Global Health, Trinity College Dublin. The aims of the study were to better understand the phenomena of self-stigma from the perspective of a person living with HIV and to identify and explore the core beliefs that cause self-stigma.

The research consisted of seventeen one-hour semi-structured interviews with people living with HIV and AIDS from Ireland, East, Southern and West Africa and East and Central Europe and followed a rigorous research process (Ferris France, 2012). All participants were living in Ireland, where the research was carried out.

WHAT DO WE KNOW ABOUT HIV-RELATED SELF-STIGMA?

By its nature, stigma is secretive, subversive and operates in silence (Health and Development Networks, 2006). It is well known that HIV and AIDS-related stigma acts as a significant barrier to HIV/AIDS prevention, testing and treatment (Parker et al., 2002, APN+, 2003, Castro and Farmer, 2005, Deacon, 2006, Health and Development Networks, 2006, USAID, 2006a, Mahajan et al., 2008).

However, much less is understood about self-stigma (internalised stigma), the root of stigma – that is the stigma imposed upon the self by the self (Health and Development Networks, 2006, USAID, 2006b, Kalichman et al., 2009). Self-stigma has the potential for adverse behavioural and emotional effects including not seeking treatment and care services (Chesney and Smith, 1999). Self-stigma can lead to a sense of isolation and may play a crucial role in the emotional reactions and cause emotional distress to many people living with HIV/AIDS (Crandall and Moriarty, 1995, Simbayi, 2007). HIV and AIDS-related stigma
has also been related to the development of depressive symptoms (Wight, 2000) and it is likely that self-defacing internal representations of being HIV positive are important in predicting long-term coping and positive living (Kalichman et al., 2009). Self-stigma is reported to lead to low self-esteem and threatens self-efficacy of people living with HIV (Health and Development Networks, 2005). A very recent study by Earnshaw (2012) reported that people with chronic illness who had self-stigma accessed care less and had a lower quality of life. Finally, an Asia-Pacific Regional Analysis of the Stigma Index Study in nine countries, involving 4395 participants found disturbingly high levels of self stigma manifesting as shame, guilt and self-loathing, for example ranging from 75% of people in Pakistan saying they were ashamed of their HIV status to 54% in Sri Lanka (GNP+. et al.).

**HOW IS THIS GUIDE ORGANISED?**

This document contains the core beliefs underlying self-stigma, organised around key themes identified as a result of an extensive literature review and the study findings as follows:

(Ferris France, 2012)
SUGGESTIONS FOR USING THIS GUIDE

This Guide can be used to develop programmes to support people living with HIV as well as by researchers to carry out more focused studies on self-stigma. For more specific research recommendations, please see (Ferris France, 2012). The following are only some suggestions for programme implementers and researchers, of which there could be many:

Inquiry-based Stress Reduction (IBSR)

The IBSR (Inquiry-based stress reduction) intervention, developed by Byron Katie (Byron and Mitchell, 2002, Byron and Mitchell, 2007) supports participants to reduce their perceived level of stress by self-inquiry of their thoughts and beliefs connected to stressful circumstances or symptoms. This meditative process, named "The Work", enables participants to identify and question the stressful beliefs or thoughts that cause their suffering. The core of IBSR is simply four questions and a turnaround, which is a way of experiencing the opposite of what the participant believes. This process is simple, powerful and can be easily implemented in daily life.

Cognitive Behavioural Therapy (CBT)

Cognitive behavioural therapy (CBT) is perhaps the most researched psychotherapeutic approach and has a growing reputation for being a highly effective treatment (Hayes, 2011) in dealing with stressful beliefs or thoughts. The technique in CBT as described by Hayes (2011) is to support clients to become aware of their thoughts, feelings, core beliefs and actions around whatever is causing them distress. The process, following the ‘coping triangle’ (Hayes, 2006) is four questions, followed by the development of a coping sentence.

Skills and Coping Training for people living with HIV

Development of a practical skills-based toolkit for people living with HIV on self-stigma including modules on:

- Disclosure (differentiating between friends, family, children, workplace and public), exploring fears and developing coping strategies using techniques such as role-play
- Sex and sexual pleasure living with HIV
- HIV treatment
- Body image
- Intimate relationships
- Illness
- Coping strategies

This toolkit could be used within National Networks of People Living with HIV and peer-support groups around the world.

Facilitated, topic-specific sessions for peer support groups of people living with HIV

Within support groups, this guide could usefully provide guidance to inform sessions on specific topics (as identified above) and encourage sharing of coping strategies.
Development of questionnaires, scales and further research studies on self-stigma

This guide could be used by researchers to assist with the further development of meaningful scales and sub-scales to measure the extent of self-stigma, as well as to design both quantitative questionnaires and qualitative studies.

Image cards: I am HIV positive and that means that ..... A number of ‘image cards’ have also been created and included in Annex 1, grouped around the key themes intended for use by practitioners, as appropriate in their programmes. They may be used to stimulate discussions, for example.

**CORE BELIEFS OF PEOPLE LIVING WITH HIV**

**Disclosure**

**Fears of rejection, being talked about, excluded, labelled, ridiculed**
- They will reject me
- I’ll be exposed
- People will stay away from me
- People will through me away
- They see me as different
- They will stigmatise my family
- If I disclose, my life will be more complicated
- If I disclose, I would have to watch my back all the time
- I will lose friends
- I won’t be able to make new friends
- I will be known as ‘the one with HIV’
- Disclosing to someone is a painful conversation to have
- If I disclose, I need to give support to that person
- If I disclose to someone, I need to allow them to disclose to someone else
- If people know, it will be damaging to my work
- People will talk about me
- They will ridicule me
- Everyone will be watching me and saying ‘I have HIV’
- Disclosure is very hard
- People will run away from me if they know I’m HIV positive
- People would make it hard for me if they know I’m HIV positive
- People will think I’m dangerous
- People will look at me in a different way
- I can’t put myself in the situation of people knowing my HIV status

**Fears of people telling others, being betrayed, used against you in an argument, discriminated against**
- I can’t trust anybody
- If I tell someone they will betray me
- They are going to look down on me
- They are going to tell
- They don’t want to know me
- They will use it against me (in an argument)
- People will talk behind my back
- It would be a big thing to people
- I have to be careful
- They would throw it back in my face
- They wouldn’t side with me
- Friends would turn nasty
- If you write it on a form they will discriminate against you

**Disclosure within family: protection, fear of them being stigmatised, fear of hurting them, losing them, being shamed**
- They should listen when I talk about it
- They never tell me what they think of it
- They should talk about it
- It would hurt them if they knew
- I have to protect them by not telling them
- The children will react badly
- People will talk about my partner
- My partner will be treated differently if people know
- My partner’s friends will blame her if they find out
- My partner will be treated as a leper if friends know
- People would hurt me if they know
- People would hurt my kids if they know
- People will label my family as HIV positive
- I would have to offer support and advice if I disclosed
- My partner will use it against me when we argue
- I’d be ashamed to tell my sons
- I’d lose their admiration
- Something would be taken away from our relationship
- They would be worried
- My mom would have a heart attack if I told her
- They would be stressed if I told them
- He will label me ‘the mom with HIV’

Perception of thoughts of others
- They won’t want to have anything to do with me
- People will stay away from me
- They look at me differently
- People change the way they look at you
- People look down on me
- They would see me as different
- They shouldn’t ask me how I got it
- They don’t need to know how I got it
- They think I’m a scum bag
- They think I couldn’t look after myself
- They think I slept with many men
- They are judgemental
- They don’t care
- They are scared

- They think gay men are morally redundant
- They think gay men have abnormal sexual appetites
- They think drug addicts are parasitic, deviant individuals
- They think its dirty
- They think I brought it on myself
- They have no sympathy for HIV positive people
- They look, act and talk differently around me
- They discriminate against me
- They treat me badly (interactions with health system)

**Consequences**

**Social exclusion**
- I’m lonely
- I’m isolated
- I’m always going to be lonely
- I’m not going to have a partner
- I don’t want to have a partner
- I don’t want to talk to anyone
- I lost friends
- I stopped socialising
- I stopped meeting people
- I have no friends
- They think I’m a drug addict or I’m gay
- I feel hurt when my friend bleached a cup (after I used it)
- If I have friends, I expose myself

**Secrecy**
- I have to live with a secret
- Living with a secret takes up a lot of energy
- I won’t be as successful as I could be in work
- I’d be embarrased
- I need to hide
- I need to hide to take my medication
- I am hurt
- I have to face the outside world by myself
• I can’t be same in the outside world as I can be in here (Open heart house)
• I can’t be honest in the outside world
• I can’t be myself in the outside world
• I can’t be open
• I can’t get close to people
• Confidentiality fuels secrecy

**Sexuality, sexual pleasure and intimate relationships**

**Beliefs and experiences with sex and pleasure within intimate relationships**

- Sex in our relationship doesn’t exist
- She can’t bring herself to have a sexual relationship with me
- No sex is one of the costs of being HIV
- It’s a part of my life that’s gone
- She can’t get close to me
- I have a disease
- I can’t be open
- I need to be careful
- We have to work around it
- She/he is going to leave me
- I will transfer the disease
- Not many people with HIV have a normal healthy relationship
- It’s not fair on another human being (to have sex with them or to have a relationship with them)
- Sex is not a priority
- I can’t have oral sex
- There’s a lot of things I can’t do [sexually] because of HIV
- I can’t satisfy him/her
- I’m not sexually active
- I have to have sex to please my partner
- Spontaneity is gone out of my life
- I’m infectious
- I have a problem with condoms
- I don’t enjoy sex
- I’m afraid I will transmit HIV to her/him
- I can’t let him touch me
- I am nervous
- I am embarrassed

- I just don’t want to do it
- I don’t feel like myself in my skin
- My body is not my own
- HIV has taken my body over
- I am not free to have sex
- My sex life is gone
- The intimacy is gone
- The experimenting is gone
- He/she is scared to have sex with me
- I have to get back what we used to have
- I have to protect the other person
- I am scared
- I’m not relaxed
- Something has been stolen from me
- It’s hard
- Something has been ripped off me
- I’m missing a part of me
- I couldn’t live with myself if I gave someone HIV
- I can’t feel loved and touched
- I can’t be a full woman/man
- I can’t let him/her know how bad I feel because it will put pressure on him
- I can’t have a normal relationship
- I don’t have a sexual self anymore
- A potential lover won’t accept my HIV status
- I can’t have a partner
- I can’t find a life partner
- I will never be loved properly

**Beliefs about disclosure within intimate relationships**

- I don’t know what to do
- They will have a bad reaction
- I can’t meet someone because I’m HIV positive
- I’m scared to start a relationship
- If I’m open I am suffering
- If you reject me I will go through pain
- If you reject me I will go through emotional trauma
- I can’t connect with people of a different sex
• It stops so many things
• I can’t have a steady relationship
• I’m afraid to get close to anyone
• I’m sad most of the time

Self perception

Self-abasement

Dirty, shame, worthless, contagious
• This is a punishment
• This is a punishment from God
• I can’t touch other people
• I can’t use the same utensil in the house
• I feel unclean
• I am an ‘undesirable’
• I am done
• I am ashamed
• People can see straight through me
• I am useless
• I am dirty
• I am not at ease with myself
• I am angry
• I have a burning rage inside that could burst at any minute
• I’m dangerous
• I can’t handle it
• I’m alone
• I have no one to talk to
• I have a low self-esteem
• It was self-inflicted
• I am smelly
• I am a terrible mother
• I am a deserter
• I am a disgusting person
• I don’t deserve anything
• I am toxic
• Something is eating away at me
• I feel a little less every day

Less than, undeserving
• I’m less than
• I’m less of a person
• I’m less human than everyone else
• I don’t deserve to be loved
• I deserve it
• I won’t get the job
• I’m inferior

Hopelessness, self-pity
• Life is over
• HIV kills you
• I’m a victim
• I don’t have as much time left as other people
• I have a death senence
• I’m being punished
• I’d doomed
• I’m alone
• I will be found dead on my own
• I’m scared
• Is not my fault
• It hurts
• I’ve done everything I possible can
• I’ve been abandoned
• I can’t find happiness anymore
• There is only so much you can take as a human being
• There is nothing for me to live for
• I don’t know who I am
• I want to commit suicide
• I have to live with it for the rest of my life
• It’s not going away
• I wish it would go away
• I don’t want to live
• I will get sick
• I will fall down into hell
• I am constantly worried about my life
I am constantly worried about the people around me
My life is not how I want it to be
I can only live day-to-day
Someone took my youth
It’s really very hard being HIV positive
I feel a burden to people
I have changed
I am angry

Restricted agency
I can’t have a child
I can’t get a job
I can’t do certain things
I have to be careful
I can’t find normal work in places of my choice
I have to choose my friends carefully for the rest of my life or chose to stay alone
I don’t get any opportunity at work
I can’t work in certain companies
I can’t travel where I want
My life has become an awful lot more difficult
I can’t share my personal items
It stops so many things

Illness, disease and death

Treatment and medical care
I don’t trust the medication
I am a guinea pig
I can’t live a normal life
The tablets aren’t a medical cure
It takes a long time for your system to adapt
I hate going into the hospital for a check up
I keep forgetting what I am talking about
HIV medication does something to the brain
I can’t retain things the way I used to
I don’t want to be used as a monkey in a cage
I have to take the medication

They don’t give me energy
I can’t sleep
I look tired all the time
I can’t do a hard job like before
I can’t play football anymore
I get stressed very easily
My body is dried and crushed
I’m at the mercy of medicine
I have to take it for the rest of my life
The medication is poisoning me
Eventually the medication is going to kill me
Medication doesn’t boost your inner self

Illness, health, wellbeing, disease and death

I’m sick
It’s a deadly disease
People don’t want to be near it
There’s something in my body that shouldn’t be there
I’m very concerned with my health
I’m in constant pain
I’m losing the battle with my health
A disease is something to eradicate
HIV turns you sick in the head
My body has changed
My body betrays me
I have to make adjustments all the time
I’m going to die
I will die and leave my kids
It can attack me at any time
I will die slowly, piece by piece
I have the potential to infect others
I can pass this onto another human being
You have to watch yourself around kids
I hate myself
The swelly belly is annoying me
I have a big rounded belly
People can tell
I have a poor body image
You can’t talk openly about HIV
ANNEX 1: IMAGE CARDS: I AM HIV POSITIVE AND THAT MEANS THAT.....

DISCLOSURE

I can’t trust anybody
If I tell someone they will
betray me They are going to look down
on me They are going to tell They don’t want
to know me They will use it against me People will talk
behind my back It would be a big thing to people I have to
be careful They would throw it back in my face They wouldn’t side
with me Friends would turn nasty If you write it on a form they will
discriminate against you

PERCEPTION OF THOUGHTS OF OTHERS

They won’t
want to have anything to do with me
People will stay away from me They look at
me differently People change the way they look at you
People look down on me They would see me as different
They shouldn’t ask me how I got it They don’t need to know how I
got it They think I’m a scum bag They think I couldn’t look after myself
They think I slept with many men They are judgemental They don’t care
They are scared They think gay men are morally redundant They think gay
men have abnormal sexual appetites They think drug addicts are parasitic, deviant
individuals They think its dirty They think I brought it on myself They have no
sympathy for HIV positive people They look, act and talk differently around me
They discriminate against me They treat me badly (interactions
with health system)
**Secrecy**

I have to live with a secret
Living with a secret takes up a lot of energy  I won't be as successful as I could be in work  I'd be embarrassed
I need to hide  I need to hide to take my medication
I am hurt  I have to face the outside world by myself
I can't be same in the outside world as I can be in here  I can't be honest in the outside world  I can't be myself in the outside world  I can't be open  I can't get close to people
Confidentiality fuels secrecy

**Sexuality, sexual pleasure and intimate relationships**

Sex in our relationship doesn't exist  She can't bring herself to have a sexual relationship with me
Sex is one of the costs of being HIV  It's a part of my life that's gone  She can't get close to me  I have a disease  I can't be open  I need to be careful  We have to work around it  She/he is going to leave me  I will transfer the disease  Not many people with HIV have a normal healthy relationship  It's not fair on another human being (to have sex with them or to have a relationship with them)  Sex is not a priority  I can't have oral sex  There's a lot of things I can't do [sexually] because of HIV  I can't satisfy him/her  I'm not sexually active  I have to have sex to please my partner  Spontaneity is gone out of my life  I'm infectious  I have a problem with condoms  I don't enjoy sex  I'm afraid I will transmit HIV to her/him  I can't let him touch me
I am nervous  I am embarrassed  I just don't want to do it  I don't feel like myself in my skin
My body is not my own  HIV has taken my body over  I am not free to have sex
My sex life is gone  I will never be loved properly  I'm sad most of the time
This is a punishment
from God
I can’t touch other people
I can’t
use the same utensil in the house
I feel unclean
I am an ‘undesirable’
I am done
I am ashamed
People can see straight
through me
I am useless
I am dirty
I am not at ease with myself
I am angry
I have a burning rage inside that could burst at any minute
I’m dangerous
I can’t
handle it
I’m alone
I have no one to talk to
I have a low self-esteem
It was self-inflicted
I am smelly
I am a terrible mother
I am a deserter
I am a disgusting person
I don’t deserve anything
I am toxic
Something is eating away at me
I feel a little less every day
I’m less than
I’m less of a person
I’m less human than everyone else
I don’t deserve to be loved
I deserve it
I won’t get the job
I’m inferior
It’s really very hard being HIV positive
I feel
a burden to people
I have changed

I’m lonely
I’m isolated
I’m always
going to be lonely
I’m not going to
have a partner
I don’t want to talk to anyone
I don’t want to go out
I lost friends
I stopped
socialising
I stopped meeting people
I have no friends
They think I’m a drug addict or I’m gay
I feel hurt when
my friend bleached a cup (after I used it)
If I have friends,
I expose myself
BODY, ILLNESS AND DEATH

HIV turns you sick in the head
My body has changed
My body
betrays me
I have to make adjustments all the time
I’m going to die
I will die and leave my kids
It can attack me at
any time
I will die slowly, piece by piece
I have the potential to infect others
I can pass this onto another human being
You have to watch yourself around kids
I hate myself
The swelly belly is annoying me
I have a big rounded belly
People can tell
I have a poor body image
You can’t talk openly about HIV
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I can’t do a hard job like before
I can’t play football anymore
I get stressed very easily
My body
is dried and crushed
I’m at the mercy of medicine
The medication is poisoning me
Medication
doesn’t boost your inner self
I don’t trust the medication
I am a guinea pig
I can’t live a normal life
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