

# An Evaluation of the Co-Design of a CityWide Pilot Anti-Stigma Training Programme

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## Foreword

The *Stop the Stigma Campaign* <http://stopthestigma.ie/> was launched by Citywide in 2018 with the aim of challenging drug-related stigma and its impact on people who use drugs. The Campaign Resource Document sets out 5 key areas of action, including Action 2) Challenge stigma in delivery of services, which states:

*‘We can engage with health care and frontline staff to develop education and training programmes to challenge the stigma that people who use drugs can experience in public services.’*

This evaluation report looks at a project led out by Citywide as part of Action 2 to develop an anti-stigma training programme to be delivered to service providers. The first stage in the project was to look at the existing evidence base on drug-related stigma; to this end, Citywide commissioned Dr Michael Barron and a team led by Prof. Catherine Comiskey, TCD School of Nursing and Midwifery, to carry out research that produced an evidence-based template for an anti-stigma training programme.

The second stage of the project involved a partnership between Citywide and the SAOL Project to work in a community project setting to develop the content of the training programme and deliver the pilot training programme. A core community development principle underlying this partnership was the involvement of people with lived experience of drug use and drug-related stigma in the co-design and delivery of the training. This principle also aligned with the human rights-based approach of the Irish Human Rights and Equality Commission (IHREC) and its commitment to strengthen the capacity of rights-holders, in this case people with lived experience of drug use, and funding was provided for this stage of the work through the IHREC grants scheme.

Oversight of the project was provided by a management team involving SAOL and Citywide, with a Co-ordinator and a Facilitator in place to carry out the work, one of whom is a person with lived experience of drug use. We were delighted to have our partners from TCD involved with the evaluation of the project and their team provided great support throughout; IHREC was also continuously supportive in recognising the need to adapt the workplan in response to external events.

This evaluation examines both the co-design process for the training and the rollout of the pilot training programme. In relation to the co-design process, the evaluation captures the crucial role of the SAOL Project as the host organisation, in particular as the impact of Covid-19 increased and intensified the significant challenges involved for the women participating in the co-design workshops. Partaking in this process meant that those who gave so freely of their expertise paid the price, at times, of reliving stigma-related trauma from their past. We were fortunate to have skilled Co-facilitators, as well as the back-up of the SAOL team, in ensuring this process was both safe and beneficial for participants and it is certainly a process that required more time and resources than we first imagined. We want to recognise the flexibility and support of IRHEC in adjusting dates to assist us in keeping the process safe and healthy, one that, in the end, provided such a successful outcome that the adage 'make haste slowly' seems most fitting.

In relation to the pilot training programme, the evaluation finds that the overall expectations that participants had of the training have been met, while at the same time providing a number of practical suggestions for improvements in presentation and content. What is most encouraging is the finding that this pilot training programme has made a difference that is statistically significant – this represents clear and independent evidence of the effectiveness of the training and of the potential for rolling it out on a broader basis.

We are very much aware of the massive challenge that faces us as a society in reducing the stigma related to drug use, but we are also convinced of the value of each step we take in that direction. This project to develop and deliver a pilot anti-stigma training programme has proved to be a valuable step forward and we welcome the recommendations in this evaluation report that will support us in taking the next steps. We are hugely grateful to all of our partners on this project and look forward to working with you all to build on what has been achieved to date.

[Anna Quigley, Citywide Drugs Crisis Campaign & Gary Broderick, SAOL Project](#)

## Authors

### *Professor Catherine Comiskey, Principal Investigator*

Professor Comiskey's research experience is in measuring and evaluating treatment and intervention outcomes and their implementation. She has special interests in substance use, infectious diseases and children's health. In 2012, Professor Comiskey was appointed by the Department of Health to chair the National Advisory Committee on Drugs and Alcohol. In 2013, she was appointed by the EU to serve on the Scientific Committee of the European Monitoring Centre for Drugs and Drug Addiction. In 2017, she was elected as the committee's Vice Chair and in 2020 she was elected as Chair. Professor Comiskey is also the sole academic advisor appointed by Minister of State to the Oversight Committee responsible for the implementation of the National Drug Strategy.

### *Dr Sonam Prakashini Banka, Research Fellow*

Dr Banka's research experience is in quantitative methodologies and working with vulnerable populations. She has special interests in health promotion, health psychology, service and intervention evaluation, child mental health and physical health, statistical modelling, depression, obesity, and substance misuse. Sonam is currently employed as a research fellow and project manager in the Institute of Population Health, School of Nursing and Midwifery, Trinity College Dublin. Sonam has a BA(Hons) in Psychology, PhD in Psychology with a focus on child health, PG Certificate in Statistics, PG Certificate in Innovation and Entrepreneurship, and a H. Dip in Data Analytics in Science.

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Mr McDonagh has over thirty years of experience as a senior business and sales manager working in a demanding sales and marketing driven environment. He has achieved received numerous personal awards during his business career and returned to education eight years ago. Dave is a graduate of the Marketing Institute of Ireland, holds a BA Honours in Psychology and has received a studentship award to pursue a PhD through Trinity College Dublin. Over the past five years, Dave has worked as a field researcher with Professor Comiskey, conducting a range of sensitive interviews involving questions on relating to drug use, and associated risk conducted with individuals who use opiates and other drugs.

### *Ms Karen Galligan, Researcher*

Karen Galligan's professional and academic background to date has afforded her excellent experience at national level as a researcher, evaluator and project manager and, at a European level, as a research manager. Karen's research experience spans across health and technology and across public, private, and community and voluntary sector. Her key areas of interest are social issues including addiction and mental health, and implementation science. Karen is currently employed as a researcher in the Institute of Population Health at Trinity College Dublin, and she is concurrently completing her PhD on Hidden Harms to Children of Parental Substance misuse. Karen also has an MSc in Applied Psychology, an MSc in IT and a BSc in Psychology.

## Acknowledgement

This report would not have been possible without the generosity of spirit of the training co-design team who allowed us to observe the process and kindly provided additional information in the focus groups. Thank you for the opportunity to hear your stories, appreciate your experiences and share your knowledge.

Thank you to the Irish Human Rights and Equality Commission (IHREC) for funding this project and making it possible to evaluate phase two.

Thank you also to Ms Louise McCulloch for her assistance at short notice with the non-participant observation, we were fortunate to be able to benefit from her wider experience.

Finally, we would like to thank the staff, the women and the leadership at CityWide and at SAOL for their vision and commitment and for inviting us to contribute to this valuable and much needed work.



## Executive Summary

### Background

In early 2018, CityWide launched a campaign to raise awareness and challenge drug-related stigma and the impact it has on people who use drugs. The campaign was called *Stop the Stigma* ([www.stopthestigma.ie](http://www.stopthestigma.ie)). Five key areas of action were identified as part of the campaign and specific actions set out to address them. Action 2 related to the stigma experienced by people who use drugs when they are engaging with public services. To address this action, Citywide commissioned phase one of this research to develop a template for a training programme that was to be delivered to staff in the relevant public services and which would involve people with experience of drug use in its eventual delivery. In phase two, this training programme was developed, and a pilot study was conducted in partnership with the SAOL Project, using a co-design process by people who use the service (co-design participants) and facilitators. The aim of this phase was to evaluate the process of this development and to evaluate the roll out and impact of the anti-stigma training programme.

### Study Design and Methodology

This evaluation used a concurrent mixed-methods study design. To address the aim and objectives of the evaluation, both quantitative and qualitative methods were appropriate. A combination of observation techniques, focus group interviews, and quantitative surveys were used within an overall implementation science framework. This framework facilitated the identification of both enablers and barriers to the training roll out process from the perspective of both those undertaking and those delivering the training. The survey measured stigma and was administered to service providers who undertook the training programme before and after the training was delivered. The research team also had extensive experience in the application of good research practice, of ethical clearance criteria and of Irish and EU data-protection legislation. The evaluation received ethical approval and all COVID-19 safety procedures were followed.

### Findings

In summary from the observation it was very clear that the co-design procedure was respected. There was clear evidence of a shared understanding, of equal power distribution, the use of tools within the process to ensure all participated and the space was deemed safe and open. One minor note for improvement might be to further examine the balance of the overarching co-design approach.

From the focus group findings evidence of enablers included the clarity of reasoning behind decisions and the clarity of purpose of the training in terms of raising awareness and accountability. The existence of trust and a safe space was highlighted and the subsequent feeling of empowerment. There was clear evidence of key enablers of stakeholder consultation, leadership, resourcing, staff capacity, organisational support and culture and communication. However as wider implementation is considered, how to maintain these will be an ongoing challenge.

Barriers to the co-design process were sometimes external practical barriers as a result of COVID-19 or the need for childcare. Internal barriers were also present from emotional fragility to the perceived scale of the task at hand given the comprehensive and detailed training template. There was also some confusion of the role of varying wider stakeholders within the governance and leadership of the project in terms of subjects covered, the scope of the programme did not include the topic of stigma within families and this was seen as a limitation.

From the perspective of the facilitators a key enabler of the co-design process was the clarity of the role and its purpose to enable the lived experience of the participants attending the service to inform the material of the training programme. Understanding what stigma is was found to be both an enabler and a challenge. This was a challenge due to the time taken within the process to define the concept of stigma within the context of drug use. However, as the process evolved having a clear definition of stigma enabled the group to have a clearer understanding of any stigma they may have experienced. Taking the time to define this concept was a worthwhile investment of facilitation time. This clear understanding enabled an unexpected therapeutic element to emerge during facilitation and this was aided by ensuring a safe environment for all. Finally, the involvement of the co-design participants as partners was seen as the key or the kernel of enablers. Challenges or barriers to the facilitation process included the emotional nature of the topic, fear of new experiences for co-design participants who had not engaged in this process before and COVID-19 disruptions. The latter also impacted upon the speed of progress. Finally, the template was both an enabler, as it was evidenced based, and a barrier again due to its comprehensive nature.

The evaluation of the impact of the training programme was conducted among a pilot group of 11 service providers who took the training course. The survey measured levels of stigma across the domains of blame, anger, pity, help, dangerousness, fear, avoidance, segregation, and coercion. Improvements in eight of these nine domains were found and three of these were statistically significant despite the very small sample sizes, these were attribution of blame, avoidance behaviour

and segregation. In terms of improving the training, participants expressed an interest in more videos and role playing as this aspect was very useful. In terms of other improvements, participants requested some further clarity on certain materials particularly the theories presented.

### Conclusion

To conclude, it was clear that the co-design process was adhered to with fidelity in spite of both unforeseen external challenges and possible anticipated internal personal past experiences. These were past experiences of stigma and past experiences as the leaders of facilitation and this success was to be applauded. The rollout of the pilot training programme found that the training package not only met the expectations of the participants but also had a short-term quantifiable impact on levels of stigma.

### Recommendations

In terms of recommendations as the co-design process was successful, recommendations are directed towards the scale up and further rollout of the program to wider services. These are outlined below.

1. Development of a bespoke copyrighted or published manual with details of the programme content and training required for delivery
2. Development of a plan for a train the trainer programme with services, starting perhaps with key named services who will act as programme promoters
3. Development of a community of practice support network or website for ongoing support for practitioners as the training roles out
4. Provision of additional resourcing to ensure the sustainability of the fidelity and rollout of the programme
5. Consider the development of an oversight or advisory board to support the recommendations
6. Development of an ongoing monitoring and evaluation framework or system to ensure the training remains current and fit for purpose
7. Seek external recognition and accreditation for the training from an accredited source.

## Chapter One: Introduction

This report was commissioned by the CityWide Drugs Crisis Campaign management and leadership team with a view to objectively and independently evaluating the co-design process, delivery, and impact of a pilot anti-stigma training programme. Phase one of the project was conducted in 2019 with the aim of developing a template for an anti-stigma training programme for delivery to staff in public services. This template was developed by CityWide Drugs Crisis and Trinity College Dublin (Barron, Galligan, & Comiskey, 2019)

### 1.1 Background and Context

In early 2018, CityWide launched a campaign to raise awareness and challenge drug-related stigma and the impact it has on people who use drugs. The campaign was called *Stop the Stigma* ([www.stopthestigma.ie](http://www.stopthestigma.ie)). The aim of the campaign was to raise awareness of the stigmatisation that people who use drugs experience, change attitudes and move towards a situation where people with experience of drug use are treated with respect and dignity (Barron et al., 2019).

A significant issue which emerged in the development of the campaign, was that people with experience of drug use experienced stigma when accessing public services. This finding is in line with a wealth of national and international research (Barron et al., 2019). The participants in CityWide research for the campaign felt that their interactions with agencies could be significantly improved by providing training to increase knowledge and understanding of addiction and of the personal, social and economic situation in which the person with experience of drug use lives (Barron et al., 2019).

Five key areas of action were identified as part of the campaign and specific actions set out to address them. Action 2 related to the stigma experienced by people who use drugs when they are engaging with public services: Action 2) Challenge stigma in delivery of services, states:

*'We can engage with health care and frontline staff to develop education and training programmes to challenge the stigma that people who use drugs can experience in public services.'*

To address this action, Citywide commissioned phase one of this research study to develop a template for a training programme that was to be delivered to staff in the relevant public services and which would involve people with experience of drug use in its eventual delivery. The aim of the training programme was to reduce drug-related stigma in public services so that people with lived experience of drug use can receive the services that they require in a fair and equal manner (Barron et al., 2019).

In phase two, this training programme was developed in partnership with the SAOL Project, using a co-design process by people who use the service (co-design participants) and facilitators, and the pilot training was rolled out. Phase two was funded by the Irish Human Rights and Equality Commission (IHREC). The aim of this phase is to evaluate the process of the development and the impact of the anti-stigma training programme.

## 1.2 Aims and Objectives of the Evaluation

The aim of this project is to evaluate the co-design process and rollout of the pilot anti-stigma training programme.

The specific objectives of the evaluation are:

1. To identify the enablers and barriers of the co-design process of the anti-stigma training programme by co-design participants and facilitators.
2. To conduct a preliminary impact evaluation of the pilot anti-stigma training programme by measuring changes in attitude before and after the training.
3. To investigate the needs and/or expectations of participants prior to attending the pilot programme and the change in their needs/expectations after the training.
4. To identify specific aspects of the rollout that may require change and improvement.

This report provides the findings from the evaluation and recommendations going forward for the wider rollout of the anti-stigma training programme.

## 1.3 Implementation Science: Evaluation Framework of the Pilot Training Programme

Fynn and colleagues conducted a scoping review in 2020 on evaluation frameworks and their applicability to real-world programme delivery (Fynn, Hardeman, Milton, & Jones, 2020). From the review, they recommended that evaluation programmes should use frameworks in practice to improve the quality of evaluation and reporting. They found that evaluation frameworks help researchers to focus their efforts on aspects that are most needed by facilitating a systematic approach to evaluation. Having a framework from the start ensures that all stakeholders have a shared understanding of the programme and the evaluation process, which provides clarity on the goals and objectives (Fynn et al., 2020).

For this evaluation report, an implementation science framework was deemed suitable. Sheehan and colleagues (Sheehan, Comiskey, Williamson, & Mgutshini, 2015) have previously discussed the use of implementation science in healthcare settings. Referring to the key literature, they note that implementation has been described as “making it happen”, rather than simply “letting it happen” or “helping it happen”. Implementation science focuses on the strategies that can promote implementation success and on the theoretical underpinnings of these strategies. Fixsen and colleagues define implementation science as “the study of the process of implementing programmes and practices that have some evidence from the research field to suggest they are worth replicating” (Fixsen et al., 2005, p. 1). An implementation science study is further characterised as one that shows “how a practice that is evidence-based or evidence-informed gets translated to different, more diverse contexts in the real world” (Fixsen et al., 2005, p. 1). Much of the recent implementation science research has focused on understanding factors that facilitate and hinder successful implementation.

The research shows that implementation is a process that takes time and occurs in incremental stages, each requiring different conditions and activities. Different authors assign different labels and meanings to the various stages of implementation. In summary, however, the research points to four stages of implementation. The first two stages (stages 1 & 2) involve exploratory and planning activities. Following this, the innovation is implemented (stage 3), before it is fully embedded in the system and evaluated (stage 4).

Each stage is essential to the implementation process and cannot be skipped. However, those implementing the innovation may need to revisit earlier stages to address challenges and ensure continued support and capacity. Implementers must also be mindful of adopting realistic timeframes. The literature indicates that completing the four stages of implementation typically takes two to four years. The four stages, as summarised by Fixsen et al (2005) are illustrated and described in Figure 1 below.

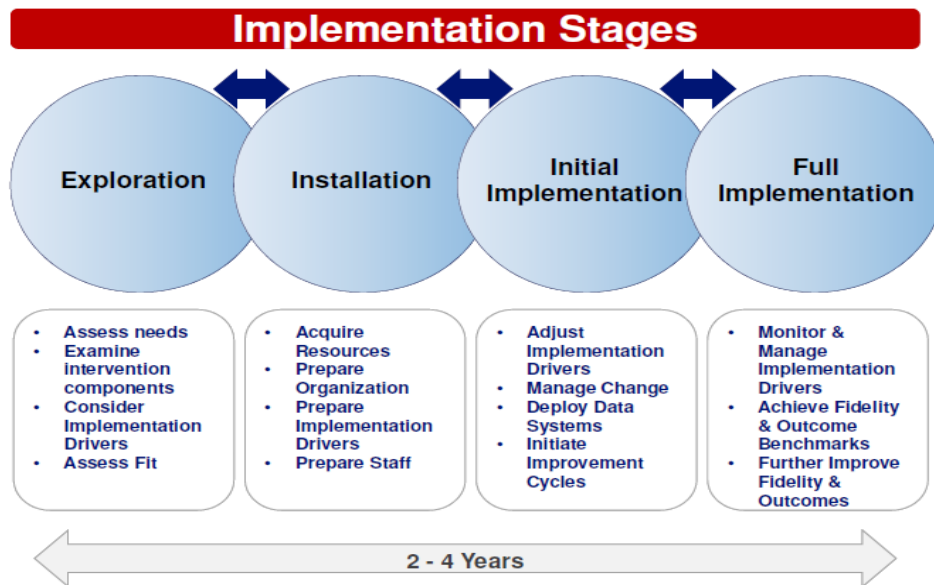


Figure 1: The Four Stages of Implementation Adapted from Fixsen et al. (2005)

Another trend in the implementation literature is the examination of the factors which facilitate effective implementation. A range of terms are used in the literature to refer to these factors, including implementation enablers, drivers, facilitators, and the core components of implementation. For the sake of simplicity, we refer to them here as implementation enablers. Despite the field not yet reaching a consensus on the exact enablers, certain factors emerge consistently from the research, as illustrated in Figure 2.

What is also clear is that certain implementation enablers are required throughout different stages, in the process to drive implementation, and that the integration of these factors is vital to implementation success. The relative importance of each of the implementation enablers will vary depending on the innovation being implemented, and the context and setting in which it is implemented. Key implementation enablers and stages are illustrated and described in Figure 3.

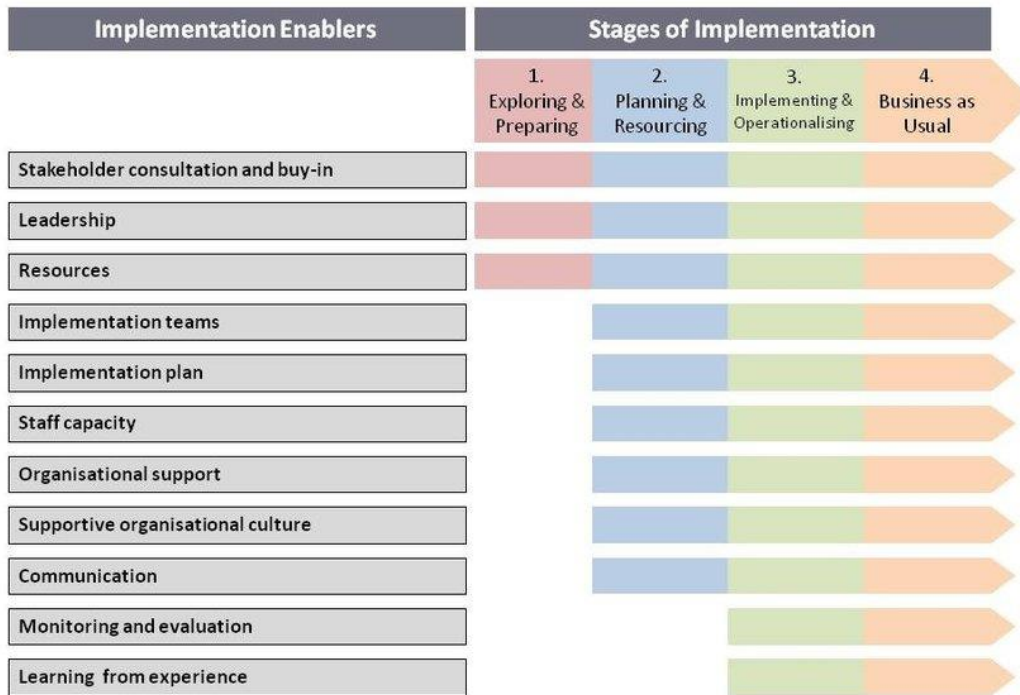


Figure 2: Implementation Enablers and Stages, adopted from Burke, Morris and McGarrigle (2012)

According to Burke and colleagues’ barriers to implementation are grouped under three headings, namely, the external environment, vested interests, and resistance to change (Burke, Morris, & McGarrigle, 2012). The framework in figures 2 and 3 above were used to summarise the process evaluation data arising from the multiple methods and to synthesise the findings on implementation.

The range of data sources captured were selected to ensure that sufficient evidence would be available to adequately evaluate the co-design process and the rollout of the pilot training programme against the contents of the framework.



## Chapter Two: Methodological Approach & Ethical Considerations

This chapter provides an outline of the various methodological approaches used to conduct this evaluation and discusses the ethical considerations. The aim of this project was to evaluate the co-design process and rollout of the pilot anti-stigma training programme. To achieve this, the research was planned within the context of an implementation science framework (see chapter one). The work of Comiskey and colleagues was drawn upon because of its relevance to implementation within healthcare contexts (Comiskey et al., 2015; Sheehan et al., 2015). Using an implementation science framework, enablers and barriers to implementation were explored.

### 2.1 Study Design

This evaluation uses a concurrent mixed-methods study design. To address the aim and objectives of this project, both quantitative and qualitative methods were deemed appropriate.

### 2.2 Methods and Data Analysis

A combination of observation techniques, focus group interviews, and quantitative surveys were used to address the following objectives of the study:

1. To identify the enablers and barriers of the co-design process of the anti-stigma training programme by co-design participants and facilitators.
2. To conduct an impact evaluation of the pilot anti-stigma training programme by measuring the change in attitude before and after the training.
3. To investigate the needs and/or expectations of participants prior to attending the pilot programme and the change in their needs/expectations after the training.
4. To identify specific aspects of the rollout that may require change and improvement.

#### 2.2.1 Qualitative Data Collection and Analysis: Process Evaluation

To address **objective 1**, to identify the enablers and barriers of the co-design process of the anti-stigma training programme by the co-design participants and facilitators, an observation of the co-design process was conducted. The observation tool was developed by an experienced independent observer and the findings are presented in chapter three. This was then followed up with a focus group with co-design participants and a focus group with the facilitators engaged in the co-design of the anti-stigma pilot training programme. The implementation science framework was used to frame the focus group questions, specifically targeting the enablers and barriers of co-designing a training programme. The data were analysed using a Thematic Analysis approach by Braun and Clarke (2006). NVivo software

was used to conduct the analysis (QSR, 2019), infographics of key themes were created using the canva.com platform. The findings are presented in chapter three.

### 2.2.2 Survey Data Collection and Analysis: Impact Evaluation

To address **objectives 2, 3 and 4**, a quantitative survey with open ended questions were administered at the start of the pilot (pre-survey) and at the end of the pilot (post-survey). Data were collected using Google Forms and were downloaded into excel sheets (Microsoft, 2019). They were converted into SPSS version 26 (.sav) file to conduct the descriptive and inferential analyses (IBM Corp, 2019). Word clouds were created using canva.com.

For **objective 2**, the Attributional Questionnaire 27 (AQ27) developed by Corrigan and colleagues (P. Corrigan, Markowitz, Watson, Rowan, & Kubiak, 2003; P. W. Corrigan, Edwards, Green, Diwan, & Penn, 2001; P. W. Corrigan, Watson, Warpinski, & Gracia, 2004) was administered to the participants in the pre-survey to measure their attitude at baseline. The score ranges from 1 to 27 for the AQ27 tool. For the post-survey, the AQ9 was administered following the advice from the participants to reduce the length of the survey, the score on each individual question ranges from 1 to 9. Both the AQ27 and AQ9 provide nine constructs of stigma, and these are blame, anger, pity, help, dangerousness, fear, avoidance, segregation, and coercion. The survey provides a vignette and participants are asked specific stigma related questions based on the vignette. The same vignette is used for the pre and post surveys, and the vignette used for this study is presented below:

*“Mark is a 30-year-old single man who has tested positive for HIV. Mark has been using drugs for 12 years. He uses drugs intravenously 7 times a week, once every day. Mark is currently renting shared accommodation. He has been hospitalised twice for an overdose.”*

Although the AQ surveys were developed to measure mental illness stigma, it has since been used successfully in other fields for example, measuring stigma within the drugs-related areas. Sattler and colleagues (2017) used the AQ9 to measure public stigma toward people with drug addiction (Sattler, Escande, Racine, & Göritz, 2017), while Raley (2011) used the AQ27 tool to measure stigma toward ethnic minorities who use drugs (Raley, 2011). Descriptive analyses were conducted for the pre and post surveys and further inferential analyses were conducted to measure the change in attitude, using a paired samples t-test. The findings are presented in chapter four.

**Objective 3** was addressed through open ended questions specifically relating to participants expectations and needs before the training, and further questions were included in the post-survey on whether those expectations/needs were met. The data from open-ended questions were analysed using visual content analysis and the findings are presented in chapter four, using word clouds.

The purpose of **objective 4** was to provide insights and identify specific aspects of the rollout that may require change and improvement. This was achieved through additional questions specifically related to the delivery of the pilot training. Participants on the programme were asked to rate the workload, the organisation of delivery, learning and teaching methods, pace of delivery, and staff responsiveness. They were also asked to identify the best features of the training and suggest improvements going forward. These findings are presented in chapter four, using descriptive analyses, visual content analysis and word clouds for open-ended questions.

### 2.3 Ethical Considerations

The research team were aware of the challenges of conducting sensitive evaluations in real-life settings. The research team also had extensive experience in the application of good research practice, of ethical clearance criteria and of Irish and EU data-protection legislation. Team members were familiar with the Trinity College Dublin Policy on Good Research Practice and with The World Medical Association's Declaration of Helsinki, which sets out ethical principles for the conduct of medical research involving human subjects. The phase one study obtained ethical approval from Trinity College Dublin, the University of Dublin, and this phase two is an evaluation of the training programme co-design process and pilot rollout and a continuation of the phase one project.

## Chapter Three: Qualitative Findings

Chapter three presents the qualitative findings. The observation data is presented within the context of observation and reflections on observation sections. Insights and interpretation of the observation data is provided.

### 3.1 Observation of the Co-Design Process

This section presents the observation findings from the facilitator notes on the process and systems in place for the co-design process, and the independent observation of a co-design session between participants and facilitators. The section starts with the facilitator observation notes on the various processes and followed by the independent observations with the independent observer's context and reflections provided in sections 3.1.2 and 3.1.3.

#### 3.1.1 Facilitator Notes on the Co-Design Process

The project began in early March 2020 and the recruitment of co-design participants was scheduled to begin shortly thereafter. However, the facilitator reported that the initial meeting with SAOL participants was delayed due to the COVID-19 pandemic. As a result, the recruitment and meetings with participants were conducted virtually. Six participants attended the virtual session in April, and they were reported to be interested and engaged. However, the facilitator noted that it was clear that conducting the process online was going to be challenging.

*“Engaging in a new group process online, outside the containing environment of SAOL, while trying to manage home life, technology, and the lockdown could prove very difficult” (Facilitator)*

From June to July 2020, the participants were able to resume face to face sessions in SAOL as a result of the easing of lockdown restrictions. The facilitator identified a need for participants to re-stabilise as it had been a difficult time for many participants. Additional supports were put in place for the co-design process in order to address the trauma arising from the discussions during the sessions.

The general approach to the co-design process is detailed below by the facilitator:

- The SAOL facilitator called each of the twelve participants who'd expressed their interest
- The SAOL facilitator ensured each woman's key worker knew about their involvement in the co-design process
- SAOL provided an additional staff member to participate in the group in case there was a need for additional support and containment within the group

- The sessions aimed to be 90 minutes long varied according to the space being used and being guided by safety recommendations.
- A schedule of time and venue was agreed with the participants and the facilitators to help avoid confusion eating into group time.
- The first session focused on providing space for the participants to say how they were feeling. Participants were reminded of what the training was about and what's involved in terms of content and commitment. And the best combination of face-to-face and online work was agreed.
- The pace of the process was guided by the participants' needs
- All the sessions involved a check in, a recap, and a wind down

From the facilitator notes, it was evident that the facilitators had various steps and systems in place to ensure that the co-design participants were supported during the process. The process was guided by the participants' needs and additional activities were put in place to address any arising issues or trauma for the participants, such as check in, recap and wind down.

### 3.1.2 Context of Independent Observation

The independent observation of the co-design process was conducted virtually via Zoom on the 16<sup>th</sup> November 2020. Figure 3 below provides the layout of the room. The laptop for the observation was located at the top of the room. The three participants were located at the opposite end of the room in an L- shape and were seated on individual desks with a chair. The two facilitators were located on opposite sides of the room but moved between their seats and the flipchart for different exercises.

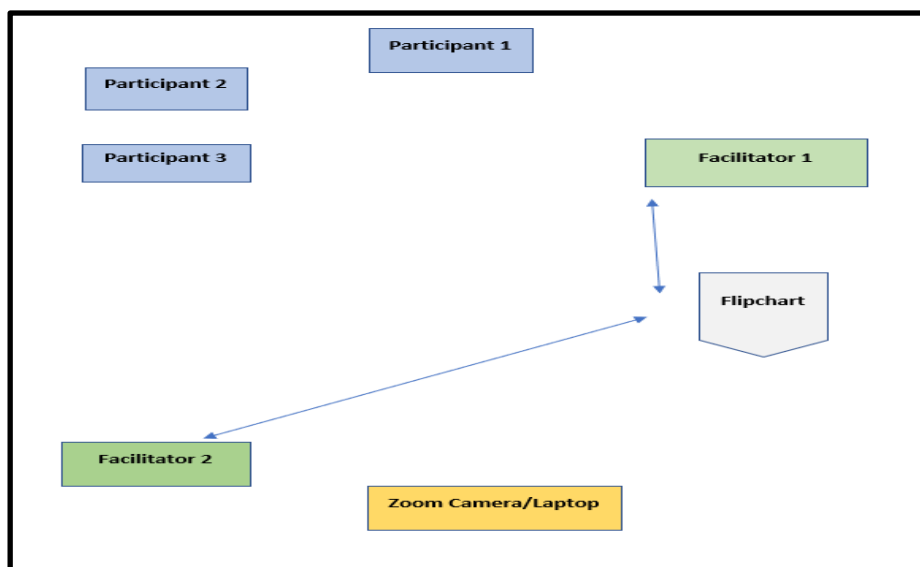


Figure 3: Room Layout

**Participants and Time Worked Together:** The facilitators and participants have worked together for some time, however, there was a break in between due to COVID-19. Attendance had been erratic since returning from the long break with COVID-19, and originally it was envisaged that the sessions would be finished by November 2020, however due to the COVID-19 restrictions, and various life events, attendance had been low. All the participants were involved since the beginning except one person who joined after the first three sessions. Facilitator one reported via email to the research team that all participants and facilitators have cohered as a group.

**Group Work to Date (16<sup>th</sup> November 2020):** The group worked on stories of stigma and recorded a scene depicting an experience of stigma. The group moved into looking at the facilitation of the CPD training. The group completed a draft of a session plan for that training and covered additional accompanying materials such as reflection sheets, theoretical materials, and the impact of drug-related stigma as identified by the group.

**Planned Work for the Group (16<sup>th</sup> November 2020):** The group covered topics on good facilitation and the role of the facilitator. They then continued the conversation about what it may be like to be in the role of facilitator with a group of service providers

**Additional Observer Notes:** It should be noted that the sound at times was not always clear and some comments could not be heard. Traffic could be heard in the background which interfered with the quality of the audio. Furthermore, the sound may have been affected by the distance/positioning between the speaker and individuals.

### 3.1.3 Independent Observer Reflections

Table 1 below provides specific reflections to observations based on the following indicators: shared understanding, power distribution, participatory tools, safe space/openness, ownership, empowerment, value, reflexivity/intentionality, inclusion, and finally, decision making. The independent observer with experience in using observational tools, particularly those looking at relationships and interactions created a guide in advance to structure the observation. This was to ensure that certain agreed markers of quality interactions for this process were considered as well as outlining how we might know if they were observed. The current observation tool was informed by the following well established tools:

1. Sustained Shared Thinking and Emotional Wellbeing (SSTEW) (Siraj, Kingston, & Melhuish, 2015)
2. Early Childhood Environment Rating Scale (ECERS) (Andersson, 1999)
3. Parenting Interactions with Children: Checklist Linked to Outcomes (PICCOLO) (Roggman, Cook, & Innocenti, 2008)

Overall, the observation findings suggest that the co-design process experience had been positive and showed that there was a shared understanding between co-design participants and facilitators, however, within the power distribution indicator, it was found that the facilitators led the group and directed the conversation through discussions and reflective exercises. Participants appeared very comfortable in the “safe space” and that was evident from the observation data. However, it was unclear from the observation if participants felt ownership or a shared responsibility for the co-design process. The independent observer reported that at times it appeared that the facilitator had more power in the process. However, it is important to note that the observer also reported that the participants knew what their role was, they were encouraged to contribute to the content, facilitators were responsive and mindful of participants’ needs, the participants were given the opportunity to speak, and everyone had a voice.

Table 1: Independent Observation Reflections

Indicator/theme	Explanation
<b>Shared Understanding</b> <i>Do all the group appear to have a shared understanding of the purpose, task and process? And if not, are they supported to share their perspective and understand other perspectives?</i>	<b>Yes</b> , all appear to have a similar understanding. One of the participants did appear at beginning to not be as familiar but other participants were able to tell her how much was left to do in process. However, overall, all appeared to have a shared understanding of the process and what was to happen.
<b>Power Distribution</b> <i>How is power distributed across the group including between facilitator and participants? How are participants empowered to express their views? Does facilitator take a neutral position or active collaborator? Does there appear to be a transparency of roles?</i>	Group was led by the facilitators who played a role in helping to direct and guide the conversation via facilitated discussions and reflective exercises. <b>Facilitators were mainly neutral</b> by the facilitation skills they used which allowed participants to shape the content themselves and reflect, allowing pauses as required. Although one of the facilitators was more directive at times when responding to participants. Session was primarily discussions and sharing of experiences rather than decisions about the process.
<b>Participatory Tools</b> <i>What participatory tools (if any) are used during the process to enhance discussions and promote equal participation?</i>	<b>Discussions and an exercise were used</b> to gather perspectives and experiences rather than tools that can help frame decision making and actions.
<b>Safe Space/Openness</b> <i>How is a safe space created so participants feel comfortable to express their views while supporting any emotional responses? How are differing views encouraged and accepted? How is empathy for all perspectives shown?</i>	<b>Participants appeared very comfortable in sharing their experiences and opinions.</b> They also showed recognition of the concept of a ‘safe space’ in a group and it was mentioned as an example in the discussion on what a facilitator needs.

<b>Ownership</b> <i>How is ownership encouraged in the group? What evidence is there of a shared responsibility?</i>	<b>It was not clear from the observation.</b> At times it appeared facilitators had more power in the process with some comments that started with “we will be...”
<b>Empowerment</b> <i>How are the participants empowered in the process? How are their capabilities, aspirations and goals encouraged? How are participants encouraged or supported to take the lead?</i>	<b>Participants role in setting the content was clear.</b> Furthermore, they were supported in the session to develop and reflect and prepare for being involved in the process as a trainer.
<b>Value</b> <i>What value is observed for participants (consider the overall outcomes of the session or through the process of engagement)?</i>	<b>The value was not clear</b> from observation itself.
<b>Reflexivity/Intentionality</b> <i>How does the facilitator guide the process when required to ensure a safe communicative space (i.e. encouraging collaboration, differing opinions, being responsive to emotions and group dynamics, paraphrasing, long pauses, pre-empting difficulties, supporting problem solving) while also keeping the goal of the session in mind?</i>	<b>Both facilitators appeared very mindful of the participants and their needs and allowed everyone to have a voice and be heard.</b> Everyone in the group had an opportunity to speak. Long pauses were allowed. However, it is not possible to observe the intentionality they used when doing this. Furthermore, some small differences in facilitation styles were observed between the facilitators. May help to consider intentionality they brought to the process particular in terms of what they consider when supporting participants and keeping them at the centre of the process.
<b>Inclusion</b> <i>An awareness of participants and their needs is shown giving additional support to include participants as required</i>	<b>Everyone had a voice and was giving an opportunity to speak.</b> When one participant struggled with an exercise, an alternative was suggested that if they struggled to write it and then try to speak it. This helped the person to still have their opinion heard.
<b>Decision Making</b> <i>How are participants encouraged to make choices for the process and/or outcomes?</i>	<b>Participants were encouraged to contribute to the content</b> as well as consider their role in the process. It was <b>unclear as to what role they have or have had in making choice for the process.</b>

### 3.2 Process Evaluation using Focus Groups

Two focus groups were conducted; a co-design participants focus group, and a facilitators focus group, the aim of these focus groups was to identify the enablers and barriers of the co-design process of the anti-stigma training programme by co-design participants and facilitators. This section presents the findings for each focus group with a specific emphasis on enablers and barriers as highlighted by the two groups. The key themes identified, and the overall findings are summarised in this section.

It is important to note that the facilitators from SAOL brought both a professional and experiential understanding of stigma to the co-design process. One of the facilitators, through her experience of using drugs and of being stigmatised herself, could converse and relate to the co-design participants as both a peer and a mentor. The other facilitator, a counsellor working with people who use drugs over many years, brought her professional expertise and experience to the process.



### 3.2.1 Co-Design Participants' Perspective: Enablers of the Co-Design Process

#### *Theme 1: Training Development and Expected Outcomes*

This is a broad theme which incorporates various sub-themes, and these are content development and delivery method, decision making process, outcome of training, and intersectionality. The participants discussed the various content development process and for each decision made, the participants were able to provide the **reasoning behind each decision** made and it indicated a great level of collaboration within the group.

*“We were looking at three morning sessions.....We were trying to keep it as close together as possible because we don't want to leave big gaps in between one morning to the next, we want it to be fresh on people's minds going in to the next session, so it is looking like the first pilot more than likely could be an online one, but it is going to be three morning sessions, that's what we've discussed”*

*(Participant 3)*

The participants were clear what the **end outcome** of the training would be and what they want the end-user to take away from the training. For example, they wanted to make people more aware of stigma and in particular the self-awareness of their own stigmas and dismissiveness. They want the end-user to feel comfortable challenging their colleagues and the culture of their organisation. Another interesting point that the participants wanted to get across was that **stigma defeats the purpose** of service providers, it delays recovery and can lead to relapse.

*“I think one of the biggest messages that I want to get out there to the service providers, whoever they are is that ah, stigma actually defeats their purpose in many ways because it is absolutely, but I don't have the research, but I have the knowledge and experience is, it delays recovery, and it leads to relapse” (Participant 2)*

*“What we'd love, would be and we've discussed this as well, ... there is a lot of times that people don't even realise that they're being dismissive, they're being stigmatising, it would be making someone sort of more aware ... they'll feel comfortable even if they hear a colleague making a comment about a person who uses drug's, that they will feel more comfortable to even challenge that, that'll change the whole culture in an organisation” (Participant 3)*

Another important topic which was highlighted in the sub-theme of end outcome, was the accountability put on service providers at the end of the training. The idea that at the end of the

training, service providers would have a duty to bring change in their organisation. This provided participants “a great deal of comfort” and reassurance that their work was valued.

*“... the fact that they explained to us in great detail the accountability at the end of the process and in the end of the training there is, who in your service is going to be in charge of stigma training and everyone else and signs and how are you going to change your organisation and what are ye going to do, so that you can see a kind of a measurable outcome, or some sort of follow up it's not like CDPE I'd add a few little points in my training and go in and forget about it, it's like what's going to happen after, what is this going to do to your organisation, who is in charge, who's got to do it, how are you going to do it, we'll help you, take the training to whatever and that gave us a great deal of comfort that we were not wasting our time because a lot of people do projects and training and nothing after it ...” (Participant 2)*

The participants discussed **intersectionality** and how they incorporated it within the training. Not only was the training focused on stigma in addiction, but it also incorporated gender, race, and sexuality.

*“we were trying to look at stigma and how addiction stigma can cross over to the guy dealing with being LGBT and the stigma he'd be experiencing in that regard as well and if he was a black person, the stigma there as well, so he could be experiencing multiple forms stigma at the same time, on top of, and how do they all cross over with each other at the same time” (Participant 4)*

### *Theme 2: A Safe Space*

Theme two depicts the **level of trust** within the group and the **safe space** that the facilitators created for the co-design participants. There was a big emphasis on the importance of building trust within the group and being able to talk about their experiences in a safe space. Participants discussed how their prior involvement in SAOL and knowing their peer from before helped build the trust within the group. Their experience in SAOL also taught them how to disclose information and how to share their experience. This was an important enabler for the co-design process and they also highlighted that if the prior relationship and trust wasn't in place, it would have hindered the process.

*“... we have a degree of trust between us all, because we all know each other from SAOL, I think if we were a group of strangers how much would you trust strangers with your experiences?” (Participant 3)*

*“An like everyone has caution, you know, safe space that’s a word to take very seriously but different people have different understandings of what that means and it being about like you can’t expect this to be a safe space, even how to disclose, it took me a long time to learn how to be safe to disclose, it took me ages and I was really bad at it until I learned by watching other people from SAOL, and how they deal with it and said, that’s how they do that, OK...” (Participant 4)*

*“I think it’s a lot easier when the trust has been built up ... And everyone here knows the rules of here, and how to behave and yeah” (Participant 2)*

*“Oh, very, very important, like you couldn’t come in, be worrying in your head like oh God I can’t trust her how can I sit here and talk about your life, (yeah, yeah) like be honest and truthful if you can’t trust your peers but, no 100% I trusted everyone I felt you know OK to come in and be able to talk” (Participant 1)*

The participants recognised that the safe space was created very effectively by the facilitators. They felt that the facilitators were compassionate, and mindful of the trauma arising from the discussions.

*“... [the facilitators] were brilliant and they really guided us and checked because some of the issues were quite traumatic to talk about, yeah, there were some days when we had, you know, tough days so they were very, very compassionate in the, are ye all OK going home now, yeah, like it was this, there was all this stuff and then we’re really good at Um, anonymity in here and the trust in the group was really vital” (Participant 2)*

### *Theme 3: Empowerment*

One of the leading enablers of the co-design process is depicted in theme three. **Empowerment** is a strong recurring theme that has come up consistently throughout the focus group. The participants discussed various situations where they felt empowered by their peers and the facilitators during the co-design process. They felt respected, they were listened to, ownership over the project, they believed in the project, they were motivated, and excited to be part of the co-design process. They were empowered throughout the whole process.

*“... we all believed in the project I believe there was a need for it...” (Participant 2)*

*“Then what’s the point of just doing it... but with this project there is a purpose in it and there is work to get out there about stigmatising” (Participant 1)*

*“Well, you know, I switched around work stuff and different stuff to try and be here because, I think, I believe in the project ... we did have some laughs (yeah, we did), there were tears but there was much more laughter and were very good at laughing at ourselves ” (Participant 2)*

*“All our opinions were listened to” (Participant 5)*

#### *Theme 4: Self-Stigmatisation and Accepting the Stigma*

Throughout the co-design process, the participants experienced an **internal shift** within themselves with regards to the extent of stigma they had experienced over the years. This internal shift is captured at various points in the focus group and is depicted in theme 4. Participants discussed how they had **accepted the stigmatisation** against them and how it was culturally acceptable to stigmatise people who use drugs.

*“I accepted it” (Participant 3)*

*“But its culturally accepted that this is how you treat people in addiction” (Participant 2)*

*“It’s the way you are brought up as well” (Participant 1)*

The co-design process made participants more aware of the stigma and started noticing it more in recent encounters and while they didn’t say anything to the service provider in question, inside they felt different about it and that they knew they were entitled to be treated with more respect.

*“I loved it because, even though I’d stigmatised myself and being stigmatised, you don’t really think about it and sometimes it might just come out naturally without you even thinking, Hmm, but from coming to this class, Hmm, it just opened your eyes and your mind and like even now when I’m, you know, outside, you’re just aware more, Hmm, and you can actually see stigmatization happening in front of your eyes (yeah) where before I wouldn’t have even noticed that” (Participant 3)*

### *Theme 5: Peer and Facilitator Support*

The final key enabler from the perspective of the participants is the **peer and facilitator support** throughout the co-design process. The level of support that the participants received was key for the success of the project. The final theme presents the **various support mechanisms** that the group and the facilitators used.

*“Like Facilitator 1 and Facilitator 2, we were all made sure at the end of each session that everybody was feeling OK and safe, you know, OK to move home without having a load of, you know...”*

*(Participant 5)*

*“Come here, did ye feel supported by each other in the programme?” (Participant 3)*

*“Oh yeah” (Several Participants)*

*“100%” (Participant 1)*

*“... its great support from the group...” (Participant 2)*

*“I liked that there is ah, I think that the facilitators for putting the whole thing together ... it's very important for you to at look at whatever, the things you're doing, because they [facilitators] managed it really well they explained everything the whole way through, they really looked after our mental health and all the other aspects” (Participant 2)*

The participants talked about the **“decompression break”** as a support mechanism. At times there were difficult discussions during the sessions and facilitators would use a decompression break where they would stop the discussion for a few minutes before resuming or have a check in chat with participants.

*“But even during some of the extreme sessions we would do like a decompression kinda of break”*

*(Participant 4)*

*“We were hurting, and we got upset and we had to do a little decompression, they brought me in here and we had a chat” (Participant 4)*

### 3.2.2 Co-Design Participants' Perspective: Barriers of the Co-Design Process and Other Challenges

#### *Theme 1: COVID-19 Disruptions*

Theme one presents the challenges faced by participants and facilitators because of **COVID-19**. COVID-19 has been a significant barrier at the start of the co-design process. The group lost three members due to **child-minding issue** and **other COVID-19 related challenges**, which led to moving their sessions to zoom. There were significant delays with the project and participants were disappointed at having lost the three members. However, the participants adapted to the situation and continued the project. For example, they did not want to lose the experiences of the three women who could no longer be part of the process, and therefore they included their stories in the various scenarios.

*“And covid and we had to take a break at one point we couldn't meet” (Participant 2)*

*“The kids, the people that dropped out with their kids like with the covid but with the five of us we could still do it, you know what I mean” (Participant 1)*

*“I was sad when the girls dropped out because they were giving so much to the group, you know, and I felt a bit bereft like, not the same, there is something missing, (yeah), but then you adapt”  
(Participant 5)*

*“We got most of their stories and they are incorporated in there, their experiences were noted, and they are in the in scripts and stuff” (Participant 2)*

#### *Theme 2: Emotional Fragility*

Throughout the conversations, there was a strong theme of **emotional fragility** among the participants. Talking about their experiences brought them back again and they found that **triggering**.

*“knew what I'd like the days I'd be coming in, I kinda gave facilitator 1 the heads up on it, I'd say to her I knew I'd be feeling a bit more fragile (emotional), like there was a couple of days I didn't want to come in...” (Participant 4)*

*“first of all, there's triggering and could, you have to be very careful about relapse in the triggering situation” (Participant 2)*

*“... some of the issues were quite traumatic to talk about, yeah, there were some days when we had, you know, tough days...” (Participant 2)*

This theme links to the facilitators’ perspective in the next section where they discuss how as a result of emotional fragility, they had to take sessions at a slower pace. While discussing the experiences have allowed participants to have that internal shift that was discussed under theme four and this was found to be an enabler, on the other side it can be seen as a barrier as certain discussions have been triggering and participants had to be mindful of **relapses**.

### *Theme 3: Stakeholder Involvement and Communication*

Theme three depicts the lack of **communication** between **stakeholders** and participants. Some participants were unclear who the stakeholders were, where the funding came from, to what extent were the stakeholders involved in the project and where do the participants fit in. Some participants were also unsure of the role of CityWide in the bigger picture and how it relates to their project.

*“... and even to meet the stakeholders a bit earlier, in terms of who are all involved... okay, so you are the trinity partners and there’s the other, the funders? is it just the 3 groups are involved?... But what has CityWide to do with the putting together process?” (Participant 2)*

*“Know where we fit into the jigsaw, like I think, I didn’t know about the 3 different aims you said, I must have missed a session when that was mentioned, I don’t know” (Participant 4)*

It is important to note that other participants knew about the stakeholders, however, not everyone in the group had the same information.

### *Theme 4: Training Template*

A detailed **training template** was provided to the participants and facilitators from phase one of the project in order to aid the co-design process. However, participants struggled with it. They reported feeling “panicked” at the size of the template. The participants would have preferred a smaller but more **precise sample training plan**, a simpler framework to work with.

*“Yeah, we used the template, but they all panicked when we showed it to them” (Participant 3)*

*“Because I think it was a bit of a panic even when you look, the girls seen the size of it” (Participant 3)*

*“Even me, do we have to read that?” (Participant 5)*

*“I’ve done train the trainer before and you just get like 12 little pages and say, it’s gonna end up something like this, this is where we’re headed (yeah), or maybe to meet you guys at the beginning to say hey, we’ve done all this research, it took us this many years, these are the people we talked to, this is what we want. We really want to make it more alive, so, ye’re input will be boom, boom and this is what we hope to end up with... A summary of short points and then a training that you’re going to be making will end up looking something like this, it could be on cookery or whatever, do you know what I mean” (Participant 2)*

#### *Theme 5: Project Scope and Inclusion of Stigma within the Family*

While the participants agreed that their opinions were listened to and all their recommendations were taken onboard, they felt that there was a need to include the topic on **stigma within the family**. However, this was **outside the scope of the project** and did not meet the brief, it was not included. The participants also agreed that it was outside the scope of the project but recommended for the topic to be included in future iterations.

*“I think in future I’d like to see stigma in your family to be addressed and how to cope with that”  
(Participant 5)*

*“So, Facilitator 1 was quite clear from the start, this group was not doing that, which I was 100% totally, that was fine with me once I knew, going forward if you do design it again, I think it’s important to bring the stigma in your family in because we all have experience of that” (Participant 5)*

*“At the time I was experiencing a lot of stigma from my sister, and we’ve all gone through it and still kinda going through it with the new sister so.... that was kinda a different understanding of where were at....” (Participant 4)*



### 3.2.3 Facilitators' Perspective: Enablers of the Co-Design Process

#### *Theme 1: Roles and Purpose*

A key enabler of co-design process was the clear understanding of the **role and purpose** of the facilitators in facilitating and enabling the lived experiences of the participants attending the service to inform the material of the training programme.

*“The co-design process is working together with the women to get their experience to design a product”, “making sure the women have input in every part of it and that’s what we did” (Facilitator 1)*

*“The best people to get the input for that, is people who have either have used drugs and access these services that know the damage and the impact that being stigmatised in these services had on their life” (Facilitator 1)*

*“Yeah, very much, it’s a collaboration” (Facilitator 2)*

*“I don’t think that there if anyone could convey the power and truth of their experience in a way that they convey it and for other people to understand” (Facilitator 2)*

The **inclusion of the different groups** in the co-design and the honesty and flexibility of the process was cited as important enablers for the group.

*“I think what worked very well was that there was somebody from SAOL and somebody wasn’t from SAOL, I think that works, it works really well and I think the fact that we could, if you like, we had enough flexibility or enough permission if you want, or understanding of process to be able to adapt week to week” (Facilitator 2)*

*“I just thought that, just being honest with like, talk to the women like, anything they ask just being honest and being and transparent and that worked well with them” (Facilitator 1)*

#### *Theme 2: Understanding Stigma*

**Understanding what stigma** is appeared to be both an enabler and a challenge. A challenge due to the time taken within the process to define the concept of stigma within the context of drug use. However, as the process evolved having a clear **definition of stigma** enabled the group to have a clear understanding of stigma.

*“People don’t understand what stigma was”, “like, about family related stigma and all like I was trying to get them to, we spent a lot of time trying to focus that it’s drug related stigma” (Facilitator 1)*

*“We had to actually keep, I think you know, I think, it was nearly the end before everyone was really clear” (Facilitator 2)*

*“But more that, a realisation, and maybe public in the sense of the group acknowledgement oh actually that was really wrong, what was happening to them was really wrong and they what did” (Facilitator 1)*

Facilitator two talked about how a **therapeutic element** emerged during their conversations which enabled the co-design participants to process their experiences of stigma and understand stigma in way they had not previously done.

*“So, they really related to stigma as a phenomenon that happens everywhere, they’re even said that, and now I’m seeing it everywhere to their own experience and that was really painful, but it seems to have allowed them to process something really harmful” (Facilitator 2)*

### *Theme 3: A Safe Space*

Providing a **safe environment** where people were respected and felt confident to speak openly and share their experiences emerged as a key enabler for the co-design process. The co-design participants expressed their feeling that they felt safe among people they knew which gave them the confidence to actively participate in the training design discussions.

*“Being in a place where they felt safe and they knew each other or like even among themselves that how open they were, they felt because they were with people, they had trust in. So, I do think that is an important piece, the environment has got a huge impact on it” (Facilitator 1)*

*“Every point along the way the women were engaged with and you know, respected as part of our decision making and that’s as trauma informed as you can get” (Facilitator 3)*

*“The fact that this is happening here in a community where they, if you like, where they already feel excepted” (Facilitator 2)*

#### *Theme 4: Co-Design Partners*

The **involvement of the co-design participants as partners** in the process was mentioned a number of times by the facilitators. This concept appears to have been the kernel of the co-design process and had an empowering and motivational impact on the co-design participants to develop the training.

*“They are the ones who have experience, and we won’t be the ones going out and delivering training to services who work with people who use drugs” (Facilitator 2)*

*“I think that when people feel quite free here and discuss that to say and are encouraged to speak up” (Facilitator 2)*

*“I mean there was part of it was quite challenging enough, it was difficult, that it is actually, very empowering, I do think, well I’m wondering if it came across in the focus group, but I do think they’re in a different place now” (Facilitator 1)*

*“There is something about the uniqueness of all of this and in then, in trying to, let's say, recreate it elsewhere and for example we've got very creative in SAOL over the last few years so making a video may not be very good at it but it doesn't stop us doing” (Facilitator 3)*

### 3.2.4 Facilitators’ Perspective: Barriers of the Co-Design Process and Other Challenges

#### *Theme 1: Managing Emotions*

The emotive nature of the topics presented challenges for both the facilitators and the co-design participants particularly in the early stages of the design process. The emotions of co-design participants when recounting their stories could sometimes boil over into anger which the facilitators had to manage to keep the process moving forward.

*“I think a lot of the anger was a bit of a challenges sometimes because it was, we’d be trying to get something done and the anger kept steering it off into somewhere else and just trying to manage that and bring it back to what we needed to get done” (Facilitator 1)*

Another emotive challenge was the fear of doing something that was a new experience for the co-design participants. A primary aim of the training outcome was the involvement of all the co-design participants in facilitating the delivery of the training to the end users, however, some of the participants expressed a reluctance to engage in this aspect, therefore slowing the process down.

*“I know that's one of the biggest fears is that they said it here a few times, that when they wouldn't facilitate” (Facilitator 1)*

*“I don't know how many times we had to, like, some people were getting nervous at the thought of facilitating so I think doing these couple of sessions of facilitating sort of took those nerves away a bit” (Facilitator 1)*

Facilitator three highlighted the need to provide emotional support for the co-design participants during the content delivery process was a consideration foremost in the minds of the facilitators, in order to ensure that the participants could contribute in a safe way however, this aspect sometimes dictated the pace of progress.

*So, therefore if they've been very honest when they see the training happening, you know, will that mean, will that make it more raw again, as they go, very aware of how people are reacting to their very, very personal story so would it have been safer to have tempered it” (Facilitator 3)*

### *Theme 2: COVID-19 Disruptions*

The covid-19 pandemic presented an unforeseen challenge for the group in a number of ways. The lack of, or reduction in available space in the buildings and the uncertainty of lockdown significantly impacted the group meetings.

*“Particularly the space in the building as a result and not really sure which classroom you're going to have, where it was going to take place and trying to manage all those pieces, are going to be locked down, are we not” (Facilitator 3)*

*“We weren't sure if we were in this SAOL or the other SAOL just down the road so that was a challenge at first” (Facilitator 1)*

The pandemic slowed down the design progress, necessitating group meetings to be spread out over a greater timeline due to government restrictions for indoor gatherings and childcare restrictions. This also impacted the number of members who remained engaged with the group throughout the process.

*“Actually, it took much longer but not much longer but I think we did about 17 sessions maybe in the end, I’ll have to come back to just check the number, because it got a bit messy, we broke for September and then, so we did eleven and then we did another six or seven I think, so it took longer”*  
(Facilitator 2)

*“it had started off on those eight at the start and then people dropped out like, when things start to open back up one of the girls went back to the course she was doing and then there was childcare issues....so yeah covid had an impact on the whole process”* (Facilitator 2)

### *Theme 3: Speed of Progress*

While the speed of progress was impacted by the COVID-19 pandemic and allowing the emotional responses of the participants to be properly facilitated for. A further consideration in the speed of progress was enabling the participants to process the topics that emerged during their conversations, while also understanding that some of the co-design participants are active substance users.

*“I think the other piece is, they were patient because all of the women in the group have been involved in substance use and it would be really awry not to acknowledge that, that is going to slow down the speed of process”* (Facilitator 3)

*“But I do think it's worth saying that and I would have noticed with some of the women, that they were processing other things in their life (yeah), probably because of this work and suddenly one woman, I was almost floored when she openly talked about domestic abuse in her life and joining the dots”* (Facilitator 3)

*“ The analysis of why you’d be using that with someone else, and what's it gonna teach them or whatever but you couldn't, It didn't happen like that at all because the processing took so much space so there's a lot of repetition there's not a huge amount of variation”* (Facilitator 2)

#### *Theme 4: Training Template*

The template provided with the training pack could be viewed as an enabler which also presented a challenge. The facilitator mentioned the template as a support guide, given the research-based evidence behind the development of the pack. However, they also mentioned that it did present a challenge for their co-design partners as evidenced by these quotes.

*“That packed a lot you’d want to see their faces when “xxx” pulled that out and then when we realised that a lot of what went into template was the experience of women here” (Facilitator 1)*

*“Yeah, the bulk was a bit scary” (Facilitator 2)*

*“There was a template there that was devised already that was informed by the research in the first place, so I guess the women’s voices were involved in that as well” (Facilitator 2)*

*I think that put them at ease them, like when “xxx” said, well this was the research that was done like and the women like once they knew that happened, they got comfortable with that, but it took for them to be told that first but when they first seen the size of it, they said no” (Facilitator 1)*

### **3.3 Summary of Findings**

The thematic map below provides a summary of the key themes identified from the co-design participants and facilitators’ focus groups. The participants and facilitators, and the co-design process is in the centre of the map. The themes from the focus groups emerge from there.

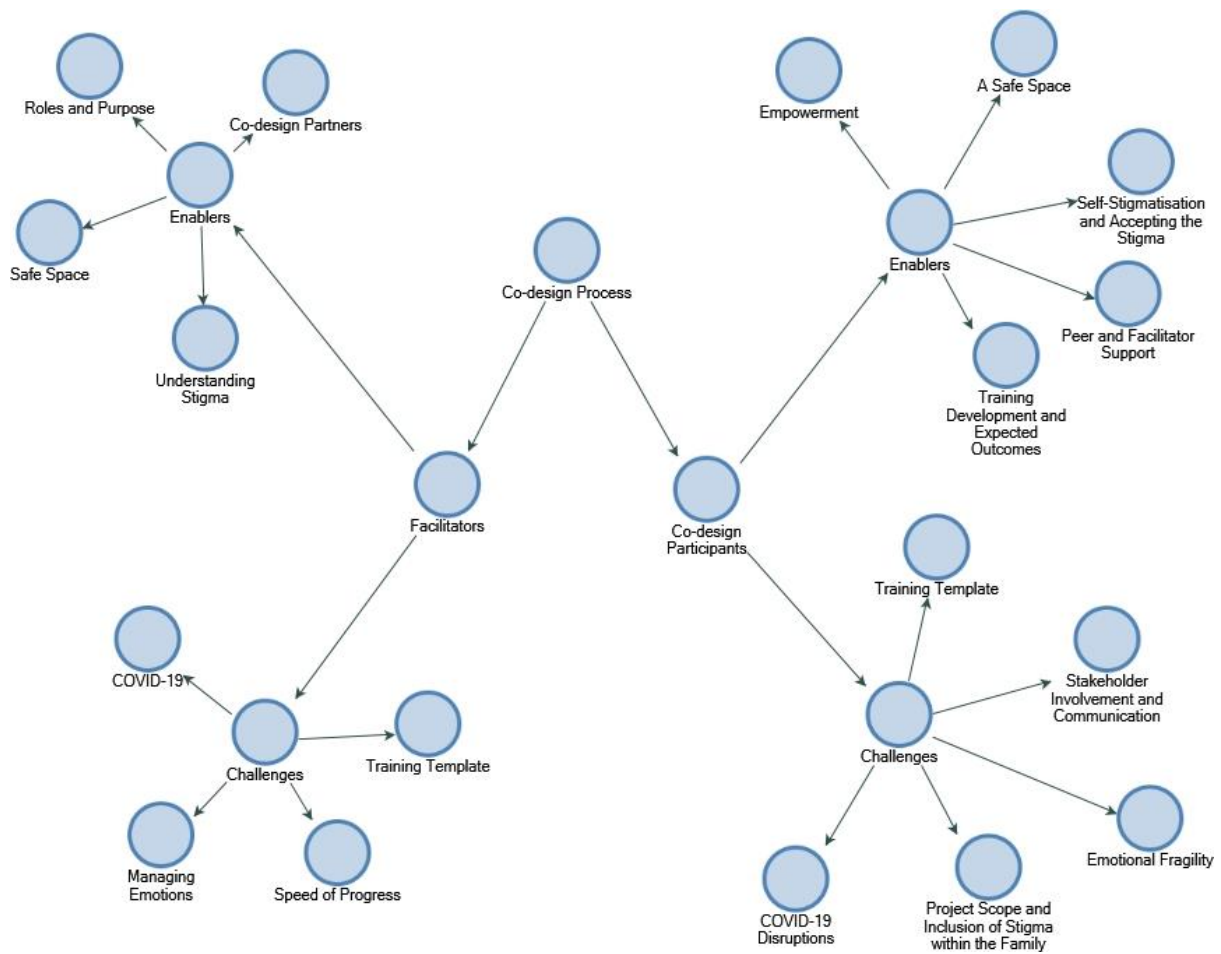


Figure 4: Thematic map of key themes

## Chapter Four: Survey Findings

In this chapter, the survey findings are reported, specifically, the demographic information of the participants of the pilot anti-stigma training programme, and the quantitative measure of stigma domains which consisted of blame, anger, pity, help, dangerousness, fear, avoidance, segregation, and coercion. Inferential analyses were computed to measure the change in stigma among participants pre and post pilot training. The last part of this chapter presents the training expectations and feedback on the content and delivery of the pilot training programme as provided by the participants.

### 4.1 Demographic Findings

In relation to the demographic findings, the majority of participants were female (63.6%) and worked within the health services (36.4%) and community addiction services (18.2%). The age ranged from 32 to 58 years of age with an average of 46.36 (SD= 9.41). The years of experience within their sector ranged from 4 to 26 years with an average of 13.45 (SD= 7.92), as shown in table 2 below.

*Table 2: Demographic Findings of Pilot Training Programme Participants (N= 11)*

<b>Demographic Variables (n= 11)</b>		
<b>Gender</b>	<b>N</b>	<b>%</b>
Male	4	36.4
Female	7	63.6
<b>Work Industry</b>		
Childcare	1	9.1
Community Addiction Services	2	18.2
Community Employment	1	9.1
Education	1	9.1
Health Services	4	36.4
Rehabilitation	1	9.1
Youth Addiction Services	1	9.1
	<b>Mean (SD)</b>	<b>Range</b>
<b>Age</b>	46.36 (9.41)	32 – 58
<b>Years of Experience</b>	13.45 (7.92)	4 – 26

### 4.2 Stigma Measure Findings

The stigma tool scoring is presented in table 3. The score on each individual question ranges from 1 to 9. The findings suggest that while the majority of participants scored lower on most of the dimensions, which indicates lower levels of stigma, except for the dimension help where a higher score is a good outcome. Certain dimensions had slightly higher mean scores such as pity, help, and avoidance. A higher score suggests that participants felt slightly higher levels of pity for people who



use drugs. There is also a strong sense of wanting to help people who use drugs; however, the mean scores also indicate slightly higher levels of avoidance behaviour.

At the end of the first survey, participants provided feedback and suggested that a shorter questionnaire would be more appropriate. This feedback was taken onboard, and the post survey was amended. In the post survey, the AQ9 questionnaire was administered and as a result, the AQ27 scoring had to be converted to AQ9 scoring for comparison purposes (see appendix 1). The score conversion is provided in Table 3, and inferential analyses were conducted using these converted scores.

*Table 3: Pre-Survey Scores of Stigmas Converted to the AQ9 Scoring (N= 11)*

<b>Stereotype Factors</b>	<b>Mean</b>	<b>Std. Deviation</b>	<b>Minimum</b>	<b>Maximum</b>
Blame	3.27	1.372	2	6
Anger	2.36	1.696	1	7
Pity	5.57	2.129	2	9
Help	7.45	2.067	4	9
Dangerousness	2.66	0.930	1	4
Fear	1.81	0.793	1	3
Avoidance	4.90	1.850	1	8
Segregation	3.81	1.015	2	5
Coercion	2.30	1.233	1	4

Table 4 presents the post survey mean scores on the stigma dimensions. Interestingly, a slight change was noted. While most of the dimensions had a lower score when compared to the pre survey, there was an increase in two dimensions; help and fear (see Figure 5), indicating that participants wanted to help more, however, their levels of fear also increased towards people who use drugs. Table 5 below explores the changes further using inferential statistics.

*Table 4: Post-Survey Scores of Stigmas Using the AQ9 Scoring (N= 9)*

<b>Stereotype Factors</b>	<b>Mean</b>	<b>Std. Deviation</b>	<b>Minimum</b>	<b>Maximum</b>
Blame	2.11	0.782	1	3
Anger	1.78	0.833	1	3
Pity	5.44	2.877	1	9
Help	8.44	1.130	6	9
Dangerousness	2.56	1.333	1	5
Fear	2.78	2.048	1	7
Avoidance	1.78	0.972	1	4
Segregation	1.78	1.394	1	5
Coercion	1.44	1.333	1	5

A paired samples t-test was conducted to measure the statistical change in stigma from the pre to the post survey. The two dimensions help and fear, while it indicated an increase, this was not found to be statistically significant ( $p > 0.05$ ). However, statistically significant change was found for the dimensions blame ( $p = 0.042$ ), avoidance ( $p = 0.001$ ) and segregation ( $p = 0.017$ ), as shown in Table 5 and highlighted in bold in Figure 5. These findings suggest that there was a significant drop in the mean scores after the training for dimensions blame, avoidance and segregation, indicating a change in participants' level of stigma. Although no significant differences were found for anger, pity, dangerousness, and coercion.

Table 5: Paired Samples T-test Output (N= 9)

Stereotype Factors	Pre-Training Mean Scores	Post Training Mean Scores	Paired Samples T-test ( $p < 0.05$ )
Blame	3.27	2.11	<b>0.042*</b>
Anger	2.36	1.78	0.337
Pity	5.57	5.44	0.887
Help	7.45	8.44	0.105
Dangerousness	2.66	2.56	0.726
Fear	1.81	2.78	0.119
Avoidance	4.90	1.78	<b>0.001*</b>
Segregation	3.81	1.78	<b>0.017*</b>
Coercion	2.30	1.44	0.217

**\* Statistically significant at 0.05**

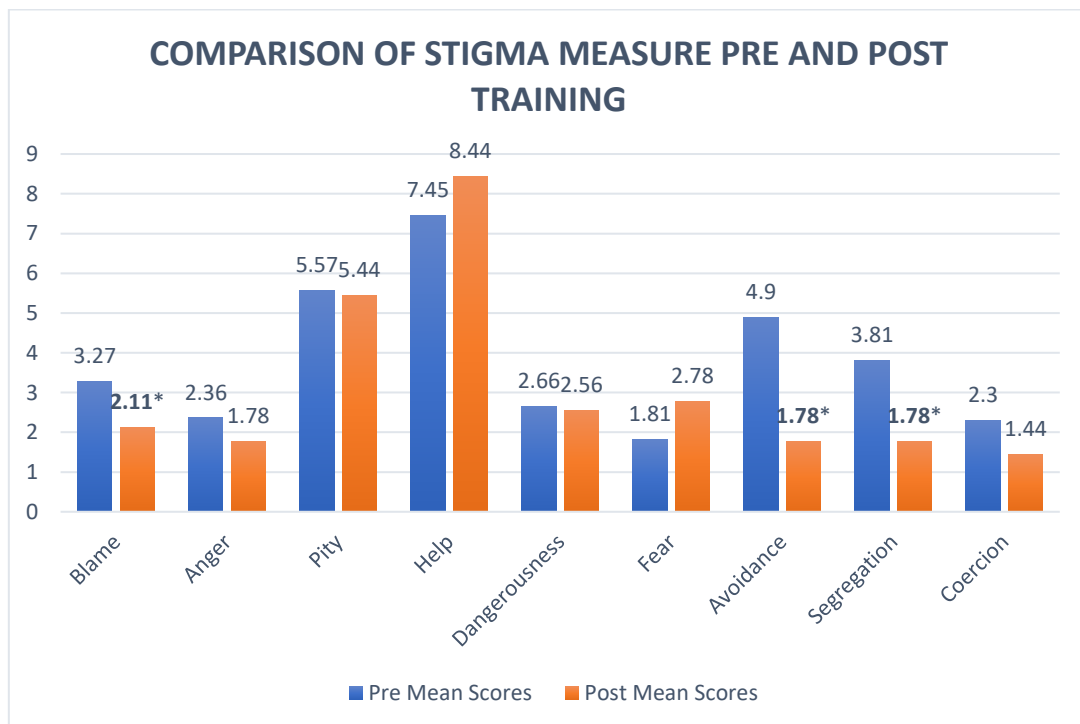


Figure 5: Comparison of Stigma Measure Pre And Post Training

### 4.3 Participants' Training Expectations

At the start of the training, participants were asked about their expectations of the pilot anti-stigma training programme. Participants' expectations included understanding stigma, how to address the issue, learning more about their own stigmas, how it affects their practice, the impact it has on service users and services, and increase their general knowledge on stigma. The key themes are presented in Figure 6 below.

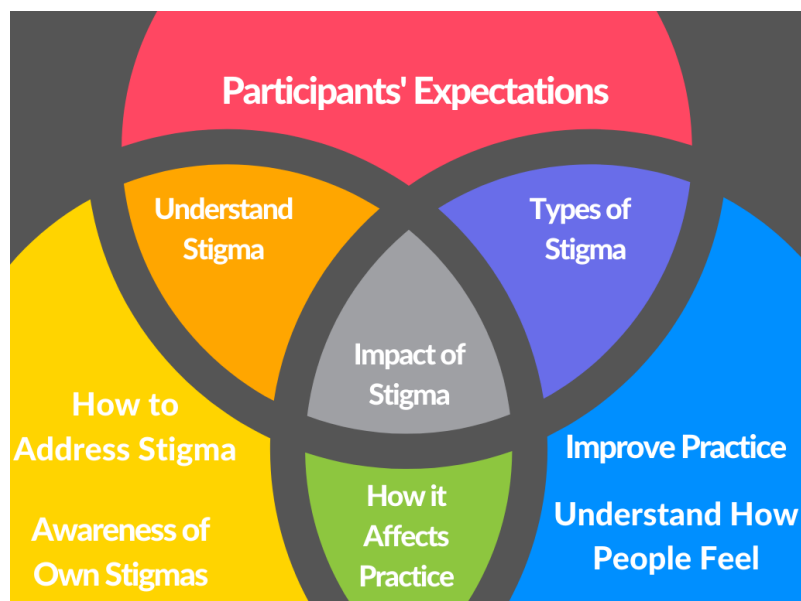


Figure 6: Participants' Expectations Prior to the Training

In the follow-up survey, participants were asked what they gained from the training. The participants reported gaining more insights and awareness of stigma, they reported learning about different types of stigma, and it allowed them to reflect on their own stigmas. They also found it to be thought provoking and improved their understanding of the challenges that people who use drugs face, the impact of labelling, the language used, and ways to improve their services. These key themes are reported in Figure 7.

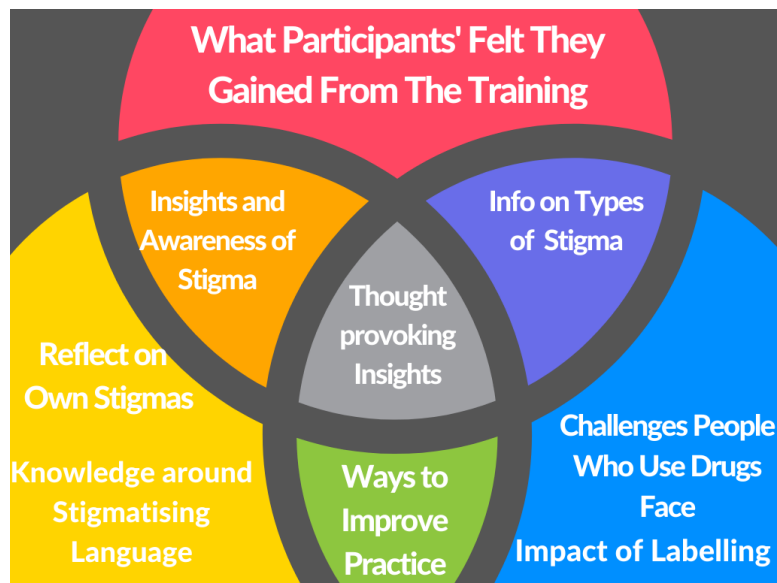


Figure 7: What Participants Gained from the Training

#### 4.4 Training Feedback

The survey collected data on the content and delivery feedback from participants after the completion of the pilot training. These are presented in this section.

##### 4.4.1 Best Features of the Training

When asked about the best features of the training, five main themes were identified from participants' response.

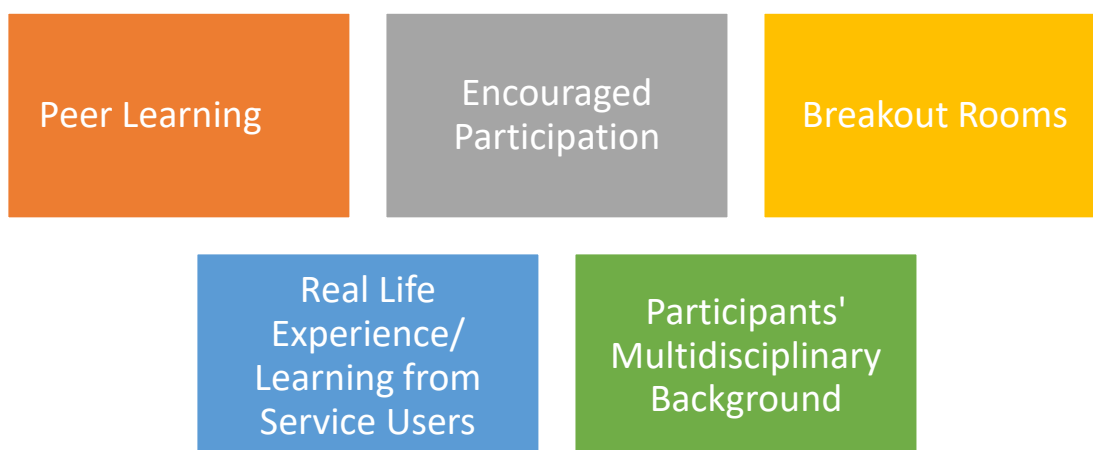


Figure 8: Key themes on Best Features of the Training

Participants reported that peer learning was one of the best features of the training as well as learning from people from multidisciplinary backgrounds.

“the groups and peoples’ different ideas” (*Participant 1*)

“...having a mix of people in recovery and those working in the sector really worked well”

(*Participant 2*)

“...interagency work” (*Participant 3*)

The facilitators created an atmosphere where participants felt encouraged participation in the training, and they found the use of breakout rooms to be an effective feature of the training.

“The atmosphere facilitated by trainers to ensure participation” (*Participant 4*)

“The breakout rooms” (*Participant 5*)

Finally, the participants appreciated the learning from real life experience of their peer and from service users.

“The real-life experiences that were disclosed by the participants” (*Participant 8*)

“participation of people in recovery and former drug users” (*Participant 6*)

#### 4.4.2 Training Improvement Suggestions

Participants were asked for improvement suggestions regarding the training delivery, and six key themes were identified.

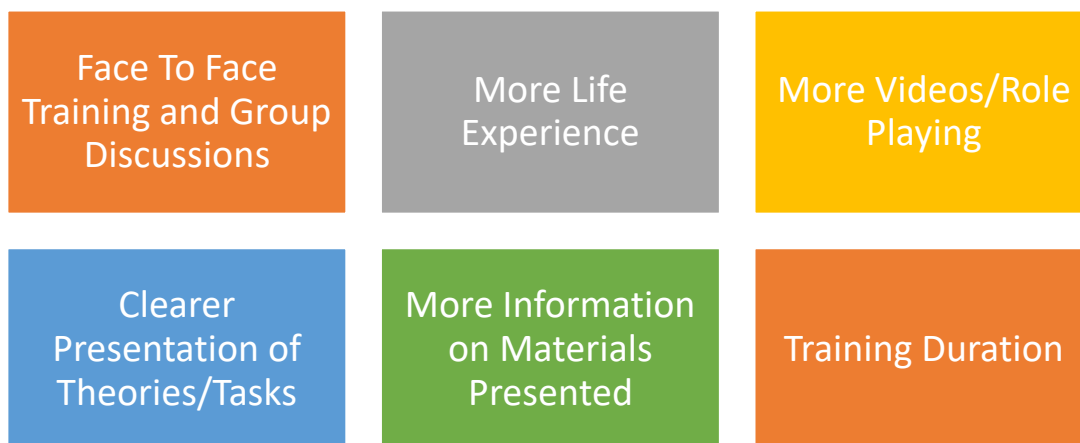


Figure 9: Key themes on Training Improvements

Participants suggested that they would prefer more face to face training delivery, however, they are aware that given the pandemic, it is not a feasible.

“... having group in room I know that not possible because of COVID find zoom drains you”

*(Participant 7)*

“Being in person” *(Participant 8)*

Participants reported that they would have liked to see more life experience in the training and more videos and role playing.

“A little more life experience” *(Participant 9)*

“Role plays, show more videos” *(Participant 4)*

Clearer presentation of certain materials was a suggested improvement, in particular for the theories presented, tasks in the breakout rooms, and more information on some materials presented in the training.

“... maybe slightly more info on some of the materials presented which was really interesting”

*(Participant 5)*

“... tasks in breakout rooms were unclear” *(Participant 9)*

“Clearer presentation of theories” *(Participant 2)*

The final theme was the duration of the training. While some participants would have preferred a longer training programme, others would have liked a shorter duration.

“A little longer as some of the assignments were a bit rushed” *(Participant 3)*

“The course could probably be shortened into two mornings...” *(Participant 5)*

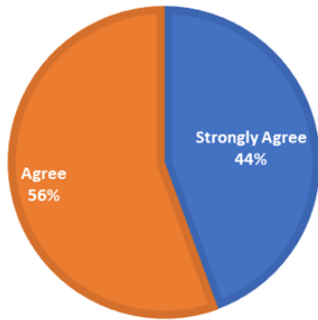
#### 4.4.3 Overall Delivery Feedback

Participants were asked six specific questions on the delivery of the training programme, and these were based on the workload, teaching methods, presentation of ideas and concept, organisation, staff responsiveness and the pace of the training. Overall, the feedback was positive. All the participants agreed that the workload was manageable, and the teaching methods encouraged participation. The majority agreed that ideas and concepts were presented clearly, the training was well organised, the

staff were responsive to participants' needs, and the pace of the training. However, some participants did respond "neutral" to the last four questions, see Figure 10 for more information.

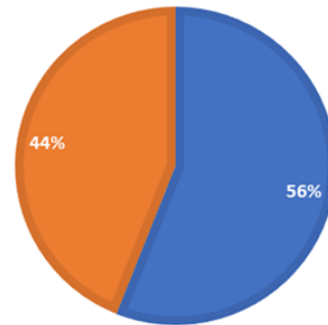
### MANAGEABLE WORKLOAD

■ Strongly Agree ■ Agree



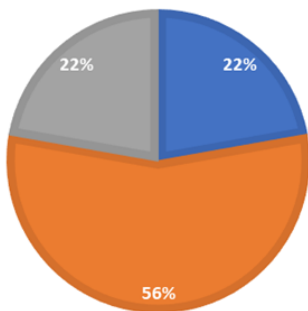
### TEACHING METHOD ENCOURAGED PARTICIPATION

■ Strongly Agree ■ Agree



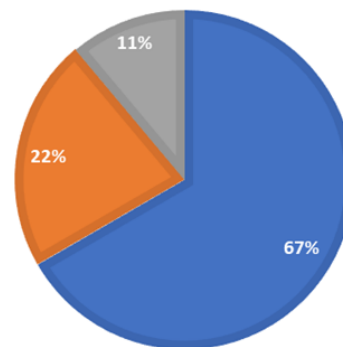
### IDEAS AND CONCEPT PRESENTED CLEARLY

■ Strongly Agree ■ Agree ■ Neutral



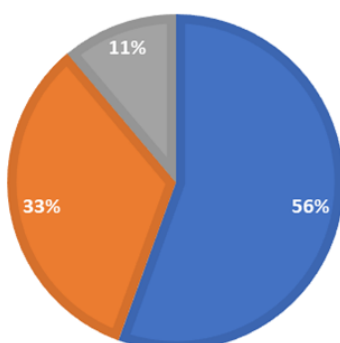
### WELL ORGANISED

■ Strongly Agree ■ Agree ■ Neutral



### STAFF RESPONSIVENESS

■ Strongly Agree ■ Agree ■ Neutral



### APPROPRIATE PACE

■ Strongly Agree ■ Agree ■ Neutral

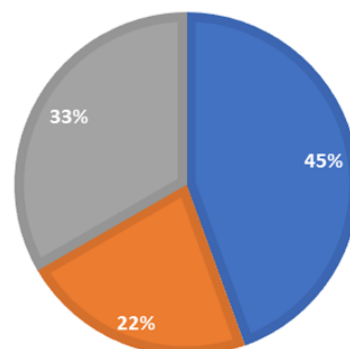


Figure 10: Overall Delivery Feedback

## 4.5 Summary of Findings

The key findings from the survey data were significant change in stigma after the training. A statistically significant drop in levels of stigma was reported for three dimensions these were blame, avoidance and segregation. A general improvement was noted in the levels of stigma after the training.

The overall participant expectations of the training were met, and they were mostly around improving their general knowledge, having better awareness of stigma and self-stigmas, understanding the impact it has on service users and service provision. Participants learnt about labelling and the language used, and also how to improve their practice within their services.

In relation to the training feedback from participants, overall, it was very positive. The best features of the training included the peer learning from different sectors, learning from real life experience, the collaboration with service users, the encouraged participation, and they found the breakout rooms very useful. However, participants would have liked more clarity and information on materials and theories presented in the sessions, clearer instructions in breakout sessions, more videos and role playing, and ideally, they would have preferred face to face training. When asked about the content delivery, the teaching methods, the pace, staff responsiveness, organisation, and workload management, the responses were overwhelmingly positive.



## Chapter Five: Conclusion and Recommendations

### Observation

In summary, from the observation it was very clear that the co-design procedure was respected. There was clear evidence of a shared understanding, of equal power distribution, the use of tools within the process to ensure all participated and the space was deemed safe and open. Participants were empowered in the process of content building and there was time provided for reflection and encouragement of differing opinions and collaboration was encouraged. In terms of inclusion and decision making everyone was given an opportunity to speak and be involved in decision making. One minor note for improvement might be to further examine the balance of the overarching co-design approach within the overall process as this was not always evident during this chosen observation session.

### Focus groups

Further support for the findings above and evidence on the presence or absence of implementation enablers and barriers across the four stage of implementation were found within the focus group results. Enablers included the clarity of reasoning behind decisions and the clarity of purpose of the training in terms of raising awareness and accountability. The existence of trust and a safe space was highlighted and the subsequent feeling of empowerment. Participants felt empowered by their peers and the facilitators during the co-design process. They felt respected and excited to be part of the co-design process. There was clear evidence of key enablers of stakeholder consultation, leadership, resourcing, staff capacity, organisational support and culture and communication. However as wider implementation is considered, how to maintain these will be an ongoing challenge. There was also room for improvement in communication in terms of the bigger picture and who were the wider stakeholders and what was their role, from the role of the evaluation team to the role of the funder. Further enablers included the fact that the co-design process made participants more aware of the stigma, they felt different about it and that they knew they were entitled to be treated with more respect. Tools such as the decompression break assisted with enabling this shift when difficult discussions arose.

Barriers to the co-design process were sometimes external practical barriers as a result of COVID-19 or the need for childcare. Internal barriers were also present from emotional fragility to the scale of the challenge and the training template. The scope of the programme did not include the topic of stigma within families and this was seen as a limitation.

The facilitator focus group findings mirrored many of the findings on enablers as identified by the service users from communication to safe spaces, clarity of purpose and working together as partners. An additional finding was the unexpected emergence of the therapeutic element in the co-design process. Challenges were also faced within these enablers, for example the challenge of managing past emotions and possible future facilitation fears during the process. Again, the training template was both an enabler in terms of background and a challenge in terms of breath and scale.

#### Pilot training survey findings

The survey findings measured stigma across nine domains and results from the sample of participants those who underwent the pilot training illustrated improvements in eight of the nine domains. Three of these improvements were statistically significant despite the very small sample sizes, these were attribution of blame, avoidance behaviour and segregation. Participants' expectations of the training programme included understanding stigma, how to address the issue, learning more about their own stigmas, how it affects their practice, the impact it has on service users and services, and increase their general knowledge on stigma. These expectations were met as evidenced by the follow-up comments provided. In addition, participants reported that peer learning was one of the best features of the training as well as learning from people from multidisciplinary backgrounds.

In terms of improving the training, participants expressed an interest in more videos and role playing as this aspect was very useful. In terms of other improvements, participants requested some further clarity on certain materials particularly the theories presented and perhaps more clarity on the breakout sessions.

In summary, to conclude, it was clear that the co-design process was adhered to with fidelity in spite of both unforeseen external challenges and possible anticipated internal personal past experiences of stigma and past experiences as the leaders of facilitation and this is to be applauded. The rollout of the pilot training found that the training package not only met the expectations of the participants but also had a short-term impact on levels of stigma. Further enhancements in certain program materials may be of benefit.

In terms of recommendations as the co-design process was successful, recommendations are directed towards the scale up and further rollout of the program to wider services.

1. Development of a bespoke copyrighted or published manual with details of the programme content and training required for delivery
2. Development of a plan for a train the trainer programme with services, starting perhaps with key named services who will act as programme promoters
3. Development of a community of practice support network or website for ongoing support for practitioners as the training roles out
4. Provision of additional resourcing to ensure the sustainability of the fidelity and rollout of the programme
5. Possibly the development of an oversight or advisory board to support the recommendations
6. Development of an ongoing monitoring and evaluation framework or system to ensure the training remains current and fit for purpose
7. Seek external recognition and accreditation for the training from an accredited source.

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## Appendices

### Appendix 1

Table 6: Pre-Survey Stigma Scores for A27

<b>Stereotype Factors</b>	<b>Mean</b>	<b>Std. Deviation</b>	<b>Minimum</b>	<b>Maximum</b>
Blame	9.82	4.119	5	18
Anger	7.09	5.088	3	20
Pity	16.73	6.389	6	27
Help	22.36	6.201	11	27
Dangerousness	8	2.793	3	12
Fear	5.45	2.382	3	9
Avoidance	14.73	5.551	3	23
Segregation	11.45	3.045	5	16
Coercion	6.91	3.7	3	13

“THEY SEE  
THE ADDICTION.  
THEY DON'T  
SEE US.”



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