Fast-Track Cities London

A framework for empowerment programmes to tackle internalised stigma

Acknowledgements

A special thank you to all those who were involved in developing this empowerment programme Framework to tackle internalised stigma; including the community of practice, Healthy London Partnership and Healthy Dialogues.

This Empowerment Programme Framework was co-produced by a community of practice with a wealth of expertise and research in HIV and empowerment. The community of practice represented a diverse range of organisations working endlessly to end HIV stigma and provide support to those living with HIV within the UK and globally. We are thankful for their contribution in the production of this framework.

4M Network
My health, My choice, My child, My life

AFRICA ADVOCACY FOUNDATION

BEYOND stigma
Supporting people on the journey from selfstigma to self worth

Change Grow Live

POSITIVELY UK

METRO
Embrace Difference

Terrence Higgins Trust

1991 – 2021 PositiveEast
Providing better futures for HIV positive people for 30 years

Thrive LDN

Facilitated by:

Healthy Dialogues LTD
— Behaviour Change Solutions For Health —

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Introduction

Fast-Track Cities London

In 2018, London Councils, NHS England, Public Health England and the Mayor of London signed the Fast-Track Cities declaration. The Fast-Track Cities declaration is a global initiative to end the HIV epidemic by 2030. Cities across the globe that have been heavily affected by the epidemic have been at the forefront of responding to HIV and are uniquely placed to lead the Fast-Track action towards achieving 90-90-90: *‘90% people living with HIV knowing their HIV status; 90% of people who know their HIV-positive status on treatment; 90% of people on treatment with suppressed viral loads’.*

The Fast-Track Cities London Initiative has been funded to deliver various workstreams which will support London towards reaching the 2030 goals of ‘getting to zero’. This set of goals includes reaching a ‘zero stigma’ attitude to HIV, stamping out stigma and discrimination. The Fast-Track Cities London Stigma Subgroup has identified and engaged widely on three key pieces of work to achieve this: tackling internalised/self-stigma, tackling stigma in ‘environments and places’ (starting with healthcare settings), and tackling stigma in society.

As the capital, London carries a high proportion of the national HIV epidemic. For many people, living with HIV continues to be a stigmatising condition that can have a negative impact on their quality of life. In 2017, 36,436 people were diagnosed with HIV in London, an increase of 35% as compared to 2008. Improving the quality of life for those living with HIV in London is vital.

Tackling internalised/self-stigma, a community of practice

To achieve the first goal of tacking internalised/self-stigma, a community of practice (COP) was formed by the Fast-Track Cities Stigma London Subgroup. A COP is a group of people who share a common concern or have a shared interest in a topic:

they come together to share best practice and help fulfil individual and group goals. Eight organisations with specialist experience in supporting those living with HIV make up the COP group, with Healthy Dialogues Ltd facilitating the fortnightly meetings.

What we did

The aim of the COP group was to meet fortnightly to co-develop an adaptable framework for an Empowerment Programme for people living with HIV who experience internalised/self-stigma. This framework would then be used by organisations to support people living with HIV to have the necessary skills and techniques to develop resilience and confidence to tackle internalised/self-stigma.

From the period of May to July 2021, six fortnightly COP meetings took place. Members brought together evidence of best practice and shared their experiences and knowledge of how to successfully support and improve the quality of life for those living with HIV. The focus was to address internalised/self-stigma within individuals by developing an evidence-based adaptable empowerment framework that could be used by any organisation wishing to address internalised/self-stigma for those living with HIV.

What is internalised/self-stigma?

Internalised/self-stigma refers to absorbed negative beliefs and feelings about oneself. In this case, it relates to an individual's feelings of devaluation due to an HIV-positive diagnosis.

What this may mean for people with an HIV status

This issue can manifest in a person with an HIV status feeling shame, guilt, low self-esteem, or feeling unlovable. This person may have a negative perception of themselves, may feel like an outsider, and likely to experience stigma or rejection.

A person may also have pre-existing or additional identities or characteristics that they may believe make them less valuable within their communities, such as gender identity, faith-based identity, sexuality, ethnicity, immigration status, drug use or sex work. These intersecting stigmas can compound and increase an individual's sense of feeling like an outsider. This can result in individuals not seeking necessary care or treatment or withdrawing from societal opportunities.

The empowerment framework

Five key outcomes were devised from the COP group to build the framework of the ‘Empowerment Programme’. For each outcome a short description has been provided around why this is an important aspect of the programme to help address internalised/self-stigma. Alongside the outcomes, elements to be considered when delivering these outcomes, including essential and advanced content, are also provided.

The five key outcomes of the Empowerment Programme are:

- Developing a support network
- Understanding internalised/self-stigma
- Understanding what HIV is, U=U and living well with HIV
- Building self-acceptance, self-esteem, and an individual’s sense of power
- Developing skills: including self-advocacy, public advocacy, and ambassador skills

Additional competencies for peer supporters and guidance for evaluating the empowerment programme have also been provided.

Peer supporter competencies

In the empowerment programme, the peer supporter role involves sharing experiences in a way that inspires hope, fostering a support network, sharing information, giving advice and signposting to further information and support.

The following outlines the competencies a peer supporter must encompass. They have been themed under the following categories: knowledge of HIV, U=U and living well with HIV; knowledge of peer support; peer support approach; confidentiality, safeguarding and psychological safety; evaluation and secondary competencies.

Primary competencies

Knowledge of HIV, U=U and living well with HIV

- Insight into wellbeing and self-management strategies.
- Basic knowledge and understanding of HIV and treatments and the confidence to explain these to others.
- A clear knowledge base around safer sex and risk reduction.

Knowledge of peer support

- An understanding of the different forms of peer support e.g., one-to-one, group settings, and how these contribute to supporting people living with HIV.
- Having a lived experience of HIV and understanding the needs of the people living with HIV.
- An understanding of the needs of specific groups living with HIV, and how to tailor services accordingly to these groups.

Characteristics of a peer supporter

- Effective listening and communication skills.
- Ability to recognise and be respectful of diversity.
- Ability to be empathetic, caring, and compassionate – peer supports must provide unconditional positive regard.
- Ability to explore and understand the dreams, desires, drivers, and barriers different people have.

- Ability to not over-identify with a presented issue.
- Ability to provide a solution focus and problem-solving approach.
- Be a well-rounded individual with hobbies and interests (outside of work settings) that can be drawn upon within group discussions.

Confidentiality, safeguarding and psychological safety

- Understanding of confidentiality.
- Understanding of safeguarding for people accessing support and those providing support.
- Ability to ensure safety for all parties.
- Ability to conduct themselves professionally, including seeking personal and professional support and supervision, giving and receiving support and feedback, and understanding boundaries and how to set them.

Evaluation

- Understanding of evaluation and recording the impact of peer support.

Secondary competencies and skills include:

- Understanding of monitoring and ability to maintain accurate records.
- Ability to communicate information around reproductive health needs and choices.
- Knowledge of current approaches to drug and alcohol use and the issues involved.
- Ability to signpost to further support services or information.
- Ability to demonstrate practical knowledge of sexual health.
- Ability to collaborate with other agencies.
- Sense of humour!

Developing a support network

Why building a support network matters

“Everyone living with HIV should have access to peer support.” Peer support is when people with similar experiences come together to help each other by sharing knowledge, experience, and practical help. Developing a support network should feature in each step of the empowerment programme. People who have peer support benefit from better health and wellbeing, feel more in control of their health, have better understanding of their health condition and adhere better to treatment. They also feel more confident, less lonely, and better connected to others.

An empowerment programme should be peer led and should include the following elements:

- A discussion of the aims and objectives of the programme, what participants should expect from taking part in the programme and what type of activities the programme includes.
- A discussion on the importance and principles of confidentiality and the General Data Protection Regulation, and how to respond if someone discloses something of concern within the programme session.
- An assessment of the different levels of knowledge and experience within the group.
- A physically safe and comfortable environment. The facilitator should identify appropriate ways of facilitating and structuring a peer support session that is flexible to meet varied needs within the group. The programme should allow for frequent breaks and opportunities for participants to opt out when they want or need to.
- A psychologically-safe environment within the group that includes a ‘safe space’ and a ‘brave space’. The facilitator should enable inclusive in-group decision making, invite equal participation from all group members, and express gratitude for contributions from the group.

- Fun, engaging, and thought-provoking activities and discussion.
- Reflective learning activities for participants to explore the topics discussed in relation to themselves and to enable further learning and reflection outside of the programme activities. Reflective learning activities could include journaling or peer-group reflective practice.
- The use of empowering and solution-focused language.
- Inclusive content and resources and aftercare resources.

Essential content

The programme should include group work activities and discussions that complement the other programme outcomes and enable participants to:

- Build a peer group or community.
- Explore how to live well within their own existing community and what ‘good’ support means for them.
- Share their knowledge and experiences in a respectful and psychologically safe environment.
- Have space to talk about sexuality, culture, spirituality, and faith.
- Build on their existing or new communication skills including active listening skills and demonstrating empathy.
- Explore and discuss their feelings and emotional reactions within the different topics discussed.
- To meet and learn from people who are living with HIV and have experienced internalised/self-stigma and now live well with HIV and feel empowered.

Advanced content

- Advanced communication skills, including structuring a conversation and goal setting.
- Training for peer mentors.

Resources

Here are some training resources and guidance to support your programme development.

National Standards for Peer Support in HIV

http://hivpeersupport.com/wp-content/uploads/2017/08/national_standards_final_web.pdf

By Positively UK, British HIV Association, National HIV Nurses Association, Children's HIV Association, Terence Higgins Trust and UK-CAB

This document outlines the set of standards essential for peer support for HIV. It includes the description of what that means for people living with HIV, the people providing peer support, and the health, social care and HIV service providers that support them. It also includes sets of competencies and skills that people providing peer support must demonstrate.

Read time: 1 hour

Developing Peer Support in the Community

https://www.mind.org.uk/media-a/4247/peer-support-toolkit-final.pdf

By McPin Foundation, St George's University of London; Mind

This toolkit is for people providing peer support in the community. With a focus on mental health, the guide outlines a range of activities that can be used to understand how peer support works, define the core values of peer support, and some reflective activities that can be used to build peer support within your group.

Read time: 2 hours

Understanding internalised/self-stigma

Introduction

This introductory module of the empowerment programme is about educating people living with HIV about internalised/self-stigma through reflection and teaching. It is about creating a safe space for self-expression, exploring beliefs and identity, and helping people connect what they learn about internalised/self-stigma to their own lives.

Essential content

The programme should include group work activities and discussion that enable participants to:

- Know what internalised/self-stigma is and why it is important to talk about it, using reflective exercises.
- To understand how prevalent internalised/self-stigma is and that it is a normal and understandable human response.
- Explore and reflect on up-to-date facts and statistics of internalised/self-stigma and prior beliefs of HIV.
- Explore the origins of internalised/self-stigma and how it is perpetuated.
- Explore how they view their own identity including, where appropriate, intersecting characteristics. These can include faith-based identity, gender identity, sexuality, ethnicity, immigration status, drug use or sex work. Reflect on what aspects of their identity they embrace and aspects they do not embrace.
- Understand what other types of stigma are, for example, external stigma and perceived or anticipated stigma, and how they can be connected. Inclusion of an exploration of social voices and preconceptions from, for example, faith-

based organisations, family, school, and peers and an exploration of their own beliefs of HIV, prior to their diagnosis.

- Identify and challenge their own experiences of internalised/self-stigma, including shame that is linked with their perception of their good and bad behaviours and social taboos.
- Build skills in emotional intelligence, including how to identify and understand their emotions.
- Understand the power of language and how it can affect our feelings and responses.
- Share stories from people who have moved from internalised/self-stigma to self-love and self-worth.

Resources

Here are some training resources and guidance to support your programme development.

Understanding and challenging HIV Stigma-Toolkit for Action Introduction & Module A: Naming the Problem

https://www.icrw.org/files/images/Understanding-and-challenging-HIV-stigma-Introduction-and-Module-A.pdf

By International HIV/AIDS Alliance; Academy for Educational Development; International Centre for Research on Women

This toolkit is designed to help facilitators to plan and organise educational sessions to raise awareness and promote practical action to challenge HIV stigma and discrimination. Module A is about helping people to recognise stigma within themselves and others and exploring their experiences of stigma.

Read time: 15 minutes

The language of HIV: a guide for nurses

https://www.nhivna.org/file/5dcbdcb83254e/BP-19-2.pdf

By Chelsea and Westminster NHS Trust, Salamander Trust and University of South Florida

This guide highlights the power of language and how it impacts on how we think about ourselves and how we see others. It looks at typical phrases used in relation to HIV and how they can be adapted to be more positive, acknowledging people living with HIV as fellow human beings

Read time: 17 minutes

Understand what HIV is, U=U and living well with HIV

Introduction

In this module, participants should have an opportunity to build their empowerment through learning about HIV, their treatment choices, U=U and living well with HIV. Participants will have the opportunity to build on their own knowledge of topics around HIV and holistic approaches to looking after their health and wellbeing while debunking harmful myths and misconceptions.

Essential content

The programme should include group work activities and discussion that enable participants to:

- Have basic knowledge of HIV, the different types of treatments and how they work.
- Be confident in explaining the clear messages about U=U (undetectable = untransmittable) and know where to find research evidence, statistics and trusted resources on where to learn more.
- Understand treatments for prevention (PEP/PrEP), as well as traditional prevention methods such as condom use.
- Explore the benefits of being undetectable at an individual, community, national and global level. Understanding how U=U impacts on sexual health and sexual freedom and understanding U=U in the context of those who are not virally suppressed.
- Explore and debunk myths and misconceptions.
- Explore the Equality Act 2010 and what that means for them.
- Explore why some people struggle with HIV treatment and the coping mechanisms they might use.

- Understand the links between HIV, U=U and physical and emotional health and wellbeing and personal development.
- Explore the mental health continuum in terms of their own mental and emotional wellbeing, including recognising and acknowledging symptoms of decreased emotional wellbeing or mental health. To know ways to live well with HIV, including the five ways to wellbeing.
- Know where to access further health and social care support and information on financial support and guidance, including multilingual and culturally-specific resources where possible.

Resources

Here are some training resources and guidance to support your programme development.

LOOPEDIN

https://loopedin.nat.org.uk/

By National Aids Trust

Loopedin allows us to create bespoke informational webpages about a range of topics around HIV. You can use this resource to support your conversations about HIV with others.

Read time: 3 mins – 1 hr +

Talking money: financial capacity building workshop

https://goodshep.org.au/wp-content/uploads/2020/12/Talking-Money-Facilitators-Guide_Women.pdf

By Victoria State Government. Good Shepherd Microfinance

This facilitator guide is about building financial resilience of participants so that they can make informed and enabling financial decisions. It includes a range of different topics including money management, understanding credit, identifying support services available and setting a SMART money plan.

Read time: 30 minutes

Looking after number 1

https://www.homeless.org.uk/sites/default/files/site-attachments/Looking%20after%20number%201%20-%20workshop%20guide.pdf

By Homeless link

The workshops in this facilitator guide encourage individuals to discuss their health and wellbeing openly, address stigma around mental health issues and provides tools for them to improve their health and wellbeing. The guide can be used for delivering single workshops or a series of workshops on health and wellbeing.

Read time: *13 minutes*

About HIV

https://www.aidsmap.com/about-hiv

By Aids Map

This web-resource provides a wealth of information on all topics related to HIV and health and wellbeing. Explore this resource for basic and in-depth reading materials in a range of languages that you can share and short videos you can present in your empowerment programmes.

Read time: 3 mins – 1 hr+

Questions about U=U: what, when, who, why….?

https://i-base.info/u-equals-u-qa/

By HIV i-Base

The i-Base website was set up to provide timely and up-to-date information about HIV treatment for people living with HIV and health care professionals. The website includes technical and non-technical publications you can use to raise awareness of U=U and to learn more about U=U. They also provide a Q&A service where they will answer any questions about HIV treatments you may have.

Read time: 3 mins – 1 hr+

Building self-acceptance, self-esteem, and an individual’s sense of power

Introduction

This module builds on ‘Understanding Internalised/self-stigma’ to empower participants to challenge their own self-limiting beliefs and prioritise their journey to self-acceptance. It is about enabling people living with HIV to reclaim their value and build their self-esteem and sense of power. It includes an exploration of their values, core beliefs (for example, feeling loved and belonging) and attitudes.

Essential content

The programme should include group work activities and discussion that enable participants to:

- Identify and challenge their own self-limiting beliefs about what other people think about people living with HIV, their body, their sexuality, shame, guilt, and fears about sharing their HIV status.
- Build self-esteem, including activities to draw on and celebrate personal strengths and resources, and overcome challenges and adversities.
- Build mental wellbeing, for example, by using mindfulness exercises or creative arts-based workshops.
- To know how to identify feelings of stress, frustration, anger, and trauma. To identify current helpful and unhelpful coping mechanisms and build on or develop coping mechanisms that work well.
- Draw on experiences of peers who share their stories of visible recovery and empowerment.
- Know where to access further mental health and wellbeing information and support, including specialised services, health and wellbeing services, and

faith-based support. Participants should also be provided with safeguarding guidance on how to identify good and safe support outside of the peer support group.

Advanced content

Structured CBT or Inquiry-based Stress Reduction programme that addresses HIV internalised/self-stigma beliefs delivered by appropriately trained facilitators or coaches.

Resources

Here are some training resources and guidance to support your programme development.

Understanding and challenging HIV stigma. Toolkit for action. Modules B & C: More understanding, less fear, sex, morality shame & blame

https://www.icrw.org/files/images/Understanding-and-challenging-HIV-stigma-Modules-B-and-C.pdf

By International HIV/AIDS Alliance; Academy for Educational Development; International Centre for Research on Women

From the Understanding and challenging HIV stigma Toolkit for action, this facilitator guide presents an eclectic range of exercises that facilitators can use to challenge fears of HIV, internalised/self-stigma and shame.

Read time: 14 minutes

From the Inside Out: Dealing with TB-related self-stigma and shame

http://www.beyondstigma.org/resources.html

By Beyond Stigma; KNCV Tuberculosis Foundation

This toolkit draws on Inquiry-Based Stress Reduction tools to address internalised/self-stigma in people with tuberculosis. The workshop guide was developed from programmes working with people living with HIV and can be easily adapted for people living with HIV. Module 1 presents a range of activities that can be used to understand internalised/self-stigma. It also includes a module about measuring internalised/self-stigma. The toolkit is complete with Facilitator Guidance and participant handouts.

Read time: 3 mins – 1hr+

Developing Skills

Introduction

In this module participants will develop and build on their existing skills to mobilise and assert rights for themselves and others living with HIV. The aim of this module is to start small by enabling participants to recognise themselves as change makers in their own story and build up to becoming role models and change makers for their peers and others living with HIV.

The module begins with self-advocacy skills that enable people to communicate confidently about HIV and speak up for themselves within clinical and other settings. For those who wish to go further, they can explore opportunities and methods to share their story in public settings in the optional Introduction to Public-Advocacy.

In the advanced Ambassadors Skills option, participants will learn key skills for building and implementing campaigns and anti-stigma interventions.

Essential content

The programme should include group work activities and discussions that enable participants to:

- Develop and understand self-advocacy skills such as:
    - Recognising their own existing strength and resilience
    - Communicating factual information about HIV and U=U with confidence.
    - A basic understanding of health and social care policies and systems and their rights to enable self-advocacy with confidence.
    - Navigating personal boundaries around their story, experiences, and what they are comfortable sharing. To explore the benefits and challenges of sharing their story.
- Understand activism and advocacy in all forms and explore options they are comfortable with.

Optional content: Introduction to public advocacy

These optional additional programme activities should introduce participants to public-advocacy and enable participants to:

- Explore a range of creative techniques to develop their public-advocacy skills, such as photography, storytelling, creative writing skills, and use of social media to effect change on a societal level.
- Know how to identify opportunities to mobilise and assert their rights including understanding systems and how to advocate for or effect change.
- Use different opportunities and platforms to share their story of living well with HIV and becoming role models for people who are on the road to recovery, for example news articles, websites, media, and events.
- Explore different types of activism, including activism that is not related to HIV.

Advanced optional: ambassador skills

This advanced optional programme should include activities that inspire and enable participants to:

- Develop their skills, including media and public speaking skills.
- Work with others to develop and implement their own anti-stigma interventions.
- Understand the importance of working in collaboration or partnership with other services and agencies.
- Explore methods for fundraising for resources.
- Undertake campaigning work.
- Undertake suicide prevention training.

Resources

Here are some training resources and guidance to support your programme development.

Changing perceptions- Activist Toolkit

https://changingperceptions.co.uk/toolkit/

By Changing Perceptions

Drawing on the knowledge and experiences of the early AIDS activists, this toolkit provides a step-by-step guide to understanding activism and becoming an activist. It is intended for people who are starting out on their activism journey and looks at challenging stereotypes, unlawful practices, and harmful narratives so that people can live free from stigma and discrimination.

Read time: 3 mins – 1hr+

Catwalk for Power

https://positivelyuk.org/c4ptoolkit/

By Positively UK

The Catwalk4POwer toolkit is a creative guide for women with HIV and other allies. The toolkit will take you through a series of ‘Struts’ that empower women to perform and celebrate their power, beauty, and creativity. Explore the range of workshop facilitator guides on leadership skills, event management, and creative writing to name but a few.

Read time: 1 hour

4M’s Training Manual

https://4mmm.org/training-manual/

By Salamander Trust

This manual is a step-by-step guide for Trainers (Mentor Mothers) to deliver Training of Trainer workshops for other Mentor Mothers/women living with HIV. It is a four-day residential programme that looks at the different aspects of the pregnancy journey, as well as the role of Mentor Mothers in supporting their peers.

Read time: 1 hour 30

Zero Suicide Alliance

https://www.zerosuicidealliance.com/training

By Thrive London

Zero Suicide Alliance provides a range of awareness training sessions to equip people with the necessary skills to look out for someone who is struggling, someone experiencing social isolation, or someone with suicidal thoughts. It is a 3-step interactive online training resource tool that you can share with people to help them gain the confidence and skills to support others and help break down the stigma around suicide.

Read time: 1 Hour

Evaluating your programme

It is always valuable to understand and capture the impact and learning of your programme so that you can share your successes with funders or other similar services and know where you can make improvements. It is also important to capture whether your programme has achieved its goals and objectives. We can obtain this information by using multiple ways to gather feedback.

Within this evaluation framework, we have provided three methods by which you should evaluate your programme. These include an Empowerment Programme Evaluation Questionnaire, case studies, and self-reflective practice. The questionnaire and case study are mandatory. The self-reflection exercise is recommended as an additional way to enhance your practice and share your learning with your colleagues.

Quantitative methods

Empowerment Programme Evaluation Questionnaire

The first is a 10-item questionnaire that must be given to participants before, immediately after the programme, and three months following the empowerment programme. The 10 items using a 4-point Likert scale are positively framed and scored i.e., the higher the score, the more positive effect the programme has had on this individual. Items on this scale aim to measure wellbeing, self-esteem, internalised/self-stigma, and knowledge of HIV. Items 1, 2 and 5 have been taken from two validated scales; Rosenberg Self-esteem scale, and The Warwick Edinburgh Mental Wellbeing scale.

An individual can score a total of 40, indicating that this empowerment programme has had a positive impact on their wellbeing, self-esteem, internalised/self-stigma and knowledge of HIV. Attached with the questionnaire is a feedback form for individuals to complete should they wish to provide any written feedback. This can help the individuals to explain or expand around their responses.

Quantitative methods are useful in providing an objective picture around the effectiveness or impact of a programme. To best understand what your data has shown you will need to interpret and analyse it. If you wish to, you can input the completed scores into a graph format which is often useful for funders or other organisations to see. Analysing data at an essential level can be as simple as finding trends or patterns. For instance, you can combine all completed scores of your programme to produce a graph so that it is visually easier to see trends or patterns from the responses.

Note: If you notice that an individual has scored 'strongly disagree' on more than half of the items, as a guide, it would be advised to arrange a follow-up discussion to understand their scoring better. Please also follow your own organisational policies and procedures for any follow-up discussions.

Qualitative methods

Case studies

Alongside quantitative data, funders and other organisations are often interested in learning more detail about the impact of a program through case study examples. Case studies are a good way of telling the story of a programme through the perspective of the facilitator. We have attached a guide on how to write your case study. You must include your case study as part of your evaluation on completion of the empowerment programme.

Self-reflective practice

Self-reflective practice is a useful method to assess our own thoughts and actions for the purposes of personal and professional learning and improving our working practice. We have attached a template based on the Gibbs reflective cycle as a guide for programme facilitators to use. Reflective practice can be done as often or as little as you require. It is an effective way to continue to develop your personal and professional practice. You can share or discuss your reflective practice with colleagues and peers to seek feedback or guidance from others.

Empowerment Programme Evaluation Questionnaire

We invite you to complete this questionnaire to measure the impact of the empowerment programme on your wellbeing, self-esteem and internalise/self-stigma. You will be given this questionnaire before, immediately after, and three months following your participation in the empowerment programme.

There are 10 items on this scale. Please circle the response which is most appropriate for you. The total maximum score is 40, reflecting a positive indication of this empowerment programme, with the minimum score being 10. There are also additional questions asking for your feedback about this empowerment programme. You are welcome to complete this with your programme facilitator.

As a result of this empowerment program:

1. **I feel that I have a number of good qualities***

Strongly agree (4), Agree (3), Disagree (2), Strongly disagree (1)

2. **I take a positive attitude towards myself***

Strongly agree (4), Agree (3), Disagree (2), Strongly disagree (1)

3. **I do not feel shame about my HIV status**

Strongly agree (4), Agree (3), Disagree (2), Strongly disagree (1)

4. **I feel equipped to deal with difficult situations in my life**

Strongly agree (4), Agree (3), Disagree (2), Strongly disagree (1)

5. **I feel capable and empowered to face the future ****

Strongly agree (4), Agree (3), Disagree (2), Strongly disagree (1)

6. **I am able to make and maintain meaningful connections with others**

Strongly agree (4), Agree (3), Disagree (2), Strongly disagree (1)

7. **My HIV status does not limit my life on a day-to-day basis**

Strongly agree (4), Agree (3), Disagree (2), Strongly disagree (1)

8. I have enough knowledge about U=U

Strongly agree (4), Agree (3), Disagree (2), Strongly disagree (1)

9. I have enough knowledge around living well with HIV

Strongly agree (4), Agree (3), Disagree (2), Strongly disagree (1)

10. I feel confident about where to go if I need more information around living well with HIV.

Strongly agree (4), Agree (3), Disagree (2), Strongly disagree (1)

Total score: ......

**** Rosenberg self-esteem scale***

*****The Warwick-Edinburgh Mental Wellbeing Scale***

What did you enjoy most about this programme?

What would you change about this programme?

What are the one or two things that have had the most impact on you that you will be taking away from your experience of this programme?

Any comments around how the program was facilitated incl. size of group, venue, number of sessions, and timings?

Thank you for completing this questionnaire and feedback form.

Case study template for programme facilitators

This template is for programme facilitators to use to present their reflections in the form of a case study. Programme should consider the results from their Empowerment Programme Evaluation Questionnaire data, what worked well, challenges and key learnings.

Name of facilitator:

Date:

Organisation details:

Contact details of facilitator: (telephone/ email):

Title of project/ case study:

Please describe your empowerment programme, including;

- Who delivered the programme
- Who was the empowerment programme for?
- What was the purpose of the programme, based on your service/organisation?
- What activities did you include?
- How was it delivered?
- What were your evaluation results, pre vs post questionnaire?

What (if any) barriers did you come across and how did you overcome them?

What was the impact of the programme on the participants? You can describe this in terms of:

- Developing a supportive network
- Understanding what HIV is, U=U, and health & wellbeing
- Understanding internalise/self-stigma
- Building self-acceptance, self-esteem, and power
- Developing skills

Personal comments/ quotes from participants:

Overall, if you could sum up the benefits in one sentence what would you say?
Recommendations or advice for other services who may be trying a similar approach:

Self-reflection template for programme facilitators

This template can be used by you to help you understand and reflect on your experience of your programme delivery, where you can develop your practice and to share your learning with your colleagues. The following topics provide a guide as to how you should present your reflection. The topics are based on the Gibbs's Reflective Cycle.[1]

Description:

- How did you deliver the programme?
- When and where did you deliver it?
- Who was present?
- What did you and others do?
- What did you hope for?

Feelings:

- What were you feeling during your programme delivery?
- What were you feeling before and after your programme delivery?
- What do you think other people were feeling after the programme?
- What do you think about your programme now?

Evaluation:

- What worked and what didn't work in the programme?
- What are your reflections on your questionnaire data results?
- What was good or bad about the experience?

Analysis:

- Why did things go well?
- Why didn't they go well?
- What sense can you make of the situation?

Conclusions:

- What did you learn from your programme delivery?
- How could this have been a more positive experience for you and your participants?
- What else could you have done?

Action plan:

- What could you do differently?
- What skills do you need to develop for you to handle this situation in the future?
- How will you develop the required skills?

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[1] Gibbs, G. (1988). *Learning by doing: A guide to teaching and learning methods.* London: Further Education Unit.

Case studies

The following chapter showcases a range of empowerment programme case studies provided by members of the community of practice who developed this framework.

Positive East: Peer support by peer mentor trained volunteers

By: Antonio Giacalone

Our peer support programme is delivered by trained peer mentor volunteers. Peer mentors provide one-to-one support and/or delivery of peer support groups.

Who was the empowerment programme for?

People living with HIV. The aim is to identify support needs of individuals and to build a support plan to address the key issues identified. A key issue that comes up very frequently is peer support: people who engage in this programme want to talk to someone who shares with them the experience of living with HIV. They themselves may present with specific issues including difficulties around disclosure, relationship issues, stigma, and treatment adherence. At other times we identify issues including internalised/self-stigma, or the negative impact and effect of living with HIV. In either case, the aim of engaging in peer support is to provide people with the opportunity to build a relationship with a person who has a similar experience and explore with them the experience of living with HIV and how to navigate all aspects that diagnosis can bring.

At Positive East, our peer support programme is part of a continuum of psycho support and forms part of the wellbeing approach of the organisation. The peer support team can refer the mentee into our advice team for practical issues such as housing, immigration, and benefits advice, or into our counselling and women’s psychology services.

What was the purpose of the programme?

The purpose of the programme, aside from the experience of sharing with someone similar the issues of living with HIV, is to reduce the sense of isolation and empower people, so that they feel confident about themselves and the future and help manage their diagnosis and knowledge of HIV.

How was it delivered?

The one-to-one programme is made up of six, one-hour-long sessions that can be extended to twelve if deemed appropriate. Before the COVID-19 pandemic, peer support was delivered face-to-face. In the last 18 months it has been delivered via video conferencing or telephone. People that engage in the programme are also informed about and encouraged to engage in the group workshops and activities that we provide on various topics to enhance their knowledge and networking opportunities.

Due to the pandemic, the support group programme has been delivered online and organised by peer mentor volunteers. The programme title was “Conversation around disclosure”. The aim of the programme was to provide a safe and confidential space to share personal experiences of disclosure. When we learn from our peers, we feel more connected, less isolated, and better able to network with others.

One-to-one peer support

We strive to personally match mentors with mentees, making sure that the two have common ground upon which to build from (aside from the experience of living with HIV). This ensures their relationship has the best possible chance of success.

We once supported a 47-year-old lady from Ghana. She presented with very little medical knowledge of HIV. She was also experiencing high levels of anxiety and stress and had low self-esteem. We learned this was because she was experiencing stigma from her immediate family and from her faith community. After an initial consultation with this lady, we asked her if she would be happy to engage with a gay male peer mentor volunteer of similar age as we had no African women volunteers available. She agreed and they began to work together. She engaged with the programme for 12 sessions. Some of the issues that were explored in these sessions included:

- African culture beliefs and attitudes towards HIV

- Difficulties of being dependant on relatives due to immigration status
- Feeling ostracised because of her status and being given plastic plates and glasses
- Feelings of isolation and depression
- Feeling unlovable
- Disclosure and fear of rejection

I was amazed to hear how this relationship between these two people from different backgrounds, social settings, and gender identities managed to build a strong rapport and trusting relationship over a period of several weeks.

Support group programme

The peer mentor volunteers reported that disclosure was a subject that was always relevant for people. Participants in the group reported that the decision process of discourse was always relevant for them and that it also changed depending on how they felt, their circumstances, and who they were disclosing to. They also mentioned that aside from talking about disclosure, it was important to broaden the conversation about HIV more generally. They wanted to explore other topics and aspects of living with HIV. In addition, they wanted to meet for purely social activity, and they were tired of meeting through camera.

The peer mentors are working on other topics to discuss in the support group with the support of the peer support team. They are also very keen to do social activities as requested by the participants, which will be revisited once COVID-19 restrictions lift and they are deemed safe for all involved.

Personal comments/ quotes from participants:

The most common feedback we hear from participants is that hearing other people share their experience of disclosure helps them to feel less isolated in their experience.

The lady from Ghana reported an increase in self-confidence, a better understanding of external stigma and how to manage it, an improved overall sense of wellbeing, and a more hopeful and positive look in the future.

Benefits of engaging in peer support

Engaging in peer support gives a person the opportunity to explore their experience of living with HIV in relation to other people and the wider world. It can be a very empowering experience that can lead to an improved way of managing the diagnosis in a constructive and healthy way. It can also lead to increased sense of wellbeing and confidence, which are naturally catalysts for positive change. Being in the company of others who share the same diagnosis can be a reparative and healing experience that works even without engaging in a formal discussion about living with HIV.

Personal Recommendation

My suggestion would be to always look outside of the box. As the above case demonstrated, peer support can work extremely well even if participants differ in their characteristics and experiences. Encourage participants to work with different people, as differences can lead to better understanding of ourselves and others.

The individual should be worked with at their pace so that they are in control and their thoughts, feelings, and decisions.

In addition, it is important to remember that people living with HIV are whole people, with diverse needs, who are not defined by their status. Too much focus on the HIV itself poses the risk that people’s sense of self is diminished, as they begin to lose touch with other parts of themselves and of their lives.

Terrence Higgins Trust: Stigma and resilience workshops

By Jim Fielder and Takudzwa Mukiwa

A programme of work co-designed and delivered by peers living with HIV to support participants through a series of three workshops, helping them to understand stigma, build confidence, and strengthen their resilience.

Who delivered the programme?

This empowerment programme was co-designed by peer supporters living with HIV. The peer supporters explored what they would want from a workshop series. The group explored the desired outcomes, content, and delivery methods. They also explored how best to market it to ensure everyone who could benefit from the programme would do so.

The subsequent workshop series was delivered and evaluated by three co-facilitators living with HIV who used their own diverse experiences to facilitate group conversation.

Who was the empowerment programme for?

Anyone living with HIV looking to build confidence and strengthen resilience through addressing internalised and/or enacted stigma.

What was the purpose of the programme based on your service/ organisation?

To offer a safe peer-led space for people living with HIV to share stories of stigma and discrimination, enabling them to build a toolkit to address and overcome stigma and improve overall wellbeing.

What activities did you include?

The programme was delivered via a series of three workshops. The first was about understanding stigma, the second looked at tools and strategies to build confidence, and the third looked at strategies to strengthen resilience. Storytelling, reflection exercises, and group discussions were among the activities used in the workshops. We sent follow up resources to all participants in the form of a toolkit to enable self-directed learning.

How was it delivered?

The workshop series was delivered via Zoom, as face-to-face workshops were not possible during the COVID-19 pandemic.

What (if any) barriers did you come across and how did you overcome them?

We encouraged attendees to switch on their cameras during Zoom workshops to better enable rapport building within the group. However, one of the key barriers we encountered was that some participants did not have the confidence to do this. We addressed this by advising all participants that they could join the group without their camera if they were more comfortable that way, and we ensured that they were included in the discussion throughout regardless. As a result, we noticed that those who had their cameras off for session one felt more comfortable and confident to turn them on for sessions two and three.

Not all attendees were always available during the programme workshops. For those few attendees who arrived late or needed to leave early due to childcare commitments we ensured that the more optional activities were at the beginning and end of the sessions and that key activities were delivered in the middle of the workshop times.

What was the impact of the programme on the participants?

- The programme brought a group of people living with HIV together over the course of three workshops. The peer facilitators created space for attendees to get to know each other and build rapport together, enabling them to bond over time.
- In the first session we outlined the key facts about HIV and U=U, giving the participants the knowledge and the tools to address stigma when they experience it. The group discussed educating others who do not have an up-to-date knowledge of HIV in today’s world.
- At the end of the programme:

- 79% of participants agreed ‘I have increased confidence to enable me to overcome stigma’
- 81% of participants agreed ‘I recognise and am able to draw upon my own strengths to help me deal positively with change and difficult situations
- 88% agreed ‘I have gained tools and techniques to build resilience’
- 97% agreed ‘I felt confident to use Zoom to participate in the workshops’
- 80% agreed ‘My confidence improved from the beginning of the session’

Participants fed back that they had improved confidence to talk about living with HIV for the first time with friends, family, or new sexual partners following the programme.

Personal comments/ quotes from participants:

‘I will accept myself and that I am enough. HIV doesn’t define me. I have been through a long journey to be here today and I am doing ok. I AM doing ok!’

‘Work have asked me to be a people’s champion but I have not come out or disclosed my status to them. They want me to look at diversity and inclusivity. These workshops and especially today have given me the confidence to think yes I can do that job and maybe even come out at work, thank you for that’

‘I thought the workshops were amazing for building resilience, my confidence has improved so much! The only thing I could think about would be if we could have more sessions or a way to keep in touch as it’s all been so helpful’

Personal recommendation

We found that storytelling was the most powerful tool in bringing the group together as it enabled participants space and time to tell their stories and to understand each other’s experiences, successes, and failures.

We also found that having three co-facilitators all living with HIV with different experiences to share to deliver the programme was highly valuable.

Positively UK: Catwalk4Power

By Silvia Petretti

Catwalk4Power was started in 2017 by a small group of women living with HIV (WLHIV) attending a peer-led support group in London. The WLHIV worked in collaboration with a group of women feminist activists and artists. Collaboratively they organised a series of creative workshops which supported the making of artefacts, outfits and created safe spaces for discussions about key issues for WLHIV, such as understanding U=U, safe relationships, intimacy and pleasure, leadership, and increasing personal power.

Who was the (empowerment) programme for?

The Catwalk4Power was created to address silence around women with HIV through the tools of creativity and performance.

What was the purpose of the programme?

It aimed to challenge stereotypes and prejudices and to develop women's confidence and leadership skills.

How was it delivered?

Collaboratively women living with HIV and feminist activists and artists organised a series of creative workshops. These workshops supported the making of artefacts and outfits and created safe spaces for discussions about key issues for women living with HIV, such as understanding U=U, leadership and increasing personal power. Activities included in the workshops included sharing our stories, creating key messages, and collective poetry for example.

One of the most fun workshops we did is called "Our Amazing Bodies". During this workshop women create, draw, sew, glue props and artifacts inspired by women's bodies (for example, breasts, eyes, mouths, vulvas, uterus and hands), and discuss pleasure, intimacy, relationships, and how HIV has affected these factors. The workshop enables women to open up about issues around their sexual and reproductive health and rights and provides themes for the performance. The props produced can be used during the Catwalk4Power.

The workshops culminated in a performance in front of over 150 people, including a parliamentarian, for International Women's Day, where 34 women living with HIV (the majority black and racially-minoritized women) participated openly. The performance included speeches, collective poetry, and the 'Catwalk4Power' where women with HIV strutted proudly in their creations. The Catwalk4Power was invited for a workshop at the International AIDS Conference, and self-funded through market stalls to attend. In 2019 three Catwalks4Power were funded for three different locations in the UK.

What (if any) barriers did you come across and how did you overcome them?

Initially women had a lot of fear around performing openly as women with HIV and they lacked confidence. Our workshops focused on self-esteem and self-love, using movement and positive affirmations like: "I am powerful" "I am enough" "I am kind" "I am here". We also developed a collective call and response chant: "The Power Is Ours". During these workshops women practiced "Strutting Skills' with the support of a skilled dominatrix and performer, Madam Storm.

We used positive feedback circles in which women identified each other's strengths and qualities and gave appreciative feedback.

We addressed the barriers by giving women space to discuss safely and the option to create disguises and face covers to protect themselves and not to be recognised during the performance. However, when it came to the event, none of the women wanted to wear their pre-prepared masks. They all did the Catwalk4Power showing their faces.

A key learning point is that it is important to have ample time to discuss safety and confidentiality, as well as having alternative options to address issues raised. Women should be free to choose what feels right to them. A supportive, compassionate, and encouraging environment, in which women can have fun and feel free, is essential.

Personal comments/ quotes from participants:

Feedback from participants showed that the model is incredibly successful in increasing women's confidence, self-esteem, and ability to step in the public arena. In the words of a participant:

> *"After diagnosis, I lost my confidence and self-esteem. I couldn't get myself to think I deserved the best in life. Being part of the Catwalk4Power was transformative, it was organic; it was us, women living with HIV, everyday women who can often be overwhelmed with social inequalities and intersections that can make us underestimate our abilities, who lead and created the event. Everyday women who sometimes forget how much skills and resources we have as individuals and as a community"*

In this poem, created during a workshop, a participant describes the Catwalk4Power:

"Catwalk 4 Power is about women being seen, and loud
Owning their space and feeling proud.
More than a fashion show, or a pussy parade
Not haute couture, or a dressed-up charade
It's about being visible, bravely stepping from the shadows of shame
Being empowered to say I am here, and this is my name.
Catwalk 4 Power is not just about heels
It's a sisterhood of people who know how it feels
To receive a diagnosis and be close to psychosis."

Benefit of engaging in peer support:

When women living with HIV are given the environment and funding to gather, magic happens, and support systems and communities evolve. In Catwalk4Power, women worked together and invested their time collaboratively, because this was a project they believed in and felt involved in from the beginning.

4M Mentor Mothers Network CIC (4MNet): Developing a national network of mentor mothers

By Angelina Namiba & Longret Kwardem

4MNet CIC was developed and led by women living with HIV, with a multidisciplinary advisory steering group which includes Mentor Mothers (MMs), clinicians, academics, and researchers. There are other Mentor Mother programmes around the world, but they tend to be non-peer led with a biomedical focus on preventing vertical transmission and ensuring treatment adherence. 4MNet CIC believes in the meaningful involvement and leadership of women living with HIV to address stigma using community safe spaces.

Who was the empowerment programme for?

The 4M Programme, ‘My Health, My Choice, My Child, My Life’, is an innovative peer-led grassroots network, that provides training for women living with HIV to become qualified Mentor Mothers (MMs) and offer their peers (other women living with HIV planning to conceive, or expectant and new mothers) psychosocial support in their pregnancy journey and beyond. It also provides a safe virtual community space for MMs to address intersecting issues we face whilst living with HIV. We use our collective voice to safely explore and address HIV stigma, ensure our sexual and reproductive health and rights, and improve our quality of life.

How it is delivered

At 4M, we believe we women are the experts in the support we need. Our approach is holistic, about our minds and spirit, not just our bodies. We use a collaborative approach to address intersectionalities that exist for women, building the movement for women’s rights.

MM training is highly interactive and participatory, delivered in collaboration with other HIV organisations and clinics. Training aim is for participants to gain an understanding and/or enhance their knowledge and skills around:

- Preconception Planning: basics of HIV, preventing onward and vertical transmission; safer conception/what to consider if/when planning to conceive.
- Pregnancy: what happens during pregnancy; BHIVA guidelines/interventions to prevent onward transmission; how to apply these at a personal level/strategy around talking to significant others about HIV
- Delivery: Available options and when which would be suitable/making informed choices around Sexual & Reproductive Health & Rights
- Aftercare: For both the woman and her baby/the importance of staying engaged in health and social care services before/during and after delivery and breastfeeding options
- Creative Writing/Peer support: To give participants a safe and creative space in which to explore, share and reflect upon their experiences of living with HIV; as well as to explore, enhance and reinforce their role as effective 'Mentor Mothers', through creative writing exercises. MMs were trained to use photography and creative writing to explore our visions for better futures post-lockdown where all elements we need to be happy, healthy, and safe are present: no HIV stigma, discrimination, poverty, violence; where there is gender equality, racial/ social justice and our meaningful involvement ensured.
- The programme team provides one-to-one support and supervision to MMs and the program team receives supervision from pro-bono psychologists. Included in the supervision is mindfulness and support to address personal issues and stigma.

Additional support for MMs includes:

- Support to develop personal and professional capacity to improve their quality of life through practical one-to-one mentoring, training, and opportunities for paid and unpaid involvement within the network.
- Opportunities for information and knowledge exchange through our webinar series for women living with HIV, and with health and social care providers.

- Opportunities to work with clinicians to improve the pregnancy experience of women living with HIV by having them on the 4MNet Steering group.
- Opportunities to collaborate with researchers using participatory research to build the evidence base.
- Opportunities to work in partnership with organisations addressing issues affecting women living with HIV perinatally for a holistic approach for example, domestic violence, housing, immigration, mental health.
- Opportunities to advocate for change, through consultations and influencing policy to improve quality of life of women living with HIV and their babies.

Overall, these combined 4M approaches serve to safely explore and address internalised and external stigma that Mentor Mothers and their mentees face or perceive in their lived realities.

Impact of the programme on the participants

4MNet CIC currently has 35 members including MMs trained in the UK and East Africa.

An evaluation of the 4M WhatsApp platform found that the closed group is considered by Mentor Mothers (MMs) "*an accessible safe space for mutual support*". A six-month post-training evaluation of the MM training found self-reported impact as improved self-confidence, reduced sense of isolation and a greater sense of community.

A one-year-on post-MM training evaluation found that 4M is a highly valuable and acceptable peer-led platform for the education and self-development of women living with HIV, fostering resilience and self-efficacy. Nearly 90% of Mentor Mothers reported that both their knowledge about HIV and pregnancy and confidence in action planning had improved. The creative writing component was also rated highly. Mentor Mothers reported that this had been their first opportunity to share their journeys in such a way in a safe space.

Through involvement in the network women feel enabled to participate and be safely visible within their communities. They are dispelling stigma by showing that women living with HIV are normal people with normal lives.

They also felt the programme helped them to build their self-awareness:

"What we feel is important for our future as women is that we have abundant knowledge care and love and not worry about stigma, services, acknowledging and realising ourselves. We would like a future where we find our voice …. a future where women self-appreciate and feel that everyone has value ……one of the ways we can achieve this is to focus on building our self-confidence because it starts with me……. When I am appreciating me, I am building the self …one way we can make this happen is to continue with these uplifting sessions and to create opportunities for us to connect and share both the challenges and the fun because that helps us to be grounded and focused….so to continue with these sessions".

- A quote from the creative session held on 29th January 2021.

Personal comments/ quotes from participants and colleagues:

"As an HIV clinician, I have the seen the impact that peer mentoring from 4M has on women going through their pregnancy journey, empowering them with the knowledge and agency to make decisions about their health that lasts well beyond pregnancy. 4M have advised on the 2018 BHIVA Pregnancy guidelines directly impacting on the clinical care of pregnant women in the UK. As Chair of the steering group, it has been a pleasure to work on a project led by women living with HIV and the development of 4M as a CIC has been a particularly impressive achievement. 4M's international presence has deservedly grown in recent years due to their prize-winning research and invited conference plenaries, as well as multiple collaborations."

- Steering Group Chair, Dr Rageshri Dhairyawan

"The training has brought us together more than any other training because all of us were able to volunteer to tell our own story… Everybody, even the quietest of the quietest in that group that I have known for a few years, opened up for the first time. People were cheerful, emotional and grateful at the same time. I have been attending training, I have never seen anything like that... It brought empathy; you understand someone better"

- MM, One-year Evaluation of the pregnancy Journey training

“Having a supportive network has given me a foundation to fall back on allowing me to step up again from that level rather than fall down into the depths”

- 4MNet Member, the impact of the network

“My favourite aspect of the 4M Network WhatsApp group is] being connected to other women, from all over the country… it just helps me to know that there are other people that I can speak to, if I need to. Just knowing that there's that support network.”

- 4MNet Member, evaluation of the 4M Network

“It was a very good experience because it was a shared and calm environment. I was free to talk about my experience and hear from others with the same experience and encourage others. It was a good and empowering experience”

- MM, One year post MM training

Recommendations and advice for other services who may be trying a similar approach:

- Use sensitive, positive, and safe language .
- Value our work and recognise our expertise as leaders. Put ourselves at the heart of decision making, and actively involve us as the experts that we are. Ask health care providers, researchers, policymakers, and other stakeholders to “Listen to us… Learn from us… Work with us” and recognise us as equal partners in our own holistic quality of life, wellbeing, healthcare, and rights.
- Recognise and fund and support peer-led Mentor Mother programmes, women’s rights, and independent movement-building as critical for addressing HIV stigma and ensure women’s sexual and reproductive health and rights.
- Ensure Mentor Mothers have access to digital tools like mobile phones, data, and internet, and have the ability to use them.
- Recognise the value of our model The 4M approach to perinatal peer support works. The often top-down biomedical models of differentiated services disempower us as women: ‘elimination of mother-to-child transmission’ or ‘getting to zero’ movements may ignore the principles of respectful maternity care, can increase self-stigma, and violate our sexual and reproductive health and rights.
- Develop partnership working, buy-in and referrals from clinicians and relevant non-government organisations, to ensure our services are known and available to women.

We delivered programmes in the UK and in East Africa. The UK programme was delivered in partnership with Community Based Organisations across eight regions of the UK. The East African programme was delivered in partnership with Community Based Organisations working with young women and adolescent girls across four regions; two in Kenya and two in Uganda.

Challenges/barriers we came across whilst delivering the UK programme.

- Recruitment and retention of Mentor Mothers in the 2-day training sessions (often due to conflicting personal and family commitments)
- MM concerns about attending training delivered by strangers and concerns about confidentiality
- Psychosocial stress: some of the participants were not comfortable with sharing their experiences as this was very new to them. In some instances, participants broke down in tears and had to be counselled and supported.
- Most pertinently, given the pressures faced by many voluntary sector organizations, one training session was cancelled because of the closure of a host organization through/due to funding cuts.

In order to address some of these challenges we:

- Created bespoke flyers for organizations to circulate to potential participants, in addition to other recruitment methods
- Visited organizations prior to delivering the training to introduce our 4M Concept and the training programme to potential participants
- Used proactive communication and rigorous follow-up (including reminder texts and emails) to and with booked participants
- The training was delivered by a minimum of two trainers and each day one was assigned as the go-to one-to-one support person
- Met childcare costs where the host HIV charity had funding constraints
- Used social media (Twitter and Facebook) to raise further awareness of the project

Challenges/barriers we came across whilst delivering the East Africa programme.

- Geographic spread: there was a clear need for further capacity building as the organisations we partnered with to host the training covered large areas and were therefore not able to reach out to all the facilities within their coverage areas. Which called for a need for further training to reach more Mentor Mothers.
- Language issues: Some of the sessions had to be delivered in the local languages and others required translations. In both Kenya and Uganda some of the participants were not fully conversant in English. Luckily, the trainers spoke both Kiswahili and Luganda - the local languages needed for the participants who needed translations.
- Psychosocial stress: Some of the participants were not comfortable with sharing their experiences as this was very new to them. In some instances, participants broke down in tears and had to be counselled and supported. The training was delivered by a minimum of three trainers (we had more participants in East Africa), and each day one was assigned as the go-to one-to-one support person.
- IT issues: The programme was affected by communication barriers between host organisations, particularly when it came to conducting post-training follow-up as several of the trained participants did not have mobile phones. A learning point was to ensure that future programmes consider mobile phone access for participants in the grant application process.
- Engaging men: Many of the participants were young mothers and post-training evaluation revealed the need to involve men in such interventions if the young mothers and their mentees are to adhere to treatment as well as clinic visits. This is because many of them were/are dependent on partners and had to prioritise home obligations.
- Health care centre relationships: There were challenges associated with the engagement of health care providers. It was reported that MMs are often ignored and stigmatised by midwives is some hospitals. We are calling for an urgent need to raise awareness amongst health centre staff of their obligations

to all those in their care, as well as the value of perinatal peer support programmes.

Aspects of the programme we have improved:

- We followed the initial training with a Training of Trainers session for MMs in the UK, to enable them to deliver the Pregnancy Journey training
- We set up the 4MNetwork WhatsApp platform to continue enabling MMs in building their skills and capacity to support their peers
- We developed a fully comprehensive Training Manual for Mentor Mothers https://4mmm.org/training-manual/, which includes a Mental Health Annexe. This can be adapted and delivered in any context and to suit different regions internationally.
- In line with the current COVID-19 situation, we have adapted the manual into shorter sessions that can be delivered virtually.

Beyond Stigma: We Are the Change: A programme for people living with HIV on self-stigma and shame

By Camille Rich & Nadine Ferris Francis

Between 2013-2018, Trócaire, Zimbabwe Network of People Living with HIV and AIDS, Beyond Stigma and The Community for The Work in Zimbabwe collaborated to create the 'We are the Change' programme in Zimbabwe.

Who was the empowerment programme for?
For people living with HIV in Zimbabwe.

What was the purpose of the programme?
The purpose of this programme was to explore the core beliefs of self-stigma amongst people living with HIV in Zimbabwe and to use Inquiry-Based Stress Reduction (IBSR) to reduce this self-stigma. IBSR, developed by Byron Katie, gives individuals the power to address self-stigma and stigma-related conditions themselves, through a community-based, peer-to-peer approach. It supports participants to improve wellbeing and positively affects self-agency and self-esteem.

To develop an informed curriculum, formative research was conducted through qualitative interviews with people living with HIV. The core beliefs underlying HIV-related self-stigma were organised into categories: disclosure; sexuality and sexual pleasure; self-perception, body, illness, death, guilt, and shame. Using these findings, a 12-week self-stigma programme was implemented. Each of the key underlying beliefs of HIV self-stigma were explored in the context of HIV in Zimbabwe. These courses incorporated IBSR to challenge negative thoughts about themselves and their

HIV status. The participants delved into these topics through self-inquiry, and group discussions.

How was the programme delivered?

The initial training included both group and one-to-one sessions with Certified Facilitators of IBSR: The Work. Subsequently participants continue to meet regularly to maintain their practice and connect with facilitators in the global community of IBSR: The Work. Those who attended the programme were then trained to continue the programme through the 'Cycle of Change'. The programme was run in its entirety three times. The second and third times were delivered by locally-trained coaches supported by International Certified Facilitators. It was further adapted on each delivery to ensure it was responsive and locally applicable.

IBSR: The Work is a facilitated meditative technique of self-inquiry used to manage stress and other negative thoughts. It can be applied to any condition or perceived stressful situation, supporting people to reduce their levels of stress by reflecting on thoughts and beliefs connected to stressful circumstances and symptoms.

The Four Questions are a key self-inquiry tool used in The Work: IBSR.

1. Is it true? (Yes or no. If no, move to 3.)
2. Can you absolutely know that it's true? (Yes or no.)
3. How do you react, what happens, when you believe that thought?
4. Who would you be without the thought?

Then a process of Turn Arounds is applied.

What (if any) barriers did you come across and how did you overcome them?

There were some initial concerns that IBSR: The Work may not be applicable or useful within the local context of Zimbabwe. Therefore, to ensure that our approach to IBSR would be culturally appropriate, we conducted a thorough study prior to the intervention. This allowed us to better understand how self-stigma manifested amongst people living with HIV in Zimbabwe and create a programme tailored to their experiences. Our data demonstrates that the programme adapted to the Zimbabwean context was successful and useful to our participants. Other barriers include the need for local Coaches to be trained sufficiently to deliver the intervention to ensure high quality. It is a psychological intervention and as such, requires appropriate support. A final barrier is fidelity to the model of IBSR which is a specific application of a technique involving four questions and turnarounds.

What was the impact of the programme on the participants?

By the end of the We are the Change program, our participants had a deep grasp on the concept of self-stigma and how it impacts their lives. Over 50 people living with HIV had participated in the programme. The participants reported that IBSR helped them to reduce negative thoughts and inspired them to think more positively about themselves and their future. They stated that using IBSR was a helpful tool to improve wellbeing.

Qualitatively, participants reported being able to live more positively with HIV, experiencing lessened fears about disclosure, feeling they are not limited by their HIV status, and experiencing more peacefulness. Quantitatively, results show statistically significant improvements in several areas: 87% of participants felt improvement in their daily activities, 78% of participants felt a decrease in depression, 65% of participants reported improved life satisfaction, 52% of participants felt their self-stigma reduce, and 48% of participants reported decreased fears around disclosure.

With long-term monitoring we found that the impact of the intervention on participants lasts at least 12-months after the delivery of the training. We believe that the course was successful in reducing self-stigma and improving quality of life. Participants also gained a supportive community through group work, mentorship, and peer facilitations.

Personal comments/ quotes from participants:

"I have held campaigns against stigma at national level but there was a portion within me which I had not unearthed. Inside of me there was suffering and war and this was addressed by IBSR:The Work."

- Nyasha Tugwete, Coach of The Work

"… to be honest with you I was very sceptical, I was not sure if this method was going to work here in Africa especially in Zimbabwe.... So when I started doing IBSR:the Work … that's when I can say it found me and I've fallen in love with it."

- Sylvia Vumbunu, Coach of The Work

"Knowledge is power. Some people say [HIV] is the end of life but… [The Work: IBSR helps by] restoring their hopes."

- Nyasha Tugwete, Coach of The Work

"I am now confident that I can do whatever those that are [HIV] negative are doing. Before, one of my friends asked me why I wasn't applying for a teaching course and I told her that I couldn't because I was HIV positive. I now want to attempt to apply for a teaching course. My self-esteem was very low but it has now been boosted. I used to limit myself."

- Post-course interview research participant

"I used to find it difficult to disclose my status to some of my relatives. Due to the course, I have disclosed my status to those relatives."

- Post-course interview research participant

Overall, if you could sum up the benefits in one sentence what would you say?

We are the Change gave participants living with HIV the tools and an ongoing approach to reduce self-stigma, decrease negative self-judgements, and improve their overall quality of life and self-worth.

Recommendations or advice for other services who may be trying a similar approach:

Conducting research to inform your intervention is critical in creating a programme that is culturally relevant and effective for your participants. Take the time to conduct interviews, gather data, or analyse existing information in order to design an informed curriculum based on the local community or situation. This will help ensure that your intervention is properly tailored for the population you aim to serve and that your participants will have the best chance of reaching your objectives.

IBSR is an excellent strategy to reduce self-stigma and improve wellness. Therefore, it is advisable to create a system in which the strategies of IBSR can be passed on by training local facilitators. We call this the 'Cycle of Change' to train new coaches of 'The Work'. The training for Coaches of The Work gives individuals added skills in self-reflection and stress-reduction and enables them to facilitate other members of their peer group. Participation at this level requires significant commitment, the impact on individual lives is transformative, and it allows for the intervention to be sustained by community members living with HIV. As the cycle continues, new entrants are introduced and facilitated by previous participants, and the intervention expands within the community. As more coaches are trained, more courses can be offered, and a larger number of community members can be reached. We recommend a training programme such as this for the sustainability of your programme and the continuation of IBSR in the community in which you work.

Beyond Stigma: Embrace Yourself: A video series on thought, self-stigma, self-worth, and self-love

By Camille Rich & Nadine Ferris Francis

In 2020, Beyond Stigma and Centre for Supporting Community Development Initiatives (SCDI) Vietnam partnered to create a video series called ‘Embrace Yourself’.

Who was the empowerment programme for?

This empowerment series is intended to reach marginalised groups including sex workers, people living with HIV, transgender people, people who use drugs, and men who have sex with men.

What was the purpose of the programme?

Embrace Yourself are guided YouTube videos on thought, self-stigma, self-worth, and self-love. The aim is to deliver focused video messages on self-stigma, shame, thought, and thinking via social media.

How was it delivered?

Beyond Stigma and SCDI Vietnam have worked together to specifically reduce self-stigma amongst sex workers living in Vietnam since 2015. The series was created based on the learning from the face-to-face workshops on self-stigma and was produced in both English and Vietnamese to reach their local community members. Four episodes have been currently created, with two more on the way.

Each episode discusses a different topic relating to self-stigma and self-love. Animations are used to help the viewer visualize topics and follow along. The video invites the viewer to participate in small exercises including thought questioning, visualization, and thinking exercises. This allows the viewer to relate the video to their own lives while also learning about these different topics. All episodes are on both Beyond Stigma and SCDI's website and were shared widely amongst their communities.

Both SCDI and Beyond Stigma used social media platforms, in particular Facebook (which is very popular in Vietnam) and Twitter.

What (if any) barriers did you come across and how did you overcome them?

When the videos were first being designed, the series was created in English. However, we quickly realized this would not allow viewing access to the many clients of SCDI Vietnam who only speak Vietnamese. The series was produced with limited resources and internal organisational video editor capacity as expected funding was not secured. Additionally, when COVID-19 hit, the production of the video series had to be put on pause. However, the final episodes have been planned for once COVID-19 restrictions have been lifted.

What was the impact of the programme on the participants?

This programme was successful in creating accessible information on self-stigma, thought processing, and self-worth. Marginalised communities may not always be able to participate in a formal intervention program. By creating the Embrace Yourself video series, we were able to bring important lessons to people all around the world. Having the videos in both English and Vietnamese enabled us to reach more people in the Beyond Stigma and SCDI Vietnam community. We were able to reach over 400 viewers on some videos. Those who have seen our videos have reported the enjoyment and ease of the short and easy to understand videos. Created in digestible segments, the Embrace Yourself series tackles a different lesson in each episode. Viewers develop skills to question their thoughts, analyse the power of their thinking and understand how our beliefs influence our daily lives. The video hosts walk the viewers through short exercises in order to practice and relate the lessons to their own lives. These lessons are critical for reducing self-stigma, decreasing negativity, and building a better awareness of oneself. Additionally, these skills can be used easily in one's personal life.

Personal comments/ quotes from participants:

“Beautiful! I would love to share this and the following with people new to the Work! I love how short this is - and look forward to the next one!”

- *Viewer*

“So helpful to go through exercises that relate to my own life. It made the videos feel relatable and easy to understand.”

- *Viewer*

Overall, if you could sum up the benefits in one sentence what would you say?

The Embrace Yourself series creates accessible and clear lessons on self-stigma and negative thinking so that viewers and marginalised groups can easily develop at-home skills for thinking positively.

Recommendations or advice for other services who may be trying a similar approach:

It is important to consider the populations you are targeting when creating a video series. By making both an English and Vietnamese series of Embrace Yourself videos we were able to reach marginalised populations in both communities. Additionally, local context and hosts can help make the videos more relatable for viewers.

We recommend creating videos that are easy and enjoyable to watch. Sticking to one lesson or skill per video allows viewers to digest the material and accomplish an important task in a manageable amount of time. This will allow more people to engage with your series who may not have the time to watch a longer detailed video. Additionally, finding ways to have your audience engage with the video through exercises or at home skills is critical in finalizing their skills or the intended objectives.

Video Series: http://www.beyondstigma.org/videos-and-content.html