

Putting Together the Puzzle

AIVL's Training Module on stigma, discrimination and injecting drug use, is comprised of a number of components. These components have been developed to support and be utilised in conjunction with each other. These components are:

- **Trainers' Guide**
- **Trainers' Notes (this document)**
- **PowerPoint Presentation**
- **Participant Handouts**

The Training Module as a complete package has been designed to be used as is, while at the same time designed to be flexible so that trainers can adapt the module components to suit their needs, capacity and experience. While tips, quotes and examples are provided throughout, we encourage trainers and drug user organisations (DUO) to adapt for their own context and for their own local experiences to personalise the training wherever possible. It is strongly suggested that trainers are familiar with all components of the module, in particular the Trainers' Notes and have done sufficient preparation before delivering a workshop.

The Training Module is designed to provide information for health care and medical professionals (doctors, nurses, pharmacists, dentists) and students of these fields to:

- identify the various ways in which people who inject drugs (PWID), people on pharmacotherapy programs and people with hepatitis C and/or other BBVs experience stigma and discrimination in health care settings;
- recognise and understand the impact of stigma and discrimination on people's access to health services; and;

- develop strategies and practical skills for preventing and challenging stigma and discrimination and improve health service delivery.

It is not the intention of this training module to lay blame or cause distress, rather its aim is to raise awareness of the issues pertaining to stigma and discrimination in health care settings, to provide opportunities for discussion on issues which are often left unaddressed. It also aims to provide practical advice for health care professionals and students on treating clients (and future patients) in a respectful, non-judgemental and unbiased manner.

About the Trainers' Notes

The Trainers' Notes provide trainers with the conceptual framework and practical tools that can be used toward developing positive attitudes and environments that challenge stigma and discrimination. The Trainers' Notes supplement the PowerPoint presentation by including theory, discussion and/or activities to guide trainers and it is crucial that adequate time is given for these to occur.

The training notes are not intended to be spoken directly to participants; rather they are preliminary readings and prompts to give trainer's guidance on the direction and aims of the workshop and each session. Some areas have more trainers' notes than others, which is not necessarily an indication that more time should be spent in those areas. More information may have been needed to explain a complex issue and/or to provide trainers' with background material in order for them to gain a better understanding of the issue/s and any concerns which may arise.

Trainers are encouraged to adapt their session workshop

plans depending on the training time available, participant needs, desired learning outcomes and existing training materials. Trainers' should also as a matter of course, ensure they are familiarised and feel comfortable and confident with the content of the PowerPoint presentation and corresponding Trainers' Notes.

It is recommended that two hours minimum is given to deliver the workshop program and allow extra time if short breaks are to be included. Depending on the level of facilitating experience and confidence, trainers may need more or less than two hours. It is suggested that prior to the workshop, trainers run through the material to determine the exact length of time needed to comfortably cover all the material in the workshop program.

In addition to the two hour workshop, a set of 'optional extras' are available for those workshops that can be extended for more than two hours, as further information for sessions and/or as in some cases, offers alternative

activities. In those cases the 'optional extras' can be slotted into the 'core' material to expand and enhance the workshop session plan. Trainers may use the 'optional extras' to bolster a topic that they wish to focus in on, or when an alternative activity may be better suited to a particular audience. The trainers' notes indicate exactly where in the session structure the 'optional extras' best fit.



Workshop Content

Session 1: Introduction and overview (10min)

- Welcome
- Introduction to Putting Together the Puzzle
- Overview of the training workshop
- Workshop learning objectives
- Who are we talking about?

Session 2: What is stigma and discrimination? (30min)

- “Rules of this workshop program”
- Social ways of looking at drug use
- Understanding drug use
- Language and PWID
- Preferred language
- The difference between stigma & discrimination
- The Elements of stigma
- The Functions of stigma
- Cycle of PWID related stigma
- What is discrimination?

Session 3: Impact of stigma and discrimination and how they act as barriers in health care settings (40min)

- Stigma as a real barrier to health service provision
- Discrimination in the health care sector
- Forms of discrimination in the health care sector
- “Meet Peter”
- “Peter’s story”
- Drug seeking behaviour (activity)
- What does all this mean and why should I care

Session 4: Strategies to decrease stigma and discrimination (30min)

- Challenging stigma
- Strategies to challenge stigma and discrimination and reduce barriers on an individual/worker level
- Strategies to challenge stigma and discrimination and reduce barriers on a service/organisational level
- Strategies to challenge stigma and discrimination and reduce barriers on a community level
- Is it worth it? (activity)

Session 5: Wrap up and evaluation (10min)

- Review of the workshop learning objectives (activity)
- Participant evaluation

Participant Handouts

- AIVL National Reporting of Discrimination Survey Results;
- Continuum of Drug Use;
- Doctor Rejected Dying Man As An Addict (media article);
- Impact of Stigma and Discrimination on Health Care Delivery to People Who Inject Drugs;
- International Harm Reduction Association and Others and the ‘Irish Independent’;
- International Network of People Who Use Drugs (INPUD) Statement and Position Paper on Language, Identity, Inclusively and Discrimination;
- ‘Junkie’ Untreated for Swine Flu (media article);
- Pharmacotherapy Treatment and Opiate Substitution Therapy;
- Social History of Drug Use;
- Sterilising of Junkies may seem Harsh, But it Does make Sense (media article);
- Stigma, Discrimination and Micro-Aggressions;
- Zinberg’s Interactive Model of Drug Use.

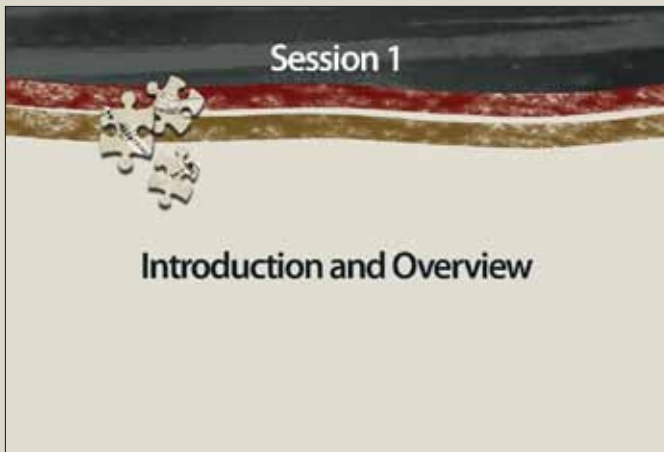
Start of presentation



Session 1



Session 1: Introduction and Overview



Time: 10 minutes

Resources: Workshop session plan, PowerPoint presentation, LCD projector & screen, computer, whiteboard (plus marker pens), paper and pens.

Handouts:

1. Workshop session plan for each participant (where applicable)
2. Pharmacotherapy Treatment and Opiate Substitution Therapy.

Objectives:

- Participants will learn about the people, organisations and processes behind the development of this training.
- Participants will gain a broad overview of the workshop's content.
- Participants will gain an understanding of the aims and objectives of the workshop.

Session 1



Introduction and Overview

Slide: Welcome



Slide Purpose: This title slide for the training should be showing as participants seat themselves and while introductions and welcomes are made.

Trainers Notes:

Welcome participants to the training workshop; 'Putting Together the Puzzle' Stigma, Discrimination and Injecting Drug Use—AIVL Training Module for Health Care Professionals and Students. Introduce yourself and your organisation.

Cover basic housekeeping such as the location of toilet facilities, availability of tea/coffee and expected breaks if applicable.

Ask each participant to introduce themselves; give their name, the organisation they work with or course of study they are undertaking. The amount of time you assign to this exercise and allow for each person to speak will depend on the size of the group; having less people in the group will give you more time to assign participants.

'Optional extra'

- Alternative ice breaker

'Optional Extra'

This ice breaker: can be used as an alternative to the one above, where participants are introducing themselves.

Refer to 'optional extra' card for more information.

'Optional extra'

- Question box

'Optional Extra'

The Question Box: exercise can be introduced here at the start of the workshop and followed up during the last session.

Refer to 'optional extra' card for more information.

Slide: : Putting Together the Puzzle: Training on stigma, discrimination and injecting drug use



Slide Purpose: This slide is used to introduce AIVL as the national peak body for the state/territory drug user organisations and as the organisation behind 'Putting Together the Puzzle'. Participants will gain an understanding of who the training is targeting and a brief overview of why AIVL felt there was a need to develop a resource of this kind.

NB: *Additionally it can be used by DUOs to reflect locally pertinent links, services or issues. For example, it could highlight a consumer advocacy group, related projects information, who to get in touch with for follow-through, or more training etc.*

Trainers Notes: It is important that participants have an understanding of the uniqueness and the role of this training. Take the group through the following dot points to describe why training on this issue is important and why, we as the affected community are best placed to develop and delivery such a resource.

Why training on PWID related stigma & discrimination?

We know through research and anecdotally that stigma and discrimination is regular experienced by PWID in health care services. In order to see an increase in drug user access to health care and quality service provision including viral hepatitis health services we need to see a shift in attitudes towards drug use and drug users'.

It is the intention of this training to provide insight and discussion around attitudes and behaviours towards drug use and drug users'; with the aim to improve experiences within health care settings and to engender therapeutic relationships between PWID and health care providers for improved health outcomes.

The scope and complexities of this topic is substantial, and one that we believe needs to be addressed from different angles. This Training Module is just one component of a broad anti-discrimination campaign that AIVL has been developing for some years. AIVL's 'Anti-Discrimination Campaign' contains a number of components which target various sections of the general community: PWID, younger members of the broader community and health care professional and students. Through targeting different groups within society, AIVL aims to reach a wide audience with the anticipation of seeing a change in attitude and behaviour toward drug use and drug users'.

This experiential learning environment encourages participants to challenge negative stereotypes and potentially harmful attitudes towards the PWID community.

Developed by AIVL

This training material was developed by AIVL, to be utilised by AIVL at the national level and by the state and territory DUO at the local level.

Who is AIVL?

The Australian & Illicit Drug Users League (AIVL) is the national peak body for the state/territory drug user organisations and represents issues of national importance

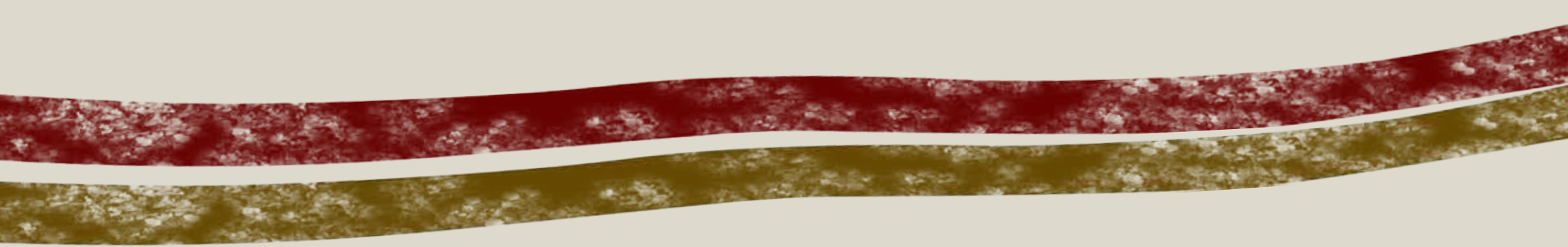
for people who inject/use or have used illicit drugs including people in drug treatment. The training was designed to be utilised by AIVL and its state/territory member organisations which are peer-based meaning they are run by and for people who inject/use or have used illicit drugs. While not all people involve in AIVL or its member organisations have direct person experience of illicit drug use, we seek to ensure, at any given time that a majority of people involved in our organisations have direct experience of the issues we represent.

It is the peer-based nature of AIVL and its member organisation that make this training module on reducing stigma and discrimination in health care settings against PWID so unique and important. Through the training AIVL provides a perspective that is often absent from workforce development in the health sector; the voice of the affected community.

As organisations run by peers for peers we have the experience and knowledge to understand the intricacies and complexities required in addressing stigma and discrimination related issues for PWID. We are in a unique position to identify the issues, causes, effects and impact of drug user-related stigma and discrimination in health care settings.

Who is it targeting?

The training is targeting health care professionals such as doctors, pharmacists, dentists, nurses and students of these fields. It is these workers or future workers we have direct contact with PWID who can have a positive influence on the experiences and health outcomes of PWID and even influence whether they do access health care services. It is not only limited to these professions, but aims to reach general workers in the health care system at all levels who are in contact with PWID. This basically means all health care workers.



Putting Together the Puzzle: Training on stigma, discrimination & injecting drug use

- Why training on PWID related stigma and discrimination?
- Developed by AIVL
- Who is AIVL?
- Who is it targeting?

Slide: Overview of Training Workshop



Slide Purpose: This slide provides participants with a brief and broad overview of what will be covered during the workshop.

Trainers Notes: Distribute participant information packs (containing a copy of the workshop session plan, handouts, DUO and/or AIVL service brochure). Take the group through the contents of their packs, explaining the purpose of the handouts and that a 'Workshop Session Plan' has been included to provide a time table of the content, when the breaks will take place (if applicable), and the 'Workshop Learning Objectives' (which will be looked at later).

This overview of the workshop provides an outline of the sessions and a breakdown of the material that is covered in each one. The workshop is broken into 5 sessions; take the group through each session, one at a time, briefly describing the topics that will be covered in each.

Read through the workshop outline:

Session 1: Introduction and overview

- Introduction and overview of the workshop
- Workshop training objectives
- Who are we talking about?

Session 2: What is stigma and discrimination?

- Definition of stigma and discrimination
- Identify and explore the reach of drug-related stigma.

Session 3: Impact of stigma and discrimination and how they act as barriers in health care settings

- Explore key sources of pre-existing stigma and discrimination
- How stigma manifests in health care settings
- The effect of stigma on PWID willingness and ability to access services.
- 'Drug Seeking behaviour' (activity)

Session 4: Strategies to decrease stigma and discrimination

- Challenging stigma and discrimination
- Reducing barriers to health care access
- Is it worth it? (activity)

Session 5: Wrap-up

- Reviewing the workshop learning objectives (activity)
- Evaluation

Overview

- Session 1** Introduction & overview
- Session 2** What is stigma & discrimination?
- Session 3** Impact of stigma & discrimination and how they act as barriers in health care settings
- Session 4** Strategies to decrease stigma & discrimination
- Session 5** Wrap-Up & evaluation



Slide: Workshop Learning Objectives



Slide Purpose: Participants will gain an understanding of the overarching learning objectives, and the knowledge the workshop aims to provide participants.

Trainers Notes: The training aims to provide participants with knowledge and the skills to improve the relationship between health care service providers and PWID, those on pharmacotherapy and those living with hepatitis C and/or other BBVs. By developing and/or enhancing the trust which should be inherent within the doctor patient relationship, better health outcomes can be achieved benefiting both doctor and patient. PWID will have a better quality of life, health care experience and return for medical treatment, while medical professionals will gain work satisfaction and return of business.

Workshop objectives: Take participants through the following learning objectives:

- **Participants will leave the workshop with a deeper understanding and awareness on how stigma and discrimination occurs in health care settings** as it relates to PWID, those on pharmacotherapy and those living with hepatitis C and/or other BBVs.
- **Participants will leave the workshop with a comprehensive understanding of the impact of stigma and discrimination** on PWID, those on pharmacotherapy and those living with hepatitis C and/or other BBVs.
- **Participants will have a comprehensive working knowledge of strategies and initiatives to prevent and challenge stigma and discrimination directed at PWID, those on pharmacotherapy and those living with hepatitis C and/or other BBVs, from an individual, organisational, and community perspective.**
- **Participants will have identified at least one personal or individual strategy to reduce barriers to access and health services for PWID, those on pharmacotherapy and those living with hepatitis C and/or other BBVs that they can implement within their personal and/or professional lives.**

During the final session participants will have an opportunity to review and discuss whether or not the workshop objectives were achieved and whether the content met with their expectations.

Workshop Learning Objectives

- Participants will leave the workshop with a deeper understanding and awareness on how stigma and discrimination occurs in health care settings
- Participants will leave the workshop with a comprehensive understanding of the impact of stigma and discrimination
- Participants will have a comprehensive working knowledge of strategies and initiatives to prevent and challenge stigma and discrimination directed at PWID, from an individual, organisational and community perspective
- Participants will have identified at least one personal or individual strategy to reduce barriers to access and health services that they can implement within their personal and/or professional lives



Slide: Who we are talking about

Who we are talking about

- PWID** People who inject drugs. Out of all 'drug users,' injecting drug users are the ones who face the greatest degree of stigma and discrimination and negative health implications.
- OST** On a snapshot day in 2011, there were 46,446 clients on OST—(69%) on methadone with the remainder either on buprenorphine or buprenorphine-naloxone. (30/09/2012)
- BBV** Based on reported cases, hepatitis B and hepatitis C transmission in Australia continued to occur predominantly among people with a recent history of injecting drug use. (30/09/2012)
- HIV** In 2010, an estimated 21 391 people living in Australia with diagnosed HIV infection.
- Hepatitis B** In 2010 an estimated 170 000 people were living in Australia with hepatitis B infection. (30/09/2012)
- Hepatitis C** An estimated 221 000 people were living in Australia with chronic hepatitis C infection, including 48 000 with moderate to severe liver disease. (30/09/2012)

Slide Purpose: To give an overview of the people we are talking about in this workshop in relation to stigma and discrimination. This includes the number of people on opiate substitution therapy (OST) and to show how many people are affected by blood borne viruses (BBV) such as hepatitis B, hepatitis C and HIV and that predominately the reported cases of BBV continue to be among people who inject drugs.

Trainers Notes: The intention is that within this workshop we are discussing, in the main, people who currently inject drugs, those with a history of injecting, (particularly those with viral hepatitis and/or other BBVs) and those on pharmacotherapy.

- It may be necessary to explain that terms such as people who inject drugs (PWID), injecting drug user (IDU), and people with a history of injecting drug use, as well as 'user' are often used interchangeably within the general community—and potentially within the workshop's facilitation.

- It is important to recognise that some users of illicit drugs experience significantly more stigma and discrimination than others. For example, PWID are a minority of the total population of people who use drugs, but it is well documented that they experience the vast majority of harms—including stigma and discrimination. The health issues related to injecting illicit drugs can be vast, giving this group a greater degree of need to access effective health care services.

PWID come from all kinds of back grounds and all walks of life; PWID range from being financially poor and unemployed, to being financially well-off and highly successful. It is the former that is generally more visible. Particularly when other factors such as homelessness, trauma, serious mental health issues, imprisonment, etc. come into play, impacting on the lives of some PWID and it is these complex issues which become highly visible.

Basically we are talking about PWID because out of all drug users, injectors face the greatest degree of discrimination and their health needs are different.

- Some groups may need pharmacotherapy or pharmacotherapy programs, explained: opiate substitution therapy (OST) prescribed in the form of methadone, Suboxone or Subutex. OST is generally dispensed through pharmacies and public or private clinics (see handout 'Pharmacotherapy Treatment & Opiate Substitution Therapy' for more information).
- Review recent research prior to workshop presentation to ensure that information on the numbers of PWID, people on OST and PWID with BBV is current.



Who we are talking about

PWID People who inject drugs. Out of **all** 'drug users,' injecting drug users are the ones who face the greatest degree of stigma and discrimination and negative health implications

OST On a snapshot day in 2011, there were 46,446 clients on OST—(69%) on methadone with the remainder either on buprenorphine or buprenorphine-naloxone (AIHW 2012)

BBV Based on reported cases, hepatitis B and hepatitis C transmission in Australia continued to occur predominantly among people with a recent history of injecting drug use (Kirby, 2012)

HIV In 2010, an estimated 21 391 people living in Australia with diagnosed HIV infection

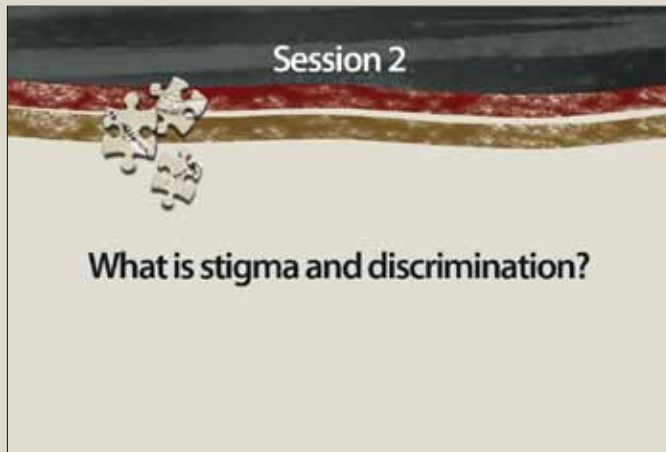
Hepatitis B In 2010 an estimated 170 000 people were living in Australia with hepatitis B infection (Kirby, 2012)

Hepatitis C An estimated 221 000 people were living in Australia with chronic hepatitis C infection, including 48 000 with moderate to **severe liver disease** (Kirby, 2012)

Session 2



Session 2: What is stigma and discrimination?



Time: 30 minutes

Resources: Workshop session plan, PowerPoint slides, projector & screen, computer, whiteboard (plus marker pens), butcher's paper, marker pens (various colours), paper and pens.

Handouts:

1. Stigma, Discrimination and Micro-Aggressions
2. The Social History of Drug Use
3. Continuum of Drug use
4. Zinberg's Interactive Model of Drug Use
5. Sterilising of Junkies May Seem Harsh, But it Does Make Sense
6. International Harm Reduction Association and Others and the 'Irish Independent'
7. International Network of People Who Use Drugs (INPUD) Statement and Position Paper on Language, Identity, Inclusively and Discrimination

Objectives:

- Participants will gain an understanding of drug use and how it is viewed by society.
- Participants will gain an understanding and learn to recognize the language, behaviours and/or actions which contribute to stigma and discrimination.
- Participants will gain an understanding of the definitions of stigma, discrimination and the difference between the two.
- Participants will gain an understanding of what stigma and discrimination is, how it happens and how to recognise when and where it occurs.

Session 2



What is stigma and discrimination?

Slide: Rules of this Workshop Program



Slide Purpose: This activity is designed to allow participants to gain some insight into the experiences of many people on pharmacotherapy programs. How they experience rules and regulations being imposed on them without any consultation or flexibility for individual circumstances. In addition the activity aims to encourage participants to consider the rules their own health service may have in place and the impact of these types of rules on their clients or patients.

Trainers Notes:

- At commencement of this section of the workshop, inform the group that a set of 'rules' have been devised to ensure the training program runs smoothly and effectively.
- Show the group the 'rules'. Ask participants how they feel about these 'rules'—some of the usual responses might be; the rules are unfair; they are too rigid, we're not children, etc.

- Ask the group what do the rules suggest about the type of people who require such rigid rules? What characteristics can be determined from them? For instance, are these people unable to meet appointments, are they often late, are they argumentative and, can they be trusted? How do you think it will make them feel about themselves? Often when we are placed in a 'box' (lumped in with others with no individual traits, needs or attributes taken into consideration) we often feel worthless.
- Ask participants would they be likely to follow the rules? Why? Why not? Would they prefer to be involved in the rule making?

NB: If participants are taking the 'rules' seriously, inform the group that the rules are not 'real': these "rules" are for demonstrating a point.

Inform the group that these rules are similar to the rules of some health care settings, such as many pharmacotherapy programs.



Rules of this Workshop Program

- 1 You will be refused admission if you return late from breaks
- 2 If you leave the room more than 3 times, you will be excluded from the whole program
- 3 If you miss more than 10 minutes you will be removed from the program
- 4 Mobile phones will not be allowed within the room **AT ANY TIME**. Failure to comply will result in confiscation and/or your removal from the program
- 5 Your belongings may be searched for any reason by the facilitator
- 6 You must not ask for these rules to be modified or changed to suit personal circumstances
- 7 If you do not like the rules, you don't have to stay

Slide: Opiate Substitution Treatment (OST)—Rules of this Workshop program



Slide Purpose: Participants will gain an understanding of the strict, ridged rules that are generally associated with OST; often created without any consultation with those they affect. The rules and regulations of OST programs throughout Australia are similar to the 'proposed rules' that have just been discussed.

Trainers Notes:

For example:

- 1) Some pharmacotherapy programs operate between specific times: if a client is late they are refused admission.
- 2) If a client doesn't attend for three consecutive days they may be excluded from the program, must repeat admission procedures and lose any privileges they may have had.

- 3) In many programs, rules are never modified or changed to suit personal circumstance such as work and/or childcare commitments or unexpected events – funerals, illness or accidents.
- 4) If a client believes the rules to be inappropriate there is often no avenue for recourse: if you can't abide by the rules then you can find another program.

Facilitate a discussion with the group bearing in mind the rules their own health service may already have in place and keeping in mind the following issues:

- How might clients feel about these restrictive rules?
- Are they likely to comply with these rules?
- How might these rules influence a client's behaviour at a health care service?
- What happens when a client breaks the rules?
- How are 'rule breaking' clients perceived?
- How might these ridge rules impact on individuals?
- What feelings might these type of rules raise for clients?

It is reasonable to suggest to the group that they should consider that in many cases, a client is judged for their non-compliance with rules rather than evaluating if the rules themselves are fair, equitable and take into account the needs of stigmatised individuals.

Make the point that many people on OST are just ordinary people with lives, children, jobs, commitments, life events etc. however, extreme stigma and discrimination often means they are not given the same sorts of considerations, flexibilities or seen as being 'like' other health service consumers. Many OST program rules tend to label everyone with the same assumed negative behaviours; that all consumers are unreliable, liars, thieves, and generally can't be trusted.

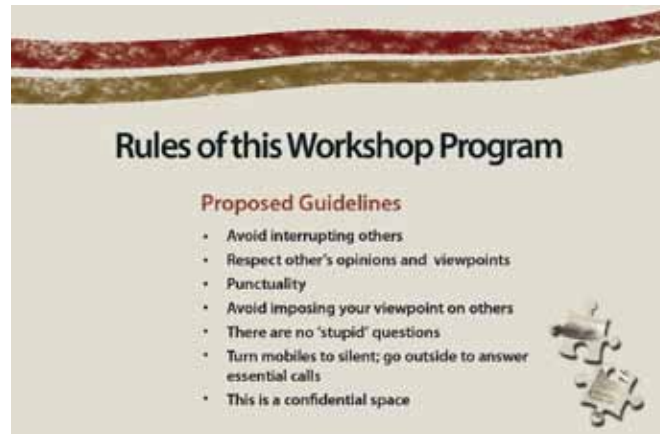
Rules of this Workshop Program

Opiate Substitution Treatment (OST) — Program Rules

- 1 Service operational hours and punctuality
- 2 Missed doses
- 3 Inflexibility
- 4 Lack of complaint mechanisms



Slide: Proposed Guidelines—Rules of this Workshop Program



Slide Purpose: To give the group the opportunity to set their own 'guidelines' for the training workshop; the guidelines proposed in the slide are a reasonable model.

Trainer Notes:

- Briefly go through each dot point, and ask the group if they have anything to add to the guidelines.
- You may wish to have a prepared copy of these guidelines on butchers' paper to display for the remainder of the workshop. These can be added to and/or referred to if guidelines are not being met.
- If you prefer not to use the above guidelines, you can remove the slide and do a quick exercise with the group using a whiteboard or flip-chart to brainstorm and agree on a customised set of guidelines for the group. (This brainstorming of guidelines will need to be planned for and extra time allocated to the workshop).

Rules of this Workshop Program

Proposed Guidelines

- Avoid interrupting others
- Respect other's opinions and viewpoints
- Punctuality
- Avoid imposing your viewpoint on others
- There are no 'stupid' questions
- Turn mobiles to silent; go outside to answer essential calls
- This is a confidential space



Slide: Social Ways of Looking at Drug Use



Slide Purpose: The slide demonstrates to participants the various ways in which drug use and drug users have socially and historically been portrayed.

Trainers Notes: Explain to the group that over time, injecting drug use and drug dependence has been understood in a variety of ways. Unfortunately many people consider PWID as evil or bad.

Emphasize to participants that the way in which drug use and drug dependence is understood by a society will impact on the way in which PWID are treated in society. The theories of how drug use is viewed, has influenced how society manages the 'condition'. If drug users are possessed by evil spirits, then lock them up. If it's lack of morals; control them. If it's a disease; find a cure for them!

- **The evil spirits concept**—The demon example shows how society has viewed the causes of illicit drug use: "demons cause it... being possessed by demons" The taking of drugs and drug 'addiction' is caused by evil spirits and/or demons entering the body and taking over.

Currently, this concept manifests through the treatment of highly troubled people and the practice of 'trepanning'—drilling holes in the heads to let the evil spirits out. This practice is still performed by 'narcologists' in Russia, with a view to excise a particular part of the brain believed to be responsible for addiction. In the concept, the problem is perceived as coming from outside the individual.

- **The moral model**—The moral model views addiction as the result of human weakness, and/or as defects of character. Those who support this model tend not to accept that there is any biological basis for addiction. They often have scant sympathy for people with serious addictions, believing either that a person with greater moral character could have the strength of will to break an addiction, or that the addict demonstrated a great moral failure in the first place by starting the addiction.

People are believed to develop problematic behaviours as a result of moral/spiritual 'impurity'. They are thought to require church/religious attendance and education. Within this concept the problem comes from inside, or within the individual. Australian examples using this model include some 12-step programs, some of which have compulsory Church attendance or an overt religious or spiritual requirement as a condition of accessing the program.

- **The disease model**—a vestige of the moral model, the concept also puts the problem inside the individual. The disease model holds that addiction is a disease, coming about as a result of either the impairment of neurochemical or behavioural processes, or of some combination of the two. The belief is the people who have that disease are 'addicts'. The issue lies in the fact that with other 'diseases' there is a cause, symptoms and often treatment, however in relation to PWID, what is the

problem/ can the cause of the disease be located within the body? Probably not. It is not as simple as telling an 'addict' to "just say no".

The disease model is the most common model used in contemporary Australia, and it is compulsory in many abstinence-only, pharmacotherapy, gaol treatment and support programs.

- **Addiction**—the term appears to be a recently coined phrase, not entering the English language until the early 20th century. The earliest use of its application appears to be racially motivated; firstly pertaining to cocaine use amongst the southern black Americans, then through the use of opium amongst Chinese Americans. Soon after the passage of the Harrison Narcotic Act in the US in 1914, the non-medical use of heroin and morphine was referred to as 'drug abuse' and drug users as 'addicts'.
- **Drug abuse (dependence)**—the concept then altered to be a medical problem/issue. Converting a 'bad' personal habit to become a physiological disorder brings it into the domain of medical intervention, for instance; methadone maintenance, nicotine patches, psych medications, naltrexone implants and 'anti-abuse' medications.

These are just a few of the ways in which drug use has been portrayed over time: The way in which drug use and drug users are viewed does not occur in a vacuum, they are social and cultural constructs. Irrespective of how drug use is viewed it is important to note that it is always in flux; changing over time and across cultures; changing both at the societal and individual level and also in relation to the particular drug(s) being used.



Social Ways of Looking at Drug Use

The evil spirits concept individual is possessed by demons; the problem comes from outside the individual. For example the '*demon drink*'

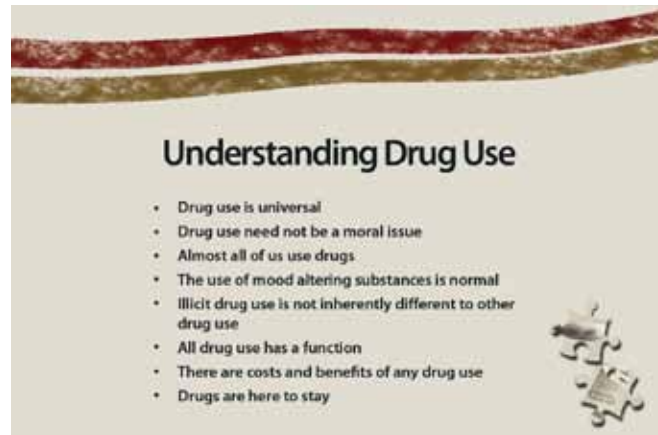
The moral model the result of moral/spiritual impurity, the problem comes from within the individual

The disease model drug use is a disease and the people who have it are 'addicts'

'Addiction' from the Latin root 'adictus' meaning 'state proclaim or bind'

'Drug abuse' (dependence)—Drug abuse (dependence) seen as a medical problem at the beginning of the 20th century with significant consequences

Slide: Understanding Drug Use



Slide Purpose: The aim of this slide is to give participants a broad appreciation of drug use in contemporary society.

Trainers Notes:

- **Drug use is universal:** Drugs and drug use are ubiquitous; the drug and the pattern of use may change over time but drug use remains part of the human condition. It changes at a societal and individual level, whereby attitudes to certain drugs may change and whereby individuals themselves change; moving in and out of drug use. What remains static is that drugs and their use have always been an aspect of all cultures.
- **Drug use need not be a moral issue:** Drug use itself is neither 'good' nor 'bad'; rather it is an individual choice and behaviour.
- **Almost all of us use drugs and many use illicit drugs:** The National Drug Strategy Household Survey shows that about 2 in 5 people in Australia (39.8%) had used an illicit drug at some point in their lifetime in 2010 (AIHW, 2010a)

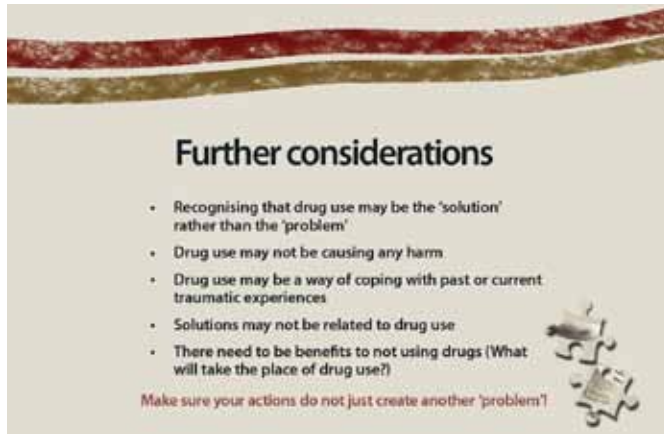
- **The use of mind altering substances is 'normal':** It is the majority rather than the minority who choose to partake in mind-altering substances, whether that is chocolate, alcohol, coffee or cigarettes.
- **Illicit drug use is not inherently different to other drug use:** What is illegal in one country is often legal in another. Over time different drugs, in various countries have moved in and out of criminal sanctioning.
- **Drug use has a function:** Regardless of how others may perceive an individuals' drug use, all drug use has a purpose, for instance; for religious ceremonies, 'rites of passage', to alter consciousness, to enhance or change mood, to overcome stress, as part of a social activity or for a combination of reasons.
- **There are costs and benefits of any drug use:** Alongside the function and effects of drug use; be they physical, emotional, spiritual, mental/psychological or social. Drug use has associated costs, such as; negative health consequences (physical or mental), overindulgence leading to economic impairment and social isolation. The benefits can be being a feeling of pleasure, being part of a social activity, stress release to name a few.
- **Drugs are here to stay:** As suggested above, drug use and even certain types of drugs can move in and out of social acceptance and rejection but regardless of how society views them, history has proven that they continue to be used.

Understanding Drug Use

- Drug use is universal
- Drug use need not be a moral issue
- Almost all of us use drugs
- The use of mood altering substances is normal
- Illicit drug use is not inherently different to other drug use
- All drug use has a function
- There are costs and benefits of any drug use
- Drugs are here to stay



Slide: Understanding Drug Use—Further considerations



Slide Purpose: The aim of this slide is to both support further discussion on drug use in contemporary society by raising the suggestion; drug use may not be a 'problem' nor 'the' problem, however drug-related stigma is definitely a problem. The aim then is to show that while often drug use is seen as a 'problem', it needs to be viewed in context—if it's a 'problem', how bad a 'problem' is it? Whose 'problem' is it? In order to address stigma and discrimination towards PWID we need to get beyond seeing drug use as a 'problem'.

Trainers Notes: It may be hard, even among service providers who are familiar with PWID and their stigma-related issues to recognize that injecting drugs can be the lesser of evils—and/or can actually be helpful.

Recognising that drug use may be the 'solution' rather than the 'problem': If someone is using drugs—illicit or licit—there may be an underlying medical issue, which may be physical and/or psychological. It may be that their drug use is 'self-medicating' the drug user finds their drug use is addressing the issue and that the drug use itself is not causing any harm, nor having any adverse consequences at all.

Drug use may be a way of coping with past or current traumatic experiences: While some PWID do not use drugs for any reason other than their personal pleasure and what the drug gives them, there are others who use drugs to cope with personal or societal pressures. As one PWID states:

"I'd be dead if I didn't use drugs, I'd be dead if I stopped, they make me able to cope with life." (John, amphetamine user, AIVL 2012)

There may be times in anyone's life where they don't have the skills to cope with their current circumstances and drugs are used as a way of 'de-stressing'. Drugs may be used, not necessarily as a means to 'get out of it', but as a short escape—a little holiday away from negativity.

Solutions may not be related to drug use: Solutions are only related to drug use if and when the problem is drug use. For example; a PWID attends a service in severe pain, the individual has been taking illicitly obtained pharmaceutical opiates. The issue is pain and pain-management; therefore the solution might be a combination of referral to a pain-management clinic and/or a prescription for pharmaceutical opiates.

There need to be benefits to not using drugs: If drug use is not a 'problem', if drug use acts as a 'solution to a problem', or if drug is not causing adverse harm or consequences, what are the benefits of taking drug use out of the equation? What will take the place of drug use?

Make sure your actions do not just create another 'problem'!

The argument can be made that drug-related stigma is often **more damaging than the actual drugs**. That is not to diminish that harms associated with drug use, however stigma means there is no honest dialogue about drugs, that PWID may be forced to hide their use or feel ashamed, isolated and cut off from help.

In any discussion about drug use in contemporary society there are always going to be some considerations—aside from those mentioned above that need to be addressed.

- 'Optional extra'
- Quotation;
 - Understanding drug use;
If they took all the drugs...
- This quotation can be added to prompt further discussion.

'Optional Extra'

'If they took all the drugs...': This quotation by Dick Gregory, an American comedian, social activist, social critic, writer, and entrepreneur can be used to stimulate a discussion on the role and meaning of people's vices in today's society.

Refer to 'optional extra' card for more information.

Further considerations

- Recognising that drug use may be the 'solution' rather than the 'problem'
- Drug use may not be causing any harm
- Drug use may be a way of coping with past or current traumatic experiences
- Solutions may not be related to drug use
- There need to be benefits to not using drugs (What will take the place of drug use?)

Make sure your actions do not just create another 'problem'!



Slide: Language and PWID—Language used to describe drug users



Slide Purpose: This slide explores how language can be used to stigmatise and discriminate against PWID. The simple use of language can have a powerful effect on influencing others and impact on how PWID are seen in society. Language can be used to denigrate, disempower or give offence, but it can also be used to empower and be inclusive.

Trainers Notes: The following describes the power of language and how it is used to influence the way PWID feel about themselves and how they are treated in society. Simple words can have certain connotations and be used negatively whether by intention or by mistake. PWID are often subjected to language which disempowers them and separates them from society.

The way in which drug use and language is used influences the way PWID feel about themselves and how they are treated in society.

- **The power of language:** Language can be incredibly powerful, it also needs to be taken in context. It is one thing to be called a 'junkie' by a member of one's own community—potentially creating a sense of belonging among one's own highly marginalised community—but

when it is used by society as a whole it becomes negative and denigrating—with associated connotations of uselessness, perversion and criminal intent.

- **Language use and stigma:** Language is used to stigmatise and discriminate—to ensure the drug user is disempowered and disengaged from the 'rest of society': Language used to refer to PWID sets up an 'us' and 'them' and a 'good'/'bad' divide.
- **Language of contamination and contagion:** Drug use when labelled as a disease, and drug users as 'dirty' or 'unclean', by extension then suggests that non-users are clean and disease free. PWID are often viewed as 'contagious'—and it is this very concept that lies at the bottom of many community members' fears—that drug use is a disease, that it is contagious (one can 'catch it') and that by association one can be contaminated.

However, it is not just drug use which the general community is fearful of 'catching', it is also disease(s)—BBVs; the general community believes PWID and disease cannot be separated.

- **Disease, illness and 'cure':** When language associated with disease and contagion is used in relation to PWID it suggests that they are 'sick' and therefore need to be 'cured'—they have the potential to 'recover from their illness'—that they can 'come back' into society (as long as they cease drug use and embrace abstinence). These concepts suggest that PWID, on commencing the use of drugs, stopped being part of the general community and subsequently that there is little or no societal contribution or value from current drug users.
- **Language and shame:** If you are constantly named and labelled in negative terms: useless, filthy, criminal or sick, you come to believe that this is as it should be, that these labels are warranted because you use drugs and therefore have something 'wrong' with you. Something you should be ashamed of.
- **Language and the media:** Internationally and in Australia the mass media in all its forms; television, magazines,

newspapers, film, radio etc. are all immensely influential and powerful. Unfortunately the media plays an enormous role in the negative portrayal of drug users and are responsible for perpetuating the stereotypical view of drug users. Often the language used to discuss and/or describe drug users is done with contempt and from a negative perspective. The negative language conjures up images of drug users as people who are unemployed, dole bludgers, thieves, liars, filthy junkies etc. PWID are a vulnerable target, and are often used to make a substandard story into a sensationalised one. When television, newspapers and magazines use such negative language they are reinforcing the stigmatised images and behaviours of drug users to large audiences. The general public accept what the media says. Taking on board and accepting the labels and stereotypes promoted relentlessly in the media.

Ask participants what they believe the impact of negative language will have on PWID? The end result is stigma and discrimination.

- 'Optional extra'
- Media article;
- - Media and the language used to portray drug users
- Can be added here

'Optional Extra'

Media and language used to portray drug users:

This additional information on the media and its use of language to describe PWID can be used to expand on the discussion on language and PWID. The media via films, television, newspapers, magazines etc. play a powerful influential role in perpetuating the stereotypes of drug users. The participant handout 'Sterilizing junkies may seem harsh, but it makes sense' is drawn upon to demonstrate how extreme the media can be.

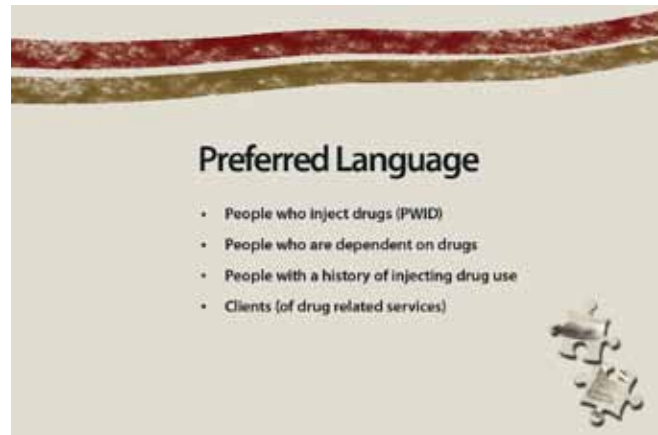
Refer to 'optional extra' card for more information.

Language and PWID

- The power of language
- Language use and stigma
- Language of contamination and contagion
- Disease, illness and 'cure'
- Language and shame
- Language and the media



Slide: Preferred Language



Slide Purpose: This slide aims to demonstrate the preferred language used to describe people who use drugs and to raise awareness that language, and particularly the terms used to name and/or describe an individual or group, are powerful and carry weighty connotations about that individual or group's persona or characteristics.

Trainers Notes:

N.B: This is not intended to initiate discussion on who is 'better' or 'worse' or current versus ex-drug users.

The power of language cannot be underrated: Words convey an incredible amount of meaning, to the extent that they can be damaging and detrimental to a person's identity and self-worth. In contrast, words can empower, they can give an individual a sense of value and they can establish a sense of belonging and 'community'.

Terminology has changed over time and throughout history—it continues to evolve just as all language does. While terminology related to PWID has developed, it also reflects how an individual sees themselves and how they are perceived by the community.

It is the responsibility of the individual to choose the words they utter and how they are spoken—to use stigmatizing or empowering language. Changes in the terminology reflective of drug users have largely come about through the work of DUOs specifically aimed at challenging stigma and discrimination.

Have the group reflect on the differing connotations associated with the following terms—terms which can quite easily be replaced by neutral and un-stigmatising language:

- 'junkies', 'substance abuses', 'drug abuses', 'druggies' versus People who inject drugs (PWID);
- 'smack heads', 'drug addicts', 'addict' **versus** People who are dependent on drugs;
- 'ex-user', 'ex-junky', 'recovering addict', 'clean', **versus** People with a history of injecting drug use;
- 'those people', 'done-heads', 'methadonians', 'them people' **versus** Clients (of drug related services).

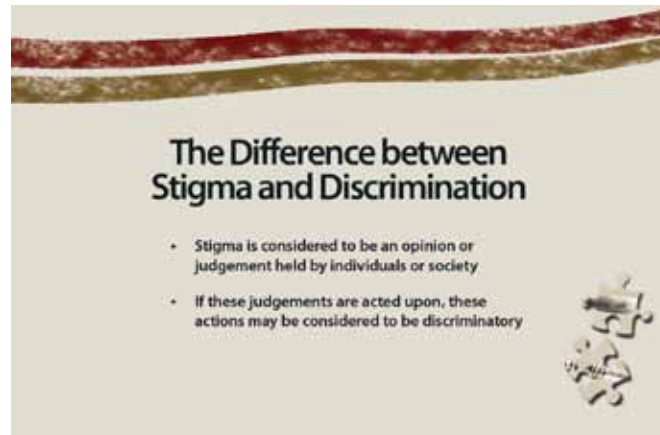
Wrap up this session by asking participants to honestly suggest when it might be appropriate to use these negative terms in professional practice.

Preferred Language

- People who inject drugs (PWID)
- People who are dependent on drugs
- People with a history of injecting drug use
- Clients (of drug related services)



Slide: The difference between stigma and discrimination



Slide Purpose: To differentiate between stigma and discrimination.

Trainers Notes:

- AIVL suggests—in short—that stigma is the thought, and discrimination is the ensuing action or outcome. Stigma and the resulting discrimination against the PWID do not exist in a vacuum, a number of complex and interrelated factors feed into the practice and a number of players act in concert to stigmatise PWID.
- In Australian society the media often portrays unrealistic and pejorative images and language in relation to PWID which result in unreal and unreflective stereotypes. These stereotypes are taken up and presumed as the only 'true' representations by many in society, and PWID become the subjects of discriminatory practices.

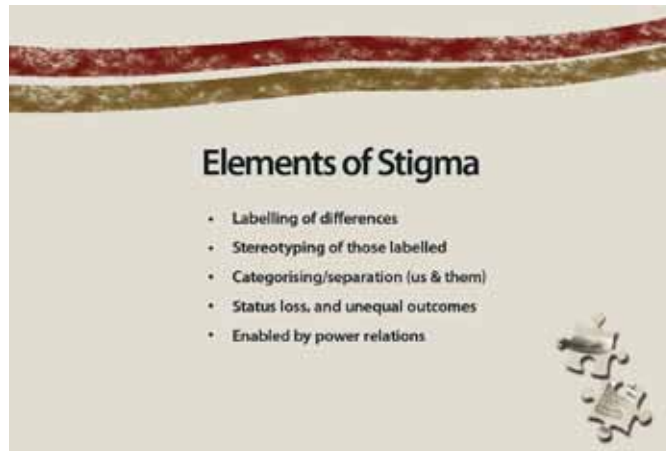


The Difference between Stigma and Discrimination

- Stigma is considered to be an opinion or judgement held by individuals or society
- If these judgements are acted upon, these actions may be considered to be discriminatory



Slide: Elements of Stigma



Slide Purpose: To give a definition of stigma, and the elements which are at its core in relation to PWID, people on pharmacotherapy programs and people with hepatitis C and/or other BBVs.

Trainers Notes: Stigma can be defined as the denigration of individuals or groups based on negative connotations associated with stereotypes. For instance: some people believe that all PWID are likely to steal or commit crime to support their drug use and therefore closely scrutinized or treated differently to others.

Some people do commit crimes to support their drug use but the problem is that this is then used to claim or assume that all people do this and it is used as an excuse to stigmatise and discriminate against all PWID. People who commit crimes come from all different backgrounds and the reasons behind why people commit crime are many and varied, it is no different when it comes to PWID.

Most contemporary social theorists share the belief that stigma is the collective sanctioning of a group as 'other' or separated from the norm—it is an acknowledgement of social rejection and social exclusion. PWID practices (using illicit drugs and associated behaviours) are discredited by society which in turn leads to stereotypes and stigmatization of individuals who participate in those discredited behaviours or are presumed to participate in such behaviours.

- **Labeling of differences:** PWID are labeled as 'different from the norm'; they are perceived as being involved in negative practices and marginalized. They are perceived to be unlike 'normal' people or different from the majority of people in society.
- **Stereotyping of those labeled:** The stereotyping of PWID perceives them all to be dressed in dirty clothes, are unwashed and smelly. PWID are labeled as 'filth' 'junkies', 'thieves' and 'liars'. The fact is that the image of the stereotypical drug user is also the same as the extreme images normally portrayed in the media (news bulletins, movies etc.)

The most visible drug users in society are usually street based drug users who are experiencing a range of complex issues, not necessarily based solely on drug use. Rather, the problems are often linked to housing, mental health, trauma, poverty, family breakdown and lack of support and it is for these reasons that they are highly visible. Not all drug users are like this or fit this image. Drug users come from every corner of society, but it tends to be this chaotic stereotype which all drug users are seen and deemed to be. It is not to say that chaotic drug use doesn't exist, but it is a minority of people that experience this kind of drug use and it should not be used to stereotype all drug users. This group of PWID is the most vulnerable and marginalised and in need of compassion and support, not vilification and discrimination.

- **Categorising/separation (us & them):** 'junkies' are perceived as 'bad' and therefore as 'other'. 'They' need to be kept separate from the rest of society so that the chance of contamination is limited.

- **Status loss and unequal outcomes:** Once categorised as a 'junky', some PWID are seen as lower in social hierarchies and subsequently don't have the same opportunities. To give an example of status loss could be of an employee who is well-respected and in a position of responsibility who is then found out to be a user of drugs. Subsequently all their actions and behaviours are seen as a reflection of them as a 'junky' and respect and responsibility are withdrawn or denied.

To give an example of unequal outcomes; two individuals who are regular patients at a doctor's clinic, require an appointment for the following day and speak with the receptionist. The receptionist gives the 'known' drug user, the answer that no appointments are available for that day, but tells the other individual that there is an appointment available that they can have, which they generally leave open for emergencies.

- **Enabled by power relations:** Power within society and power relations are a complex phenomenon which include cultural, social, religious, economic components. In order for unequal power relations to occur and for stigma to arise, society must encourage certain behaviours which are viewed more positively. Individuals or groups within these social structures have different degrees of power which are based on multiple characteristics and social status; i.e. which results in different types of employment blue collar/white collar and access to education. People higher up within society's hierarchy, have an invested interest to keep the status quo, and maintain their power position.

Power relations and an individual's standing can change depending on the context. For example an individual injecting drug user may be viewed as 'scum' within the family context, however that same individual may be well-regarded and given a measure of respect within their drug user network.

These social processes create and/or perpetuate social inequities and are used to legitimize discrimination.

Elements of Stigma

- Labelling of differences
- Stereotyping of those labelled
- Categorising/separation (us & them)
- Status loss, and unequal outcomes
- Enabled by power relations



Slide: The Functions of Stigma



Slide Purpose: All stigma has a purpose or function, whether it is positive or negative. This slide deals with the functions of stigma as perpetrated on PWID, people on pharmacotherapy programs and people with hepatitis C and/or other BBVs.

Trainers Notes: The functions listed above have been identified by the Harm Reduction Coalition (an American advocacy and capacity-building organisation promoting the health and dignity of individuals and communities impacted by drug use), through AIVL's market research on stigma and discrimination, and arising through development of AIVL's discussion paper: 'Why Wouldn't I Discriminate Against All of Them': A Report on Stigma and Discrimination towards the Injecting Drug User Community'.

It is also important to note that one of the main objectives of the *Third National Hepatitis C Strategy 2010–2013* is reducing stigma and discrimination in health care settings.

- **Difference:** Stigma is about setting the boundaries of what is deemed to be 'acceptable behaviour'. By creating an 'in' group and 'out/other' group, stigma can be seen as a deterrent to engaging in socially unacceptable behaviours.

This function of stigma is strongly linked to morals, values and social norms, emphasising personal choice at the root; in that people who engage in certain behaviours bring related treatment upon themselves. There is a perception that PWID choose to engage in 'bad' behaviours that put themselves and potentially others at risk and so the consequences for their behaviour are 'one's own fault' and 'worse', impact negatively on others in the community.

- **Danger:** Stigma is used to keep people who are perceived as dangerous/infectious away and to discourage people from engaging in behaviours that could lead to disease or contamination. This can be exemplified well in relation to PWID living with hepatitis C and other BBVs—they are often perceived as contaminated—by their drug use and virus—and association (physical or social) might put 'good' people at risk.
- **Discrimination:** Stigma can be used to legitimize discrimination. It is important to acknowledge that people might quite genuinely think they are doing the 'right thing' by the rest of the community by viewing some behaviours and actions as dangerous (to themselves and others) and that the people engaged in such behaviours do so at their own risk. However, stigma and discrimination against certain behaviours or people might not result in the positive outcomes they envisage. For example, drug users may not access health services as a result of how they are treated or perceived by staff. The consequences of this is that it actually costs society more (not only economically) in the long run.
- **Economic:** There is a school of thought that believes that stigma has an economic purpose in that resources are limited (for instance access to health services, housing, and employment) and by stigmatising 'others' distribution of these resources can be controlled. There are however many strategies for managing health resources and as a society we should ask ourselves whether discriminating against an already highly marginalised group is the most effective, ethical and humane way to manage this issue.

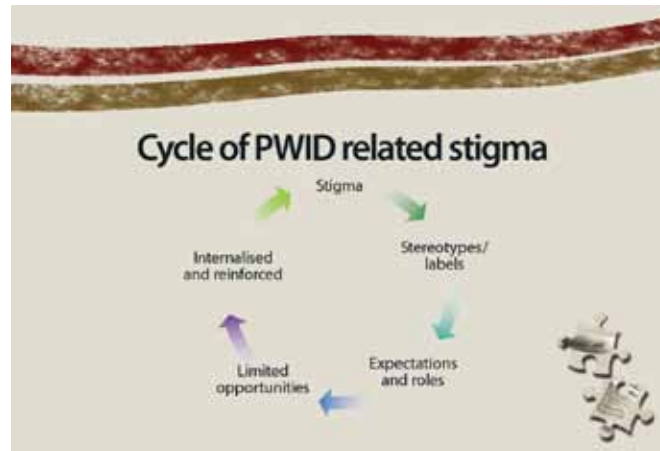
- **Stop behaviours:** AIVL's market research found that members of the general community felt that if PWID are stigmatised—enough and often enough—they will cease their use of illegal drugs. The problem with this school of thought is that in reality this does not occur, and PWID (those who aren't already 'hidden') become hidden—subsequently putting themselves at more risk.
- **Discourage uptake of behaviours:** Similar to stopping behaviours, AIVL's market research found that there are some who believe that by stigmatising PWID, non-users would see that PWID are the 'other', stigmatised, and would thereby be discouraged from taking up the behaviour. The problem with this school of thought is that stigma does not necessarily discourage individuals from taking up drug use, it simply creates a taboo subject, and generates an environment wherein even discussing related issues is seen as negative. In Australian society, drug use is such a taboo subject that our younger people are not educated about illicit drug use and any potentially associated harms, then, if and when they do come into contact with illicit drugs they are ill-equipped to make informed decisions. This can result in people contracting preventable infections such as hepatitis B and C, HIV, accidentally overdosing or experiencing other unnecessary harms.
- **Enhance the stigmatiser's own self-identity or self-esteem:** Unfortunately we live in a society wherein many of us require someone to acknowledge as 'beneath' us. This gives them someone to blame or someone to bully and the justification to say "at least I am not like them". By nature there is a pecking order or hierarchy within society. When one stigmatises another it can often make that person feel better about themselves. An example of this can be seen within the drug using community; with non-injectors often saying "at least I'm not a junky". PWID are seen as the perfect scapegoat because the illegality of injecting drug use is used by many, particularly the media to drive the general public to view all PWID as dangerous, selfish, criminals who should be in gaol and forced to quit.

The Functions of Stigma

- **Difference**—keep people out
- **Danger**—keep people away
- **Discrimination**—keep people down
- **Economic**
- **Stop behaviours**
- **Discourage uptake of behaviours**
- **Enhance the stigmatiser's own self-identity or self-esteem**



Slide: Cycle of PWID related stigma



Slide Purpose: The objective of this slide is to demonstrate how stigma is cyclical in nature; it is reinforced by community expectations and then internalized by PWID.

Trainers Notes: As we know PWID experience stigma on a regular basis. The labels and stereotypes experienced by PWID are often based on unsubstantiated perceptions. This diagram demonstrates that PWID related stigma is cyclic in nature: starting with stigma leading to a sequence of events, from one factor to the next, until coming full circle and then being propelled into a repeating cycle going around again and again.

The creation of stereotypes based on labels (such as PWID are dirty or dishonest) creates an expectation from both the general community (of PWID's actions and behaviours) and on the stigmatized how PWID believe they will be treated). If the community perceive PWID to be dishonest and unreliable, then PWID subsequently will expect to be treated as such. Any negatively perceived action or consequence is afforded to drug use or is believed to be because the individual is a drug user. For example; an individual PWID missed the bus, therefore they are perceived to be unreliable,

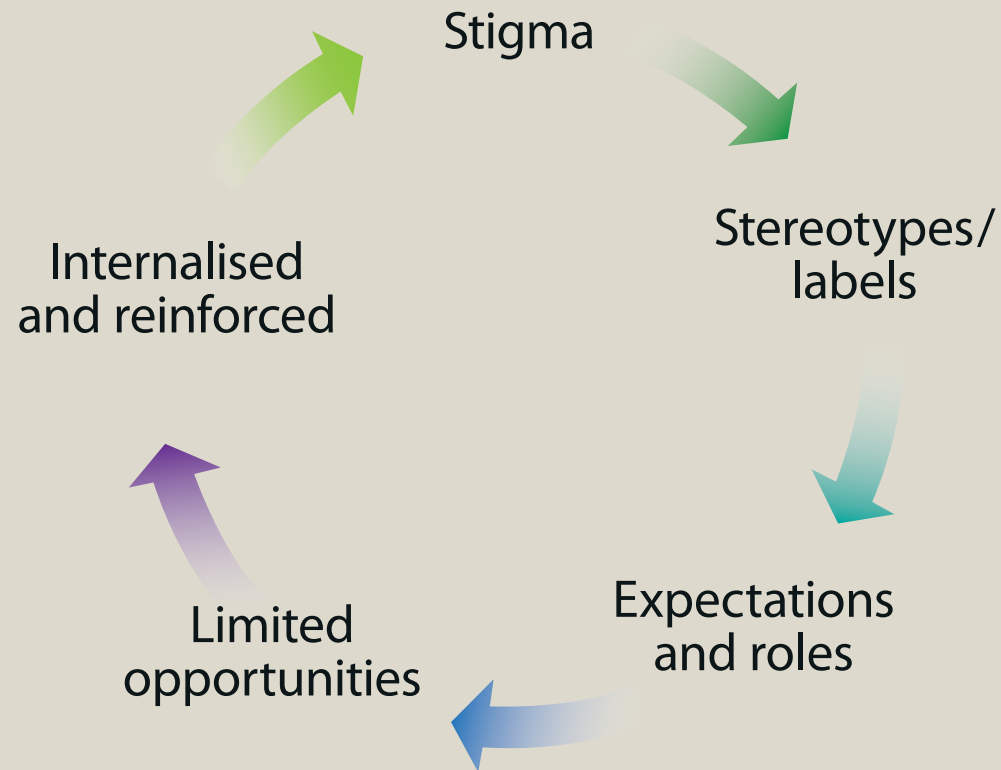
they being late is blamed on their being an 'unreliable junky'—not the bus being early, or not turning up at all, etc.

If someone is seen as unreliable and untrustworthy they are not going to be given opportunities, or will only be accorded very limited opportunities. Limited opportunities leave PWID no avenues to build self-esteem, prove they are trustworthy and it limits their choice and prospects of achievement and life improvement; including access to successful health outcomes.

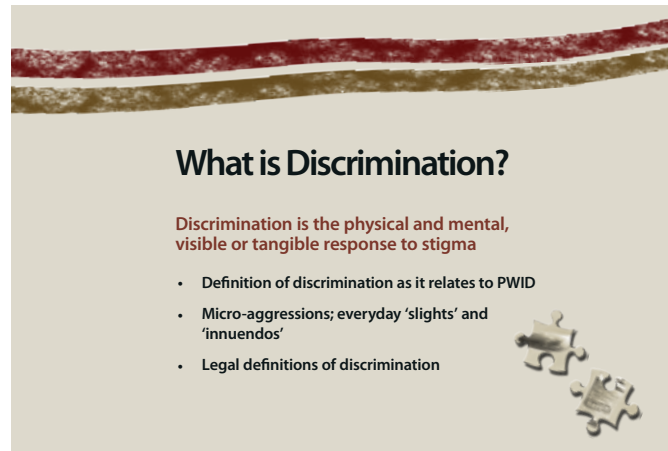
Some of the most harmful effects of stigma occur when it creates a negative self-perception. Internalized stigma is the self-acceptance of others' prejudiced views or stereotypes. This can lead to social withdrawal, a poor sense of self-worth and subsequently reluctance to seek treatment as it is seen as undeserved.

This acceptance of negative self-image leads to propelling the cycle of stigma to repeat itself again and again.

Cycle of PWID related stigma




Slide: What is discrimination?



What is Discrimination?

Discrimination is the physical and mental, visible or tangible response to stigma

- Definition of discrimination as it relates to PWID
- Micro-aggressions; everyday 'slights' and 'innuendos'
- Legal definitions of discrimination



Slide Purpose: To provide a definition of discrimination, as a result of stigma in relation to PWID, people on pharmacotherapy programs and people with hepatitis C and/or other BBVs. To clarify the difference between some forms of discrimination which are illegal, compared to discrimination based solely on someone's drug use, which may or may not meet 'discrimination' as defined in the various relevant legislation.

Trainers Notes:

- **Definition:** Discrimination is the action resulting from stigma—it is unjust or unequal treatment and outcomes based on an individual's real or perceived behaviours (in this case drug use).
- **Definition of discrimination as it relates to PWID:** Many PWID have become very use to episodes of stigma and discrimination. While they may not be in a direct position to label every disparaging look, act or negative gesture as discriminatory, they become so attuned to this treatment, and so use to it that the slightest action (real or perceived/intentional or not) is felt to be about their drug using status. Being served last at a pharmacy, or being followed by security guards in a store, can be viewed by

PWID as negative treatment based on their status as a drug user. The low hierarchy status of being a drug user makes way for such discriminatory treatment to occur. Being thought by a physician to be mis-representing their pain or symptoms is also another example of how the above discriminatory treatment occurs in practice.

Discriminatory behaviours take many forms, but all involve some form of slight, exclusion or rejection.

It is often difficult for PWID living with hepatitis C and/or other BBVs to differentiate discrimination based on drug use as opposed to their BBV status. For example, many PWID report that they have told medical practitioners that they are living with hepatitis C. They have then been assumed to be a drug user (with the associated connotations) and are treated negatively or differently to how they had been treated prior to their disclosure.

"Injecting drug users experience so much discrimination anyway that hep C is just another layer. They might not even realise that they are being discriminated against on that basis because for them it's about being a user." (DUO Representative)

- **Micro-aggressions:** Such practices are so common, researchers have labeled these 'small' everyday actions as 'micro-aggressions' and build up over time to such an extent that PWID believe that any slight, look or inappropriate comment is directed at them due to being perceived or known to be someone who does, or has injected drugs.

"...every time I walk down the street women clutch their handbags tightly under their arms, or cross the road to avoid me...I've never committed a crime, let alone been to gaol..." (Ben, PWID)

These micro-aggressions work over time to significantly affect people's self-esteem, sense of self-worth and levels of self-confidence. This happens because these micro-aggressions can seem so small and trivial that to raise them at all is often met with claims that people are 'over reacting', being 'overly sensitive', and 'paranoid', 'self-

deluded' or just plain 'wrong'. Being subjected to such treatment, particularly over long periods of time, not only acts as a way to silence people, but often also results in people becoming complicit in their own stigmatization and discrimination. People start to believe they are 'the problem' not the way they are being treated or the system around them. So no-one ever thinks they have the right to complain. No-one ever does complain. The systemic nature of the practice remains invisible and therefore continues unchecked.

- **Legal definitions of discrimination:** apply to the work context, denying access to education, accommodation, entry to premises, membership of a club or association, gender, race, medical condition, disability or the provision of services. However, it is not necessarily illegal to discriminate against PWID on the basis of drug use alone. Under anti-discrimination law it is illegal to discriminate against a person on the basis of perceived or actual hepatitis C, B or HIV status. Although it may be illegal, unfortunately we know that it still happens.

- 'Optional extra'
- Quotation;
- – Why do some deserve less?
- Can be added to further the discussion on discrimination

'Optional Extra'

Why do some deserve less?: This quotation can be inserted here after discussing 'What is discrimination?' Use the quote as a prompt to get people to think about how individuals may be treated differently because of their lifestyle choices. Trainers need to anticipate that this exercise may be challenging. Opposing views could potentially be raised, which may be confronting for some within the group. Trainers need to be prepared and experienced in order to address any difficult views and/or questions that may arise.

Refer to 'optional extra' card for more information.

What is Discrimination?

Discrimination is the physical and mental, visible or tangible response to stigma

- Definition of discrimination as it relates to PWID
- Micro-aggressions; everyday 'slights' and 'innuendos'
- Legal definitions of discrimination



Session 3



Session 3: Impact of stigma and discrimination and how they act as barriers in health care settings



Time: 40 minutes

Resources: Workshop session plan, PowerPoint slides, projector & screen, computer, whiteboard (plus marker pens), butcher's paper, marker pens (various colours).

Handouts:

1. AIVL National Reporting of Discrimination Survey Results
2. Impact of Stigma and Discrimination on Health Care Delivery to People Who Inject Drugs
3. 'Junkie' Untreated for Swine Flu
4. Doctor Rejected Dying Man as an Addict.

Objectives:

- Participants will gain an understanding of how to recognise stigma and discrimination towards PWID, people on pharmacotherapy and those with hepatitis C and/or other BBVs in health care settings.

- Participants will gain an understanding of the impact of stigma and discrimination on the health and wellbeing of PWID, people on pharmacotherapy and people with hepatitis C and/or other BBVs.
- Participants will gain an understanding of how stigma and discrimination can act as a barrier to health services and their delivery for PWID, people on pharmacotherapy and those with hepatitis C and/or other BBVs.
- Participants will have an increased knowledge of how both health care settings and health worker behaviours contribute to stigma and discrimination experienced by PWID, people on pharmacotherapy and those with hepatitis C and/or other BBVs.

Session 3



**Impact of stigma and discrimination
and how they act as barriers
in health care settings**

Slide: Stigma is a Real Barrier to Health Service Provision



Slide Purpose: To demonstrate how stigma and discrimination act as barriers to access to health service provision for PWID, people on pharmacotherapy programs and people with hepatitis C and/or other BBVs; to the extent that some will avoid seeking treatment until in crisis.

Further, to demonstrate the importance of open and honest therapeutic relationships between health service providers and PWID, as they can be hampered by stigma and discrimination, and as a consequence successful health outcomes are jeopardized.

Trainers Notes:

PWID may avoid health services rather than be seen or treated as a 'drug user': Many PWID and in particular stimulant users, don't identify as a drug user; as this means having to deal with the stereotypical labels of being a 'junkie' or 'druggie' and subsequent discrimination. So to avoid the possibility of being identified as a drug user, many will avoid health care services altogether.

For some PWID it means attempting to 'pass' as a non-user, sometimes referred to in research as 'passing'; by not acknowledging any drug use, in order to get their health/medical needs met. Hiding the visible marks and associations of drug use as much as possible are just some of things PWID might do to 'pass'. However, this can have negative consequences if their health problem/needs relate to drug use.

Stigma can be a barrier to PWID being open and honest with their health care provider: Many PWID have had personal experience of negative repercussions when they have been open and honest about their drug use. One very common example is when a person on a pharmacotherapy treatment program has their 'privileges' such as take away doses removed due to talking about current drug use (such as using heroin). This type of punitive response only creates a barrier to being open and honest.

If a patient with an abscess is fearful of being treated negatively and in a punitive way, then many will not seek treatment at all. (At least until a crisis hits, when the abscess has deteriorated to the point where they will lose a limb.) The fear of negative repercussions is not just from the health care provider themselves but can go beyond them, to child services, probation and parole.

The indignities suffered as a result of stigmatisation can prevent people who use drugs accessing health services:

The general assumption among PWID is that drug users are treated badly (or not treated at all) by many health care professionals, therefore PWID would rather not go through the pretense of seeing a health care provider for little or no outcome. Why would someone put themselves through the indignity/stress/humiliation at the risk of gain nothing?

As mentioned, the fear and concern about being discriminated against in health care settings is so real, that many will put up with any pain and discomfort until it reaches a point where they are permanently incapacitated or near death.

This quote speaks volumes:

"(He) had rectal bleeding and abdominal discomfort for some months. Everyone, all his friends and people at work, advised him to seek medical treatment...He continually demurred, saying; 'I hate the way doctors treat me!' After he finally found the courage to attend a consultation he was diagnosed with stage 4 terminal cancer and was dead in six months." (AML, 2011)

Stigma is a Real Barrier to Health Service Provision

- Many PWID will avoid health services rather than being identified as a drug user or seen as a *'druggie'* or *'junky'*
- Stigma can be a barrier to PWID being open and honest with their health care provider
- The indignities suffered as a result of stigmatisation can prevent people who use drugs accessing health services



Slide: Discrimination in the Health Care Sector

Discrimination in the Health Care Sector

- Research has shown that many people who inject drugs regularly experience negative encounters in the health sector
- Often service providers are not aware that they acting in a discriminatory manner
- ‘Micro-aggressions’ are the small slights, insults and indignities built up over time so that PWID come to believe that any ‘slight’ is based on their drug use
- Prior experiences mean that PWID **expect** to be treated unfairly and/or differently from non-drug users
- Many PWID believe that there will be negative repercussions if they make complaints

Slide Purpose: To introduce the concept that for many PWID, people on pharmacotherapy programs, people with hepatitis C and/or other BBVs, have experienced the worst and most entrenched forms of discrimination, within health care settings.

Trainer Notes:

N.B: This can be a very sensitive area for participants and some may become defensive or take personal offence as they don’t believe that they personally act in a discriminatory manner—AIVL suggest that trainers handle this topic with sensitivity and care.

Research has shown that many people who inject drugs regularly experience negative encounters in the health sector: AIVL’s on-line reporting of discriminatory practices resource and questionnaire, found that over 80% of respondents had experienced discrimination in health care settings. (Online Discrimination Survey Results, AIVL, Oct 2012)

“To generalize my experience informs me that people with hepatitis C in this society are usually labeled as IV drug users therefore as ‘criminals’, ‘addicts’ or at least ‘deviants’ or ‘failures’ and (mis) -treated according to those labels. As a health care worker myself I’m ashamed to note that the most shocking episodes of discrimination that I have heard from clients were perpetrated against them by health care workers and usually at a time when the client was vulnerable and seeking care.” (C-Change, 2001)

Often service providers are not aware that they acting in a discriminatory manner: sometimes health service providers (just like any other member of society) may not be aware that they are unconsciously reinforcing stigmatising beliefs and assumptions about PWID. A research paper on the Prejudice among health workers towards injecting drug users with hepatitis C found that it is likely that people who choose to work with PWID are those likely to be liberal minded and non-prejudicial from the outset. However the presence of ‘positive explicit attitudes’ doesn’t mean that negative biases are no longer held towards PWID. These negative attitudes may still exist and continue to manifest in more subtle ways, unconsciously without the worker being aware.

Micro-aggressions’ are the small slights, insults and indignities built up over time so that PWID come to believe that any ‘slight’ is based on their drug use: Over time PWID (like any marginalized group) experience what is termed ‘micro aggressions’. These are the unconscious manifestations of inclusion/exclusion and superiority/inferiority which members of the general community effect on to PWID; generally unconsciously enacted (but not always), they are the slights, insults and indignities PWID experience over time. Negative body language and/or verbal communication accumulate so that for PWID any slight is believed to be based on drug use—intended or not.

N.B: Although we have previously talked about micro-aggressions, it is included here to demonstrate how they occur in health care settings.

Prior experiences mean that PWID expect to be treated unfairly and/or differently from non-drug users: So common is the experience and perception of being subject to stigmatisation that PWID may anticipate discriminatory and unfair treatment prior to its actual occurring. In practice, PWID routinely experience or believe they have experienced stigmatisation and discrimination at the hands of health service providers including dentists, pharmacists, doctors and nurses. It should be noted that for many, it can be just as potent to perceive that you have been discriminated against, as it is to experience overt or obvious stigma and discrimination. It is this prior experience that automatically puts PWID on the defensive, expecting to be treated unfairly.

Many PWID believe that there will be negative repercussions if they make complaints: PWID commonly report facing barriers in attempting to assert their client rights in response to incidents of discrimination. These barriers include fear of negative consequences (for instance being removed from a treatment program, fear of loss of privileges, and harassment from the service provider). Disclosing injecting drug use to a health service provider can involve considerable risk on the part of the client.

PWID are left feeling disempowered and doubtful about the chances for change and often report difficulty following official complaints processes.

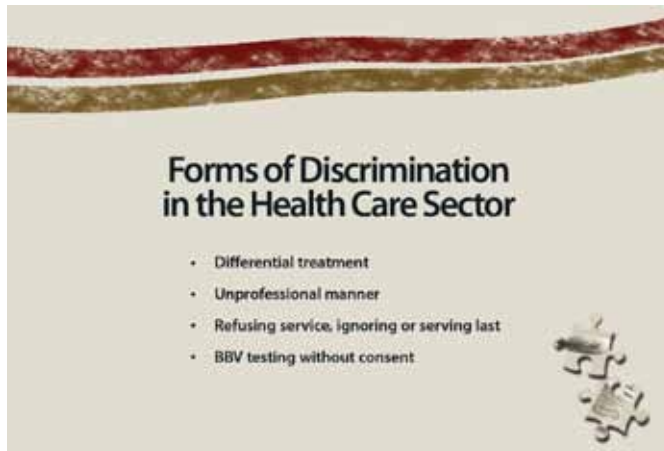
“General practices are difficult to complain to or about due to their threat and ability to refuse to service you and their knowledge of the difficulty in finding another practice willing to take methadone patients. This means I feel I can’t complain about clinical issues or even disputes about fees etc...” (Online Discrimination Survey Results, AIVL, Oct 2012)

Discrimination in the Health Care Sector

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- Many PWID believe that there will be negative repercussions if they make complaints



Slide: Forms of Discrimination in the Health Care Sector



Slide Purpose: To identify the ways in which discrimination often manifest and to provide real life examples to support the claim that discrimination routinely occurs against PWID in health and medical settings.

Trainer Notes: Discrimination comes in many forms for PWID and it directly impacts on their ability to access and negotiate through and with services; lower self-esteem, reduced confidence and mis-communication can all be outcomes of discriminatory practice. The following include personal accounts of PWID's experiences:

- **Differential treatment:** includes being made to pay prior to service delivery or appointments with general practitioners whereas other patients may not have this requirement. Two people with the same health issue receiving different treatment because one has a history of drug use and the other does not. Hospital staff insisting on double-gloving and excessive anti-contamination/safety precautions based on patient's drug use.

Delia has HCV and lives in a rural community. She experiences severe migraines related to menopause and attended a rural hospital several times in the last 5 years. She revealed her HCV status from the first visit. When seeking pain relief for debilitating migraines, she has been told 'you don't know what pain is' and 'have you come in for the Saturday night special?'. Recently Delia fell and fractured her foot, severing a tendon and required major surgery. Again, once she disclosed her status, she found staff reluctant to prescribe pain management medication for such a severe injury.

Delia says: *"I feel the emphasis was not on how can we make this patient as comfortable as we can considering the pain and operation, but on holding back due to some hidden code due to my status"* (C-Change, 2001)

"While in hospital I had to wear a different coloured armband which distinguished me from other patients. My baby also stood out from the others with 'universal precautions' written all over her cot. I thought hospitals had standard precautions in place for all patients, so I'm not sure why we had to stand out from the others" (C-Change, 2001)

- **Unprofessional manner:** inappropriate treatment or being made to feel inferior can occur in any situation, however, when they occur in a health or medical setting the impact can have devastating consequences.

"I went to the doctor for antibiotics for an infected and really badly swollen arm. He came out into the waiting room, took one look at me, told me 'I don't treat scum like you', and then picked up my bag and threw it out on the footpath" (NUAA, 1995)

"I've been told; 'I don't treat people like you'. It was really embarrassing, I had to go back out through the reception and waiting room—it was pretty obvious that something happened. I couldn't go back, never been back at all" (Toni, AIVL 2012)

- **Refusing service, ignoring or serving last:** PWID often report being served last in relation to service at dosing pharmacies (with 'real' customers being a priority) at other times due to BBV status: being the last appoint on a Friday afternoon (for 'infection control' reasons).

"I told him I was hepatitis C positive because I thought it was the right thing to do. But then when he cut his finger he flew into a panic and didn't finish the job...I have been walking around with my mouth like this for 2 months." (C-Change, 2001)

"A client had to go and have skin surgery...when she went to see the surgeon she thought she'd be honest and say 'Yes I have had HCV'...from that moment on she was told that she would be on the 'dirty list', she was told that the sheets that they used on the surgery would be burnt, that she would be the last one on the day" (C-Change, 2001)

"A person was referred by a treating dentist to a specialist to have a number of teeth extracted. The dentist told him that he must disclose to them that he has HCV when making the appointment so that they can schedule me as the last appointment of the day. 'I asked why...and was told that they would literally hose down everything in the room afterwards...'In your case we want to wipe down every inch of the room" (C-Change, 2001)

- **BBV testing without consent:** Regular complaints have been made by PWID that they have been given BBV testing without their knowledge and without pre and post-test discussion. At times they are told that it is "routine procedure" to have blood taken, but the test(s) themselves are not discussed.

"One guy I knew who came to me very distraught—thought he was going to die within two years—and that he'd infected his whole family. He'd been told over the phone and wasn't even aware that he'd actually been tested, because he'd presented with other symptoms and the doctor tested him for hep C just while he was there kind of thing." (C-Change, 2001)

"You have hep C, but at least you don't have HIV" (Jo, quoting a medical professional who told her via telephone, of blood test results that she had not consented to have done.)

Forms of Discrimination in the Health Care Sector

- Differential treatment
- Unprofessional manner
- Refusing service, ignoring or serving last
- BBV testing without consent



Slide: Forms of Discrimination in the Health Care Sector
cont.



Trainer Notes: cont.

• **Incorrect information or inadequate information:**

People are human and can make mistakes, however when they are in positions of authority and trust, it is unethical to give information without ensuring it is accurate and without thought to the impact or consequences of receiving that information.

“More recently, just in the last few weeks, there was a GP... who told a young woman very authoritatively that she had to tell everybody including her sexual partners, her employer, her house mates, everybody [that she had hepatitis C]. And at the time the woman had only had a positive antibody test and she had normal (liver function test) and he also referred her to a liver clinic” (C-Change, 2001)

• **Lecturing:** Can be viewed as somewhat unprofessional and raises questions in relation to appropriate conduct. Health care professionals have an obligation to treat people with basic dignity and respect. Lecturing may discourage PWID from accessing services, and this is of particular importance when there is only one service of its kind in a geographical area.

• **Inadequate diagnosis or investigation:** of all the complaints, experiences and issues presented to DUOs in relation to health care settings, inadequate diagnosis, care and treatment—due to real or perceived drug use—is the most commonly reported. It can also have the most dire consequences—from severe pain to premature death.

“I broke my leg in three places after a motorbike accident. At the hospital they wouldn’t give me anything other than Panadol even though the bone was sticking out through the skin” (NUAA, 1995)

“When I had my hip replacement they cracked my pelvis while jamming in the new one. I kept complaining about the pain and the doctor said to me ‘My mother just had her hip replaced and she’s not in any pain’. They didn’t test or scan for three months, they just assumed I was trying to make the most of the opportunity and get prescription drugs...They cracked my pelvis, for f – sake” (AIVL, 2012)

• **Breaching confidentiality:** Privacy and confidentiality are considered a basic legal right for adult patients within the broader Australian health care system; however, it appears that this is not necessarily practiced when it comes to PWID.

“When I went to work my supervising officer asked me if I was still on methadone. I replied “no”, then he said “yes you are because Ms F (methadone worker) told me that you are still on the methadone program.” (C-Change, 2001)

“Female IDU with 14 month old son was discharged from the detoxification centre. When her mother contacted the centre she was given all information regarding the client’s progress and discharge by a staff member. The staff in question stated to NUAA that family and friends have the right to know about the client’s progress and resulting discharge. In fact the staff would actively seek out family members and tell them what occurred.” (NUAA, 1995)

Forms of Discrimination in the Health Care Sector

- Incorrect information or inadequate information
- Lecturing
- Inadequate diagnosis or investigation
- Breaching privacy and confidentiality



Slide: Meet Peter



Slide Purpose: The aim of this activity is to demonstrate to participants how we label and stereotype people based on their appearance; they look a certain way, therefore they are assumed to have certain attributes, subsequently they are treated based on those attributes.

Trainer Notes:

- Ask the group to give their first impressions of Peter: What kind of a person is Peter? Is Peter employed or is he a student? What does he do recreationally? Is he likely to use drugs?
- Write these responses on butchers' paper.
- Summarise participant's responses back to the group prior to moving on to the next slide.

N.B. . If you are concerned about alienating participants, rather than asking the group about their own personal opinions of Peter, it may be preferable to generalize; i.e. how might the general community perceive Peter.

Meet Peter



Slide: Peter's Story



Peter's Story

Peter sought help from medical centres and hospitals four times and was sent home each time without treatment.

A nurse examined him but said it was just a virus and to go home, saying: ***"Do you realise we do have sick people in this hospital?"***

He was found dead by his mother—only a week after his plea for help. Tests confirmed he had bronchopneumonia and the swine flu influenza. Peter had never used drugs.



Slide Purpose: The aim of showing this slide is to demonstrate that the outcome of stigma and subsequent discrimination can be extreme, it can have devastating results—stigma can kill.

Trainer Notes: Ask the group and ask them to consider Peter's story:

- Why do they believe he was treated as he was?
- Would his treatment have been justified if he had used drugs? Why? Why Not?
- If participants believe that Peter's story would have been any different if he had been using drugs? If so, how would it have been different?
- How would participants have reacted if Peter had come into their health care service?

Peter's story is one of the many which prompted this training workshop. **'Stigma kills'**

'Optional extra'

Media article;

– *Stigma kills!*

Can be added to further the discussion on the impact of stigma and discrimination

'Optional Extra'

Stigma kills!: 'Stigma kills!' can be used to summarise the discussion relating to, death as an outcome of stigma and discrimination in health care settings. This additional information contains a local example, illustrating that Peter's story is not an isolated case and it doesn't just happen overseas. Additionally it can be used to introduce the next subject; 'drug seeking behaviour'.

Refer to 'optional extra' card for more information.

Peter's Story



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A nurse examined him but said it was just a virus and to go home, saying: ***“do you realise we do have sick people in this hospital?”***

He was found dead by his mother—only a week after his plea for help. Tests confirmed he had bronchopneumonia and the swine flu Influenza.

Peter had never used drugs.



Slide: Drug Seeking Behaviour



Activity Aim: The objective of this activity is to encourage fair and non-discriminatory practice in order to achieve the best therapeutic outcomes, while acknowledging that ‘drug seeking behaviour’ exists and taking in to consideration the reasons for its occurrence.

N.B: This can be a very challenging issue for participants—particularly practicing medical professionals—as you attempt to balance obligations to ‘keep patients/clients safe’, the right of the patient to have their health concerns addressed and met, and the consequences of making (what might be believed) to be an incorrect clinical decisions. With potential outcomes being medical negligence, patient’s mis-use of medications, irresponsible prescribing and/or mis-diagnosis.

Trainers Notes: There two different approaches the facilitator can use for this activity:

- Decide which activity best suits the group you are facilitating and the aim of the activity and what you are wanting to achieve. Activity 1 is more discussion based and potentially more passive, while Activity 2 may suit groups who appear to require a greater degree of ‘action’.

Activity 1:

Step 1: Use a whiteboard or flip chart/butchers’ paper (depending on what you have available) to summarise participant responses to the question “*what does the term ‘drug seeking behaviour’ mean to you in the context of your work as either a current or future health care professional?*”

Some of the key responses are likely to include:*

- People ‘doctor shopping’;
- People wanting to ‘get high’ or ‘out of it’;
- People suffering withdrawal from a drug/medication they are dependent upon;
- People wanting a prescription for certain drugs/medications to sell to others;
- People getting medications for friends, partners, family members, etc;
- People having used their prescribed medications early and needing extra or more;
- People not being able to get the drug(s) they require from another doctor;
- People having difficulty accessing their illicit ‘drug of choice’;
- People ‘self-medicating’ such as trying to self-treat or relieve symptoms related to chronic/acute pain, mental health, etc;
- People needing emotional coping mechanisms.

* Of course there could be many more responses but the above are here as a guide and can also be used as a prompt to get responses underway if needed.

Step 2: Then, using a clean whiteboard or new butchers’ paper, work with the group to summarise the key themes from their list of initial responses to the first question. This second ‘summarising’ step aims to get the participants to discuss and focus in on what they view as the key reasons why PWID might engage in ‘drug seeking behaviour’ (particularly given the potential risks involved)—what do they think are the main reasons why someone would put themselves in this situation?

Some of the key reasons you could assist the group to draw out or summarise from the list above might be:*

- People are seeking medication to alleviate, self-treat or relieve a condition or symptom(s) such as pain, anxiety, depression, etc;

- People who are attempting to assist someone else (perhaps someone they care about who is ill);
- People who cannot access their usual medication/illicit drug;
- People seeking to drugs to achieve a particular effect (alter their consciousness; change their state of mind, etc).

* Of course the group may summarise the initial list of responses differently but the above are here as a guide and can also be used as a prompt to help the group to summarise if needed.

Step 3: Following the completion of Steps 1 & 2 above, the facilitator should bring up the ‘Common Themes’ slide and take the group through the following dot points in order finish the session with a discussion about the importance of critical questioning and professional and compassionate behaviour in relation to what can be too easily or even wrongly dismissed as ‘drug seeking’ behaviour:

Some of the key reasons you could assist the group to draw out or summarise from the list above might be:

- Diagnostic response
- Validity of reason
- Outcome of turning patient away
- Treatment options
- Patient’s desired outcome
- Diagnostic tools
- Health care provider considerations
- Not all PWID ‘drug seek’

- ‘Optional extra’
- Alternative activity;
- – *Drug seeking behaviour*
- Can be used as an alternative to Activity 1

‘Optional Extra’

Activity 2, Drug seeking behaviour: Can be used as an alternative to Activity 1.

Refer to ‘optional extra’ for more information.

Drug Seeking Behaviour Activity

- What does the term mean to you?
- What do you think PWID are trying to achieve?
- How do you reconcile the two to achieve a therapeutic outcome?



Slide: Common Themes arising from drug seeking behaviour activity



Slide purpose: This slide demonstrates that there will always be a valid reason as to why someone may be 'drug seeking'.

Trainers notes: Wrap-up the 'drug seeking behaviour' activity by taking participants through the common themes slide. These are some of the common themes to why someone may be seen to be 'drug seeking'.

- **Diagnostic response:** Generally you will find that the common theme to all these responses is that they all require a diagnostic response: whether that be clinical/medical diagnosis, provision of an appropriate medication(s), a referral to another service, or a therapeutic recommendation—there will *always* be a legitimate reason that this person is in front of you.

Encourage participants to ask themselves; *why might this person have come to me/our service? What are they really looking for/seeking advice on? Am I really listening to them or making assumptions?*

- **Validity of reason:** Could there be an entirely valid reason why the person appears to be 'drug seeking' and/

or 'doctor shopping'? Have they been refused treatment elsewhere?

- **Outcome of turning patient away:** What could happen if I refuse to treat or turn the patient away? What are my medico/legal responsibilities if I turn a person away and they die as a result of not being treated?
- **Treatment options:** What options do I have to assist them and get to the bottom of their issues/problems?
- **Patient's desired outcome:** It is important to recognize that the client/patient might not get the outcome they sought in the first instance.
- **Diagnostic tools:** Medical practitioners have the diagnostic tools to make qualified decisions in relation to patients seeking care; is a medication required or some other type of therapy? For instance the 'Quality Use of Medicines', QUM Indicator, professional diagnostic ability and personal experience.
- **Health care provider considerations:** Recognise that it can be very difficult for health care providers—sometimes there will be people in front of them where their concerns about possible 'drug seeking' or 'doctor shopping' are valid.
- **Not all PWID 'drug seek':** Keep in mind that many PWID may *never* find reason to 'drug seek', while others may change doctors until they find one with the experience to treat them in non-judgmental manner.

NB: "Doctor shopping" can sometimes be viewed in the same way as drug seeking. Alternatively Dr shopping may merely be searching for a doctor who will meet their needs as a patient and someone they can trust.

Drug Seeking Behaviour Activity

Common Themes

Diagnostic response

Validity of reason

Outcome of turning patient away

Treatment options

Patient's desired outcome

Diagnostic tools

Health care provider considerations

Not all PWID 'drug seek'



Slide: What does all this mean and why should I care?



Slide Purpose: The aim of this slide is to broadly review what has been discussed so far and to reinforce for participants the forms of discrimination against PWID which have a negative impact on health service provision and access. Additionally, this seeks to affirm for participants that it is in everyone's best interest to take these issues into thoughtful consideration and practice.

Trainers Notes: So far in the workshop we have broadly discussed stigma and discrimination against PWID and the impact that it has in relation to access and health service provision. To end this session, take participants through each of the following points to concrete what the real impact that results from stigma and discrimination. Use examples and research references where possible.

What does this all mean and why should I care?

- Expectations and assumptions
- Access to health services
- Relationships and trust



**Slide: What does all this mean and why should I care?—
Expectations & assumptions**



Trainers notes: Expectations and assumptions.

- **Assumptions work both ways:** Just as many PWID anticipate negative reactions in their dealings with health services, research shows that physicians expect PWID to be aggressive and difficult patients. This self-perpetuating cycle is reinforced by each party's assumptions and expectations of the other.
- **Expecting PWID to be unreliable, liars, thieves etc:** Many health professionals expect that PWID as clients will be; dishonest in their dealings, unreliable in relation to appointments and treatment regimens and generally aggressive and difficult. PWID from previous experience (their own or others) feel stigmatized from the outset, are hyper-sensitive and may react or even overreact to any slight (intentional or not).

Poor self-esteem and lack of confidence from subjection to long term stigma and discrimination can make an individual appear that they are un-cooperative, unfriendly or defensive.

- **Positive expectations:** Those that reject traditional negative notions about PWID can counter stigma and have a positive impact on relationships. If health professionals have positive expectations of all clients they automatically create a more supportive environment for marginalised people including PWID.

What does this all mean and why should I care?

Expectations and assumptions

- Assumptions work both ways
- Expecting PWID to unreliable, liars thieves etc.
- Positive expectations



**Slide: What does all this mean and why should I care?—
Access to health services**



Trainers notes: Access to health services.

Anticipation of discrimination: We know that just that the mere anticipation of discrimination is enough to create a barrier to PWID accessing health care services. It is this anticipation that leads to deferring treatment putting the health and lives of PWID at risk.

Deferring treatment: Many PWID will not access health services or defer treatment because that very access will/ may identify them as a drug user. Why would someone seek treatment when they feel that they will only be treated badly with no positive outcomes. For many it is just not worth the trauma. For example, many PWID would rather reuse or share previously used injecting equipment, or where possible obtain new equipment through friends or pharmacies, rather than utilising a primary needle and syringe program (NSP), in fear of being labelled as a drug user, or be seen using such services by family, friends, employers, neighbours and the like.

At the extreme we know that PWID will delay/defer treatment until it is at crisis point. The deferring of treatment makes diagnosis and treatment more complex for health care workers and harder and longer for PWID to get their health and lives back to where they would like them to be. It serves no one.

What does this all mean and why should I care?

Access to health services

- Anticipation of discrimination
- Deferring treatment



Slide: What does all this mean and why should I care?— Relationships and trust



Trainers notes: Relationships and trust.

Are key to effective health service provision: If there is no sense of trust, PWID are not going to open up about the abscess that they fear has developed, or that they have put themselves at risk of a BBV and need to a blood test. The trust between patient and doctor is essential for successful health outcomes. If PWID do not disclose drug use for fear of negative repercussions, the outcome will be negative in terms of the effectiveness of service provision and treatment outcomes.

Some people (particularly in regional or rural areas) don't have a choice and must access services, despite stigmatizing language or behaviour. Having access to the only prescribing pharmacotherapy doctor in an area will affect PWID's decisions around drug related issues. The risk of being removed as a patient for disclosing illicit drug use and/or related harms is far too high a price.

- **Can be hindered by stigma & discrimination:** The fear of stigma and discrimination puts many PWID on edge and therefore the littlest possible time that is spent in health care services the least amount of negative repercussions. This hinders the building of trust within relationships. For example, many PWID on pharmacotherapy programs want to get in and out of their script renewal appointments as quickly as possible. Relationships can be severely hindered by stigmatizing behaviours and practices.
- **The lack of these can have damaging outcomes for PWID & service providers:** The implications of poor relationships and lack of trust within health service provision can be damaging to both the provider and PWID. It can lead to mis-diagnosis, lack of diagnosis, unintentional mistreatment and/or potentially result in death.

What does this all mean and why should I care?

Relationships and trust

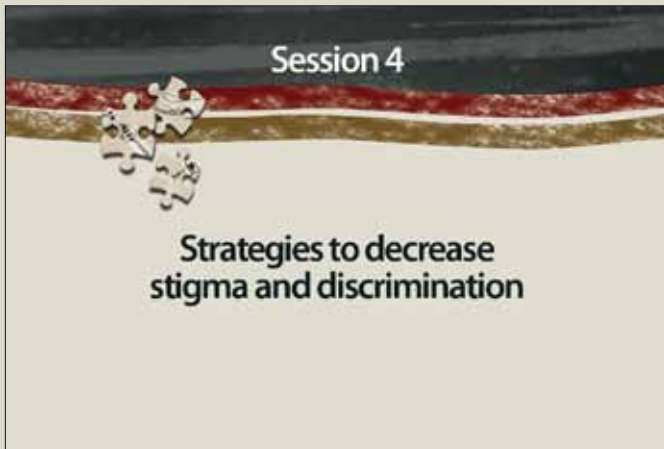
- Are key to effective health service provision
- Can be hindered by stigma & discrimination
- The lack of these can have damaging outcomes for PWID & service providers



Session 4



Session 4: Strategies to decrease stigma and discrimination



Time: 30 minutes

Resources: PowerPoint slides, LCD projector, computer, whiteboard (plus whiteboard marker pens), flipcharts with blank paper, marker pens (various colours), butchers paper.

Handouts:

1. Evaluation

Objectives:

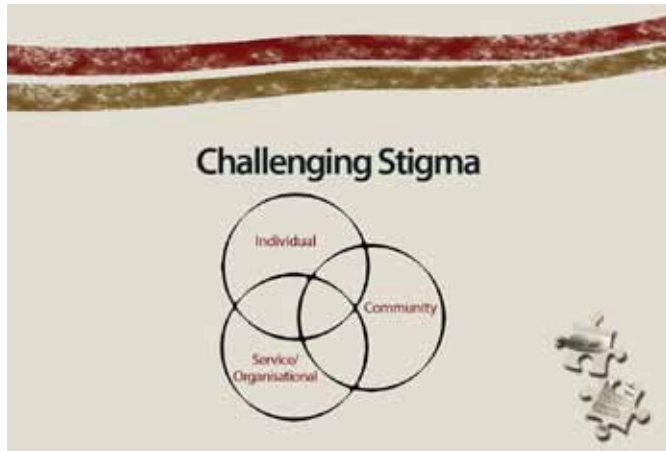
- Participants will gain practical skills and strategies to decrease the stigma and discrimination toward PWID, people on pharmacotherapy and those with hepatitis C and/or other BBVs in health care settings.
- Participants will identify strategies and/or policies that they can implement to reduce stigma and discrimination in their work place or when they commence practice.

Session 4



Strategies to decrease stigma and discrimination

Slide: Challenging stigma



Slide Purpose: To show that the stigma and discrimination experienced within health care settings and directed at PWID, those on pharmacotherapy and those living with hepatitis C and/or other BBVs, can be challenged at three levels: The individual/personal, the organisational/institutional and at the broader community level. These levels can easily influence each other, and overlap in many circumstances.

Trainer Notes: Direct participants' attention to the corresponding slide and explain that these three levels/categories effect, impact and influence each other to varying degrees. However, individuals have the capacity to challenge stigma on these different levels, and any challenge to stigma and discrimination which reduces barriers for PWID can start with one individual making change. The three levels are described as:

- **The individual/personal:** for example each person can adopt their own particular approach(s) to challenging stigma and discrimination. The individual can challenge stigma on the personal level, as an individual worker within an organisational and as a member of the broader community.
- **The organisational/institutional:** Organisations can challenge stigma and discrimination by providing appropriate services as well as creating an environment where staff are encouraged and supported to work with PWID those on pharmacotherapy and those living with hepatitis C and/or other BBVs as workers. For example, organisations can use policies and procedures to create user friendly services.
- **The community:** for example, as a member of the broader community, supporting advocacy, information and education programs regarding PWID and services for them, and adding to the voice of public opinion when stigma and discrimination occur.

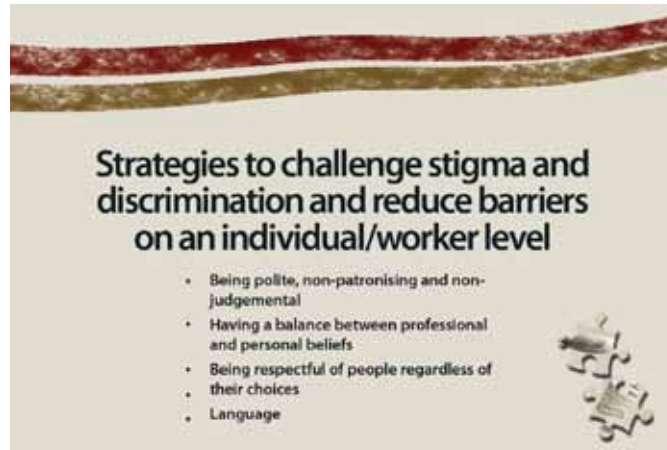
The community can challenge stigma by supporting harm reduction strategies, through advocating and delivering services for PWID those on pharmacotherapy and those living with hepatitis C and/or other BBVs. For example councils and community groups can support the location of NSP's, vending machines, disposal bins etc. The community through local media, community groups, and political groups etc. can vocally demonstrate and challenge stigma and discrimination when it occurs.

As mentioned, the individual/personal, service/organisational and community levels reflect, influence and affect each other to varying degrees. In addition, what can be achieved to challenge stigma and discrimination on one level may not be possible on another level—due to context, circumstances or other factors; however, it takes only one individual to propagate and challenge stigma and discrimination and to instigate the strategies discussed further on. What may start off as one individual's action or behaviour change to address the stigma and discrimination towards PWID, those on pharmacotherapy and those with hepatitis C and/or other BBVs can influence and encourage those around them which in turn can result in the implementation of strategies by services/organisations.

Challenging Stigma



Slide: Strategies to challenge stigma and discrimination and reduce barriers on an individual/worker level



Slide Purpose: The aim of this slide is to encourage participants to consider what they can do (in both their personal and professional lives) to challenge stigma and discrimination and reduce stigmatising barriers to PWID generally. Active positive change can encourage increased access to health services for PWID, those on pharmacotherapy and those living with hepatitis C and/or other BBVs specifically.

Trainer Notes: It is imperative that any strategies to challenge stigma and discrimination and reduce barriers to health service delivery and access for PWID incorporate the principles of human rights and self-determination to empower the individual.

As discussed previously, PWID are often viewed with their drug use as the defining feature: PWID may be drug users; however it is not all they are. If we are ever to address stigmatising barriers, PWID must be considered and engaged with in a holistic person-centred manner.

While often not recognising it, many professionals hold a great deal of power and influence over the experience for PWID which can result in improved access, therapeutic outcomes and even just as importantly good day-to-day experiences.

Below are just some of the individual actions or strategies participants can take in both their professional and personal

lives to challenge stigma and discrimination and reduce barriers to health care service and access. *Again, we strongly encourage trainers to add to this list, amend points to suit participant groups and utilise personal and DUO examples.*

Additionally, it may be timely to subtly remind participants that we should all treat people the way in which we ourselves would like to be treated—this is potentially the first step to reducing barriers.

Being polite, non-patronising and non-judgemental: All too often PWID experience a negative reaction as soon as they come face to face with someone—whether that is or isn't related to their status as an individual who uses drugs really isn't relevant, especially if the assumption is that their status is the reason for the reaction.

Ironically, many PWID on give the opportunity to respond to consumer satisfaction surveys related to drug treatment and harm reduction-related services, will make comments such as; "they're a great service—they're always nice to me", or "the staff are friendly, I like them". Taken on face value, these statements suggest enthusiastic and non-judgemental service provision, however, when they are uncovered further, the reason PWID 'like them' is that this is often the only health-related service which does treat them in a polite, friendly and non-judgemental manner. PWID experience negative encounters so often, that when a service provider is polite and/or non-judgemental it is the exception rather than the rule.

The attitudes and behaviours of those with the power to make a health service provision experience positive or negative, also have the ability to reduce barriers to health service provision and access—merely by acting in a non-judgemental, polite and friendly manner.

Having a balance between professional and personal beliefs: It can often be difficult to separate the beliefs we grow-up or mature with; those that are based on our personal experience; or those that are culturally/socially learnt or imprinted with, from those that we must adhere to in our professional lives. However, this separation of the personal and the professional is inherent to the very act of being and behaving as a 'professional'.

While recognising that we are all human, if we want to reduce barriers to health services access, and create improvements in service delivery for PWID, those on

pharmacotherapy and those living with hepatitis C and/or other BBVs; we must leave our personal beliefs 'at the door'.

Being respectful of people regardless of their choices:

Not morally judging someone for their drug use. Putting your own thoughts and beliefs aside regardless of how you feel about drug use, injecting drug use and/or illicit drug use, and treating a client without moral judgment.

We may not agree with others life choices. If we can be respectful of people who choose not to use drugs, if we can be respectful of people with differing cultural beliefs from our own, and if we can be respectful of people generally: Is there a reason why we cannot be respectful of people do who choose to use drugs

Not jumping to conclusions when a PWID asks for medications that they are automatically 'drug seeking'.

Ensuring that the time is taken to listen and to find out what the needs and issues are for your client.

Move away from stereotypes of drug users: Attending this training, we hope, is one step away from maintaining negative stereotypes of PWID. Stereotypes create an expectation of an individual or group's likely behaviour or personality. If we expect negative behaviour from PWID, we will most likely find it.

If we treat the individual as they are and as 'who' they are, rather than on behaviour, we are more likely to reduce barriers and create more positive health outcomes.

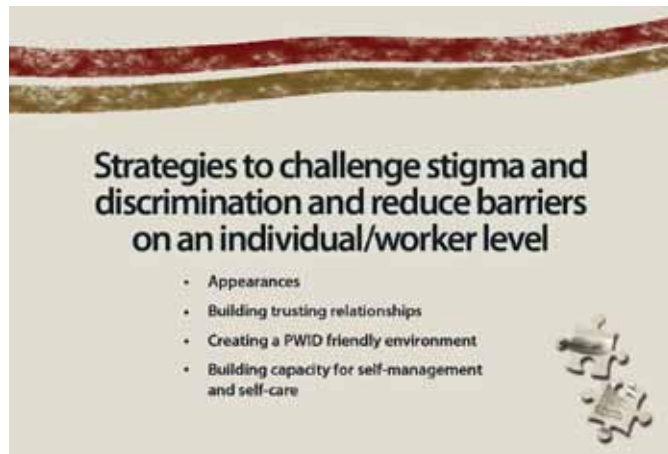
Language: We have discussed the use of language and the power of words and how the individual's choice to use appropriate terminology (both with and about PWID) can be potent in challenging stigma. We can simply use language to challenge stigma by not referring to PWID as drug 'addicts', 'junkies', drug 'abusers'. When using language to describe people or their behaviours take out the negative connotations and choose words that empower PWID. We can speak out when others are using demoralising, stigmatising language to describe someone or their behaviour. People may be using language without realising they are being discriminating. This can be done in your personal life, but most importantly can be done within the work place with colleagues. When we are talking about language it is both the written form as well as the verbal form.

Strategies to challenge stigma and discrimination and reduce barriers on an individual/worker level

- Being polite, non-patronising and non-judgemental
- Having a balance between professional and personal beliefs
- Being respectful of people regardless of their choices
- Language



Slide: Strategies to challenge stigma and discrimination and reduce barriers on an individual/worker level cont.



Trainer Notes: cont.

Appearances: Not judging people based solely by their appearances. It is important that PWID are given treatment and service like any other person regardless of their appearance/dress. The story of Peter which we discussed earlier is a prime example of someone basing their professional opinion based on appearance. We should not be deciding whether or not to treat someone, how to treat them or whether to trust them, based on how they look and the way they are dressed. We cannot assume that some PWID are more stable than others based on appearances.

Often we assume that because someone is clean, dressed nicely, that they are doing 'well'. This may not always be the case; we need to look deeper into what is happening for people to work if they are feeling stable. For this to occur there, needs to be trust for people to be open and honest.

Building trusting relationships: You're personal interactions with PWID, those on pharmacotherapy and those living with hepatitis C and/or other BBVs are extremely important, as we have discussed how damaging some discriminating behaviours can be. Importantly the one on one interaction with clients can be used to establish rapport and vehicle to building a trusting relationship. Encouraging conversations about drug use can promote shifts toward more trusting relationships between clients and health service providers. It is important to treat everyone as individuals—valuing their unique experiences and needs, and seeing them—beyond and more than simply their drug use.

Recognising your own behaviour and the possible impact it may have on establishing relationships or detrimental to an existing trusting relationship. It is not about giving PWID special treatment, but understanding how discrimination can occur and preventing this from occurring. The simple lack of open communication and clear communication can easily breakdown relationships. Not jumping to conclusion, but taking the time to find out what the real issues are so then they can be addressed.

EXAMPLE: Although urine testing is part of many OST programs and occurs often; Urine testing is detrimental to building a trusting relationship between a client and a doctor/prescriber or can easily impair an established rapport. PWID and/or those on pharmacotherapy often have to undergo urine testing as a means of screening for drug use. Aside from having to perform an embarrassing, humiliating urine test: peeing into a cup in front of a complete stranger whom is not necessarily of the same sex. Urine testing automatically says to a client that their word and what they say cannot be trusted, or believed. Often the only purpose of drug screening is seen for punitive purposes. It asserts that the client cannot simply be asked about their drug use and be trusted to tell the truth. This lack of trust prevents

a therapeutic relationship from being established. What the doctors response to the test results is another issue altogether, which can impede trusting relationships.

Trust is built over time, it doesn't just occur. By showing respect and understanding it leads to better relationships and often we need to trust a little in order to have someone trust us.

Creating a PWID friendly environment: It is important that PWID have an environment where they feel safe enough to be open and honest—without fear of judgment and repercussions. PWID as clients or patients should be given the opportunity to talk about both the positive and the negative aspects of their drug use, so that they don't automatically have to feel the need to discuss their drug use and themselves as 'bad' or flawed.

Building capacity for self-management and self-care: PWID need to be supported and encouraged to build their own capacity in relation to their own health, this includes provision of ample information and in some ways means the professional 'handing over' power.

Self-determination can be achieved by supporting PWID to be intimately involved with their treatment, and take control by making informed choices. Encourage PWID to ask questions and ensure they understand what all their options are. They are not only empowered, they are subsequently challenging a traditional stereotype of PWID as disinterested in their own self-care.

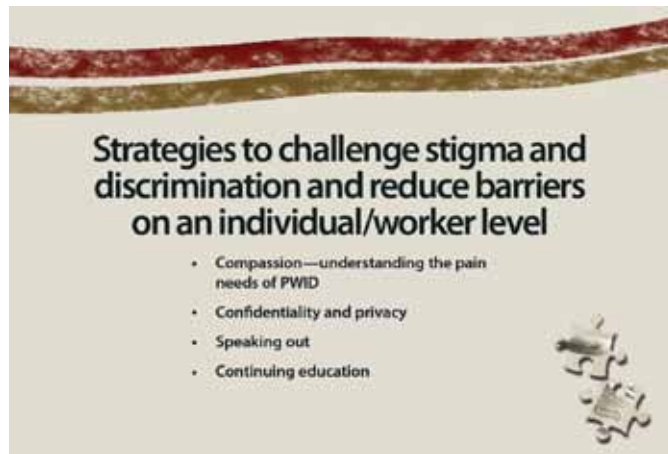


Strategies to challenge stigma and discrimination and reduce barriers on an individual/worker level

- Appearances
- Building trusting relationships
- Creating a PWID friendly environment
- Building capacity for self-management and self-care



Slide: Strategies to challenge stigma and discrimination and reduce barriers on an individual/worker level cont.



Trainer Notes: cont.

Compassion—understanding the pain needs of

PWID: To ensure that PWID, those on pharmacotherapy and those living with hepatitis C and/or other BBVs aren't ever left to suffer in pain. Ensure that medication is increased to sufficient levels for those who are suffering with chronic diseases e.g. cancer patients. If a person on pharmacotherapy is suffering from pain due to a chronic disease such as cancer, increasing their pharmacotherapy often is not enough. They will often need additional pain medication.

Having the compassion and humanity to help those in pain and in discomfort; No one ever deserves or needs to be in pain at any time regardless of what is the cause. We need to be compassionate when someone is suffering without proper medication due to the stigma and discrimination of being a drug user or having a history of drug use.

EXAMPLE: the Australian case of the man who died as a result of being turned away from a hospital as a 'drug seeker'. The man presented at the hospital in obvious agony, seen by a doctor and told to leave as he was assumed to be just seeking pain medication. Despite desperate attempts by the man and his friends, he was forced to leave a later died, an agonising death.

General practitioners can choose to treat patients requiring pharmacotherapies. Currently there is a shortage of prescribers, particularly in rural areas where waiting lists are two years. The more prescribers we have the more have access to treatment and the less stigmatizing it becomes.

Confidentiality and privacy: Maintaining confidentiality and being vigilant around privacy. Only talking with others/colleagues on a need to know basis about a client's treatment or situation. Ensuring that sensitive information such as a person's HCV or HIV status is only known by those that need to know. We can ensure that any conversations regarding sensitive issues are done in privacy.

Speaking out: As individuals we can be involved in public opinion, by advocating for change and to improve the lives of PWID, those on pharmacotherapy and those living with hepatitis C and/or other BBVs. Use your power as a voter to support parties that have policies regarding PWID and who are more likely to fight discrimination against PWID. Investigate and vote for parties that will actively seek to implement and fund policies that will improve the health and lives of PWID, those on pharmacotherapy and those living with hepatitis C and/or other BBVs.

EXAMPLE: Write letters when you are in support of something in the media or to oppose negative opinions or articles. (This can be done anonymously)

It is important to respond to negative discriminatory newspaper articles as well as articles that are supporting PWID.

Participate in online polls. Often newspapers will have an on-line poll on their website. All votes count.

Sign petitions that challenge stigma and discrimination and that show support for PWID as well as circulating them widely for others to sign.

EXAMPLE: Get-Up, an online activist website runs petitions on a range of popular issues. Get-Up has a number of petitions going at the same time on a range of issues that you can sign. Details of who to contact and write letters to are also provided to make it easier for people to actively take action. You can even vote for an issue that you think needs priority over others as well as nominating issues/topics which you think need public opinion on.

Continuing Education: Learning more about PWID, their lives and their experiences—and implementing those lessons in a positive manner is another way to challenge stigma. Attending this workshop and taking note of the issues raised is a good example of gaining education to improve competency on drugs, drug use and the lives and experiences of PWID to address the stigma directed at them.

Reinforce for participants that none of these strategies 'stand-alone', or need be the only approaches considered. You may wish to conclude this session by asking participants to suggest some of their own examples of simple and easily achievable personal strategies that they can adopt on a day-to-day basis in their dealings with PWID.

Strategies to challenge stigma and discrimination and reduce barriers on an individual/worker level

- Compassion—understanding the pain needs of PWID
- Confidentiality and privacy
- Speaking out
- Continuing education



Slide: Strategies to challenge stigma and discrimination and reduce barriers on a service/organisational level



Slide Purpose: The aim of this slide is to encourage participants to consider what they can do in their professional lives and as members of staff in a service/organisation to challenge stigma and discrimination and reduce stigmatising barriers and to encourage increased access to health services for PWID, those on pharmacotherapy and those living with hepatitis C and/or other BBVs specifically.

Trainer Notes: It is essential that any strategies to challenge stigma and discrimination and reduce barriers to health service delivery and access for PWID incorporate the principles of human rights and are empowering to the individual. The use of empowerment-based and person-centred approaches to challenge stigma and reduce barriers creates a supportive environment, allows the individual to be active in their own health care choices and makes steps toward enabling PWID as a community.

Further, in recognising and responding to the social determinants of health, in the provision of supportive operational policies and practices organisations can work toward; decreasing social stratification—by reducing inequalities in power—by reducing vulnerability and;

intervening through health care—by reducing un-equal consequences of ill-health and the prevention of ill-health.

We encourage you to include and incorporate your own or DUO's examples in identifying strategies, while other practical, supportive and empowering strategies to challenging stigma and reduce barriers that can be enacted in most health care environments include:

Policy development which is consistent with human rights principles: Health services should consider new legislation when developing and reviewing policies for consistency with human rights principles, policies and should ensure that the health and rights of PWID are protected, particularly in the health, social welfare and criminal justice systems. Ensure that your organisations reviews it policies and procedures on a regular basis.

Where possible make or adjust policies and procedures to be user friendly and to take the needs and issues of PWID, those on pharmacotherapy and those living with hepatitis C and/or other BBVs into consideration.

For a broad example, access to health care and treatment is a basic health and human right in Australia, however, many PWID are denied access to OST or removed from programs—a breach of their right to health treatment for drug dependency.

EXAMPLE: Abolishing the policy of missed appointment fees: or at the least putting mechanisms in place to assist people in remembering their appointments, such as reminder phone calls or text messages, regular recurring appointments on the same day and time. Where ever possible ensuring that a policy is in place for regular clients to be Bulk billed. Services and organisations can review their urine testing policies in consultation with PWID. Often urine testing is punitive and changing policy to decrease barriers of peoples access to health care.

Ensuring privacy protections and confidentiality in service provision: Privacy and confidentiality can both ensure or discourage access, PWID have privacy rights like all citizens, however many find they are often breached. For example,

when a client collects their pharmacotherapy medication their medical notes should be kept in a secure manner so that only the dosing pharmacist and the client are the only ones that can see them However, DUOs often report incidents wherein clients' script and records are left open for public purview. Another example is where PWIDs' BBV status is overtly displayed in hospital/clinical settings; the hep C + written in red can be instantly recognisable when it is not necessary. Ensure that personal records are not marked obviously if someone is HCV or HIV positive.

Standard forms and questionnaires: Forms at dentists and other medical services can be discriminating in identifying someone who is HCV or HIV positive. The question of why this information is being asked needs to be examined i.e. why are we asking this, what is the purpose for asking this information? Will it discriminate? Have a standard form that doesn't discriminate.

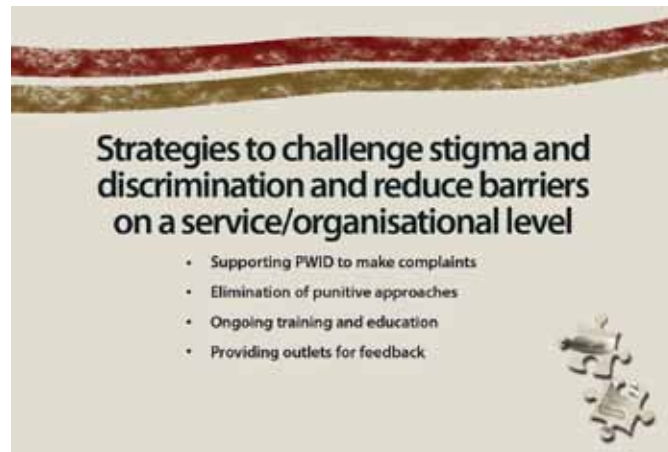
Providing outlets for feedback: Does your health care setting or course of study have an outlet or component for discussing policies or behaviours that may be stigmatising and/or discriminatory? It is important for health care staff and students to be able to explore stigma honestly and openly. In order to best explore stigma and discriminatory practice, it is also important that staff be receptive to PWID's involvement in critiquing organisational practice without fear of retribution. Have feedback forms easily assessable to clients that are more than just token gestures. We know that most PWID will not make complaints due to repercussions; therefore we need to make the avenues for making complaints simple and effective. Most importantly they need to be taken seriously, and for clients to know this. Routinely ask your clients what they think, have focus groups where clients feel they are supported by their peers.

Strategies to challenge stigma and discrimination and reduce barriers on a service/organisational level

- Policy development which is consistent with human rights principles
- Ensuring privacy protections and confidentiality in service provision
- Standard forms and questionnaires
- Providing outlets for feedback



Slide: Strategies to challenge stigma and discrimination and reduce barriers on a service/organisational level cont.



Trainer Notes: cont.

Supporting PWID to make complaints: Encouraging and supporting PWID to assert their basic human rights and to lodge complaints against those who violate those rights is another means to addressing systemic barriers.

AIML's on-line resource: 'Discrimination Know Your Rights', and in particular the 'Reporting of Discriminatory Practices Survey' has found that PWID are routinely discriminated against in healthcare settings and reluctant to make those complaints formal. The reasons expressed for not reporting discrimination include fear of repercussions, not believing that complaining will make a change or difference, and concern about the impact of complaining or redress on family members. As these direct quotes support:

- *Waste of time; some people don't listen and have different opinions to the matter*
- *I knew it wouldn't go any further*
- *No complaint procedure would change the way they feel about me*

- *Make it worse for the children*
- *Made to feel ashamed and didn't want to out myself*
- *I was too unwell and my lifestyle would have been exposed within the smaller community in which I lived at the time*

Elimination of punitive approaches: Punitive approaches act as a systematic barrier as they prevent PWID from accessing healthcare services and support in the first instance; they can cause individuals to be removed from services; and in some cases have extreme repercussions: To the extent that AIML and DUOs have been informed of cases of death and suicide. Drug treatment services are known for systematically and routinely enforcing punitive policies, most often without consideration of individual client's circumstances. Some of the best known include:

- If clients miss more than two consecutive doses of OST they are removed from the program until such time as they personally visit their prescriber; and
- If clients fail routine urine screening they can be removed from the program or lose privileges (normally access to the 'take away' doses which allow them to meet familial and social responsibilities).

Eliminating punitive drug treatment approaches is essential if the reduction and removal of systematic barriers to health service provision and access are to occur: PWID are aware that the majority of drug treatment services are punitive in nature, knowing this, many will not access services in the first instance. This is of particular concern—aside from clashing with human rights principles it is well supported and acknowledged that drug treatment services have a direct correlation with BBV transmission prevention—if the punitive measures associated with these services acts as a systematic barrier to access, and if clients are denied access or removed from services as 'punishment', then they are also denied access to BBV prevention initiatives.

In addition, the punitive nature of services is such that it acts as a systematic barrier to open and honest communication

between health service providers and clients. PWID as clients will not discuss issues of concern with service providers if the result is likely to be punitive.

Ongoing training and education: Increase staff competency through training and education. Training should extend to anyone who interacts with PWID in health care settings. Attending this workshop is just one example; others may include asking your local DUO to provide training to staff. A knowledgeable staff will be more confident and less judgmental in providing services to PWID. As those subjected to stigma and discrimination, PWID provide a unique perspective which can enhance and personalise training and education (to make it 'real').

Providing outlets for feedback: Does your health care setting or course of study have an outlet or component for discussing policies or behaviours that may be stigmatising and/or discriminatory? It is important for health care staff and students to be able to explore stigma honestly and openly. In order to best explore stigma and discriminatory practice, it is also important that staff be receptive to PWID's involvement in critiquing organisational practice without fear of retribution.

Have feedback forms easily assessable to clients that are more than just token gestures. We know that most PWID will not make complaints due to repercussions; therefore we need to make the avenues for making complaints simple and effective. Most importantly they need to be taken seriously, and for clients to know this. Routinely ask your clients what they think, have focus groups where clients feel they are supported by their peers.

Strategies to challenge stigma and discrimination and reduce barriers on a service/organisational level

- Supporting PWID to make complaints
- Elimination of punitive approaches
- Ongoing training and education
- Providing outlets for feedback



Slide: Strategies to challenge stigma and discrimination and reduce barriers on a service/organisational level cont.



Trainer Notes: cont.

Appointment cards and reminder messages:

Appointment cards and reminder messages can be a simple strategy, as PWID are often considered to be unreliable or not involved in their treatment/health-care. If it were any other group in the community it might be deemed forgetfulness, however, in relation to PWID, all too often a missed appointment is linked to drug use. Implementing simple operational processes such as appointment reminder texts or calls can impact on a variety of ways: remind clients, reduce assumptions and alleviate mis-communication.

Word of mouth works both ways: It may be timely to subtly remind participants that (like most groups in society), PWID have networks of peers, and individuals within those networks discuss issues of concerns and experiences with each other – both positive and negative. Not dissimilar to the game ‘Chinese whispers’, accounts of experiences and events grow, change or are adapted with each re-telling. In relation to PWID and health services – possibly because there are too few health services specifically catering to

PWID, those on pharmacotherapy and those living with hepatitis C and/or other BBVs—both ‘good’ and ‘bad’ experiences of services and service providers are routinely discussed and taken on board.

Continuing training of staff: Attend training and education sessions to learn more about the needs of PWID, those on pharmacotherapy and those living with hepatitis C and/or other BBVs and to keep updated on the trends and issues. Attend training that will bring you up to date on the latest drug treatments and treatments for BBVs.

Building and supporting partnerships: Service and organisations can work in partnership with drug user organisations to utilise their areas of expertise. DUO can be utilised to review documents and brochures etc. when it is on issues directly related to PWIDs. This will help to ensure that resources for PWID are well targeted and distributed.

Become a member of relevant community clubs and/or associations, for example the Australian Medical Association (AMA), DANNA, Pharmacy Guilds. This can be an avenue to become involved and to advocate for positive change. By working together and supporting each other we have a greater chance of decreasing PWID related stigma and discrimination.

Enhancing communication between service providers and PWID (as clients): Recognising that interactions between individuals and professional health-care providers can be challenging for PWID is imperative; they might be forced into situations they don’t necessarily want to be in, confidentiality is too easily breached, and privacy considerations too easily ignored when it comes to drug users. Underlying concerns can hamper effective communication and dislodge any intention of supporting self-determination.

However, with that being said, effective, supportive and empowering communication is achievable: It means not

only adopting basic communication skills (as simple as really ‘listening’), but also ensuring that operational practices support effective communication (consent, confidentiality and conflict resolution/mediation policies).

Again, emphasise with participants that these are merely a few examples of strategies that can be utilised or adopted to challenge stigma and discrimination and reduce barriers to health care access, they need not be the only strategies considered, and they certainly need the support of committed individuals to work, and work well.

Strategies to challenge stigma and discrimination and reduce barriers on a service/organisational level

- Appointment cards and reminder messages
- Continuing training of staff
- Building and supporting partnerships
- Enhancing communication between service providers and PWID (as clients)



Slide: Strategies to challenge stigma and discrimination and reduce barriers on a community level



Slide Purpose: To demonstrate to participants that the stigma and discrimination experienced within health care settings and directed at PWID, those on pharmacotherapy and those living with hepatitis C and/or other BBVs can be challenged at the broader community level, and to provide examples of strategies that work toward achieving this.

Trainer Notes: Again, it is important that participants are aware that the strategies for challenging stigma and discrimination to reduce stigmatising barriers to PWID generally, and to encourage increased access to health services for PWID, those on pharmacotherapy and those living with hepatitis C and/or other BBVs specifically not stand-alone, they require ongoing support, sometimes courage and always commitment.

The strategies listed below are suggestions only, and trainers are encouraged to adapt their own and their DUO's examples wherever possible—this can be useful in localising the content and context and is also dependent on the participant group; practicing professionals or students.

NB: When discussing the broader community and strategies that can challenge stigma and discrimination, it is essential that the power and influence of the media is not neglected—and as discussed previously, the argument cannot be divorced from...fact that the media are the voice of public opinion or drivers of it, and subsequently public health policy (or drug policy).

There are a number of options and strategies that the community as a whole, and individual members of the broader community can adopt to challenge stigma and discrimination and improve PWIDs' experience of, and access to health services, these include:

Application of evidence based frameworks: All too often evidence to support best-practice is available, and unfortunately ignored. Recent examples of this can be found in relation to the establishment and provision of NSP in community—specifically peer-distribution and culturally-targeted services; and the hesitancy of implementing programs that have been proven to save lives internationally—for instance NSP in prison and naloxone programs; and the reluctance of services to 'outreach' to community—such as hepatitis C treatment in OST settings and peer education/support and outreach (rather than the 'client' going to the service, the service goes to the 'client').

EXAMPLE: when a site has been chosen for an NSP, and there is resistance as it is in close proximity to a primary school. It is often the community/council who can step in when there is controversy over an issue such as a location this.

Inclusion of PWID on participant advisory boards: Participant advisory boards, consumer-representative panels and similar governance structures hold varying degrees of power. They are generally decision-making bodies which can choose to (or choose not to) endorse and/or support policies and ethical practice.

There is an undisputed movement toward inclusive consumer participation—the 'mental health' field is a good example of this practice—including PWID on participant advisory boards in genuine partnership breaks down barriers of 'us' and 'them' and further challenges stigma and discrimination.

Supporting awareness raising campaigns: Awareness campaigns come in a variety of forms and some can actually be stigmatizing (whether intentional or not). The community as a whole can elect to protest stigmatising and discriminatory campaigns, or raise awareness on issues for PWID through the development of their own.

The history of homosexual rights lobbying and community support for change, is a perfect example of an awareness raising campaign to challenge community attitudes— this led to fundamental transformation on many levels; addressing

stigma and discrimination, human rights, legislative debate and policy change.

Addressing Policy and advocacy issues: Stigma and discrimination directed at PWID can be challenged through advocating for improved and increased health services, specifically for PWID and those living with BBVs. This includes ensuring that there is a 'space' for PWID-related health services. A perfect example of this resides in the recent move to 'Medicare Locals': Many of these required the construction of new buildings, however many NSPs have had to fight to be given appropriate and adequate position and space from which to provide non-discriminatory and appropriate health service delivery.

Participating in community events: Supporting and participating in events such as 'World AIDS Day', 'Drug Action Week' and 'World Hepatitis Day' and 'National Hepatitis Awareness Week' may appear to be insignificant actions in and of themselves. However, through attendance and support of such events the community challenges stigma and discrimination by showing leadership, community role-modelling and affirming that the issue is sufficiently important to warrant addressing.

Conducting anti-discrimination and human rights-focused education campaigns targeting the general community, government departments and health/social services is another way in which to address systemic barriers – the broader community need to be aware that PWID have human rights, and that these need to be acknowledged and maintained.

The community can hold events to support and create a space for public debate on issues such as NSP in prisons, naloxone distribution etc. These events can raise awareness on issues, bring specialist together on the one issue, to achieve change.

Again, you may wish to add specific local examples to cement these strategies for participants, and emphasise that none of the strategies suggested over the individual/personal, organisational/institutional and broader community levels need to stand alone. Reinforce that the three levels support, impact and reflect each other, but at its very basest, change happens because one individual took action.

Strategies to challenge stigma and discrimination and reduce barriers on a community level

- Application of evidence-based frameworks
- Inclusion of PWID on participant advisory boards
- Supporting awareness raising campaigns
- Addressing policy and advocacy issues
- Participating in community events



Slide: Is it worth it?



Slide Purpose: This exercise aims to show participants that the benefits of change are truly worth the effort. That by simply making a decision to challenge or change a single behaviour/practice can lead to a domino effect, which will not only result in the benefit of others, but will ultimately benefit one's self, both professionally and personally.

Trainer Notes: The intention of this exercise is to explore how changing a personal behaviour or practice can have a positive effective on multiple areas of one's life. As this exercise follows the earlier session on providing participants with strategies and practical skills to address stigma and discrimination, it is a good way of demonstrating that using these strategies and skills to create change can occur and it is 'worth doing'. This exercise is very simple, but can achieve remarkable results.

Ask participants, keeping in mind the things we have been discussing today, to choose a personal behavior, attitude, value or practice that they wish to change. It is important that participants pick only the one area of personal change that will make the biggest difference - and focus on that. It is a lot easier to find the motivation and energy to focus on one goal rather than choosing two or three. We are more likely, by focusing on one thing, to achieve the one goal rather than multiple goals. If the right area for behavioural change is selected, increased effectiveness in this behaviour will almost certainly influence many other aspects of the participant's lives. For example someone may feel that they need to be a better listener. More effective listening will lead to a range of improvements in all kinds of related behaviours, such as team work, relationships, being a better friend/family member, less time wasted, etc. Impress upon participants it important to pick a behavior or practice that really matters to them.

Depending on the size of your group, have between four and six participants seated around a table. Each person has been asked to select one behaviour change that she or he is interested in changing. One person begins the exercise by saying, "I will..." and completes the sentence by stating one benefit that will accompany this change in behaviour. For example, you may say, "I will be more open to differing opinions – and by doing this I will hear more of other people's ideas". After the first person completes

their sentence, the next person in the circles talks about their behaviour change and benefit, such as "I will be more tolerant – which will make me a calmer person.

After each person in the circle has had a chance to discuss their specific behaviour and its benefit, the cycle begins again. Now each person mentions a second benefit that may result from changing the same behaviour, then a third benefit, continuing until each person has mentioned 6-8 benefits.

At the end of the exercise, hopefully the majority of people will find that the one personal behavioural change can have numerous benefits to many areas of their lives and that it is **worth the effort**. You may find that participants start out with benefits that they believe are 'corporately or professionally correct' and end with benefits that are more 'human'. As the exercise progresses, you may find that one or two realisations dawn upon participants. That they begin to see deep meaning in what they can achieve and become convinced that "*It is worth it!*"

Return everyone to the group and discuss what they have learnt and their reaction to the exercise.

Other suggestions: An alternative to finishing the sentence "I will..." and then stating a benefit to this behaviour change, participants could finish the sentence "When I get better at..." and then state a benefit to this behaviour change.

Is it worth it?

Pick the one area of personal change that will make the biggest difference

“I will...” and complete the sentence by stating one benefit that you believe will accompany this change in behaviour



Session 5



Session 5: Wrap up and evaluation



Time: 10 minutes

Resources: Session Plan for the entire program, PowerPoint slides, LCD projector & screen, computer, whiteboard (plus marker pens), flipcharts with blank paper, marker pens (various colours), questions from participants in the Q&A Box, Evaluation Forms, Business cards (or contact details for central contact person), Certificates of Attendance if being given out

Handouts:

1. Organisational Service Brochures (if applicable)
2. Participant evaluation form (if applicable)

Objectives:

- Participants will reflect on the information and knowledge they have gained through participating in today's workshop.
- Participants will hear what other people have learnt and gained from participating in today's workshop.
- Participants will have completed the workshop having achieved all of the workshop learning objectives.

Session 5



Wrap up and evaluation

Slide: Review of the workshop learning objectives



Slide Purpose: The aim of this slide is to have participants reflect on the workshop information and the knowledge they have gained and subsequently assess whether or not the workshop learning objectives have been achieved. Whether they considered the workshop learning objectives have been achieved.

Trainer Notes: The workshop has a set of learning objectives and it is important to determine what knowledge people have learnt and whether those objectives have been achieved; and if so how and if not, why not.

Having completed the workshop, participants now have the opportunity to reflect on the knowledge and skills they have gained and to determine whether or not the workshop meet their expectation and what they deem they have learnt. The time taken to review material will also encourage the retention of new information participants have gained.

Hand out a questionnaire to each participant, explaining that it covers questions relating to the workshop learning objectives to gather their thoughts and responses to what has been achieved. The questionnaires are to be kept by participants and are for the purpose of writing responses

only. They will only be used to report back to the group once everyone has completed their questionnaires and come back together to hear each other's answers.

Before people start you may wish to re-cap the learning objectives and content of the three main sessions. It may be useful to go through the course outline and briefly recap how each session (particular sessions 2, 3, and 4) had a specific contribution to the objectives.

The three main sessions:

- *Session 2: How to recognise stigma and discrimination and how it is experienced by PWID and;*
- *Session 3: How stigma and discrimination occur in healthcare settings and the impact it has on PWID's access to healthcare; and*
- *Session 4: Practical skills and strategies for reducing stigma and discrimination in healthcare settings.*

Workshop learning objectives:

- *Participants will leave the session with a comprehensive understanding of the impact of stigma and discrimination on PWID, those on pharmacotherapy and those living with hepatitis C and/or other BBVs.*
- *Participants will leave the session with a knowledge and awareness on issues pertaining to the manifestation of stigma and discrimination in health care settings as it relates to PWID, those on pharmacotherapy and those living with hepatitis C and/or other BBVs.*
- *Participants will have a comprehensive working knowledge of strategies and initiatives to combat stigma and discrimination directed at PWID, those on pharmacotherapy and those living with hepatitis C and/or other BBVs, at the levels of organisational, community and individual.*
- *Participants will have identified at least one personal or individual strategy to reduce barriers to access and health*

services for PWID, those on pharmacotherapy and those living with hepatitis C and/or other BBVs that they can implement within their personal and/or professional lives.

Ask participants to quietly reflect on the workshop material that has been covered, the discussions that have been raised, the examples provided of people's experiences of stigma and discrimination, the impact on people's physical and mental health and the knowledge they now feel they know to challenge and prevent stigma and discrimination. During this quiet reflection time ask participants to answer the questionnaire.

Once the participants have completed their questionnaire, bring them back as a group and ask each person to report on one thing they have learnt. Ask participants to choose only one of their answers that they wish to share with the group. Ask for a volunteer to start to start the group off.

After all the participants have finished reporting back to the group, wrap the exercise up by recapping a few of the answers people have supplied and how this reflects that the workshop succeeded in achieving all the learning objectives. You may need to recap a number of the answers so that you can individually demonstrate how the learning objectives have been achieved.

The finished questionnaires are for participants to keep for their own record.

• 'Optional extra'

• Alternative activities;

• – *Spiders web:*

• – *The application:*

• These activities can be used with this slide

Refer to 'optional extra' card for more information.



Review of the workshop learning objectives

- Participants will leave the workshop with a deeper understanding and awareness on how stigma and discrimination occurs in health care settings
- Participants will leave the workshop with a comprehensive understanding of the impact of stigma and discrimination
- Participants will have a comprehensive working knowledge of strategies and initiatives to prevent and challenge stigma and discrimination directed at PWID, from an individual, organizational and community perspective
- Participants will have identified at least one personal or individual strategy to reduce barriers to access and health services that they can implement within their personal and/or professional lives



Slide: Participant Evaluation



Activity Purpose: To formally evaluate the overall success of the workshop, including the workshop content, the delivery of information, and the training process with a view to enacting and adapting changes wherever relevant and appropriate.

Trainer Notes: This workshop is designed to reduce stigma and discrimination towards PWID and pharmacotherapy clients among health case workers: Evaluation is a key component of any training; it provides trainers with the feedback to adapt improve and/or change wherever it is relevant or appropriate for the betterment of the training, training process and the training objectives.

Having just spent time reflecting on what participants had learnt should assist them to fill out the evaluation form.

Handout evaluations and ask group to complete them.

Assure the group that all forms are anonymous and confidential. It is important that participants feel comfortable about writing open and honest answers. Let participants know that the information they are providing, both

positive comments and criticism is extremely valuable. The information collated will be used to improve and enhance future workshops.

Have an envelope or box for participants to place their completed evaluations.

Finally, thank all participants for their participation. Thanks should also be given to any key people who were involved in the program, including administrative staff (whether present or not) and the funding body.

Have available your contact details and those of your organisation for further information or training needs.

Be available for participants who wish to discuss the training process or other aspects of the course.



Participant evaluation

All evaluation forms are anonymous and confidential

All comments and feedback is welcome



Slide: Thanks for participating



Trainer Notes: Thank all participants for their willing cooperation. Evaluate your own performance in this training session.



“Thanks for participating”

