Stigma: why bother?

UNSW SYDNEY

We’ve been here before…

CONFERENCE REPORT

Hepatitis C-related discrimination in healthcare

Report of the Third Australasian Conference on Hepatitis C, Melbourne, March 2002

Carla J Treloar, Max N Hopwood and Stuart K Loveday

MJA Vol 177 2 September 2002

What were we talking about in 2002?

HOLLYWOOD CELEBRITY Pamela Anderson's announcement that she has hepatitis C was a major talking point at this recent conference. Unlike similar announcements of HIV infection, Ms Anderson has not positioned herself as a celebrity campaigner — there is no princess or pop star championing the rights of people with hepatitis C or demanding extra funding for research or services.

What were we talking about in 2002?

HOLLYWOOD CELEBRITY Pamela Anderson's announcement that she has hepatitis C was a major talking point at this recent conference. Unlike similar announcements of HIV infection, Ms Anderson has not positioned herself as a celebrity campaigner — there is no princess or pop star championing the rights of people with hepatitis C or demanding extra funding for research or services.

The participation of people from the affected communities provided opportunity for elaboration and reflection on research from the perspective of those primarily affected by hepatitis C. People with hepatitis C spoke informally of feelings of guilt, shame, low self-esteem and self-worth that arose as a result of their interactions with some healthcare professionals. They claimed that internalising stigma led to missed opportunities for care and support from social networks and had implications for people's access to healthcare services.

UNSW SYDNEY

What were we talking about in 2002?

HOLLYWOOD CELEBRITY Pamela Anderson's announcement that she has hepatitis C was a major talking point at this recent conference. Unlike similar announcements of HIV infection, Ms Anderson has not positioned herself as a celebrity campaigner — there is no princess or pop star championing the rights of people with hepatitis C or demanding extra funding for research or services.

The participation of people from the affected communities provided opportunity for elaboration and reflection on research from the perspective of those primarily affected by hepatitis C. People with hepatitis C spoke informally of feelings of guilt, shame, low self-esteem and self-worth that arose as a result of their interactions with some healthcare professionals. They claimed that internalising stigma led to missed opportunities for care and support from social networks and had implications for people's access to healthcare services.

Presentations discussed both institutional and interpersonal discrimination against people with hepatitis C. The relatively low level of community and government concern regarding this epidemic was alluded to in several presentations, suggesting a form of systemic discrimination.

UNSW SYDNEY

What were we talking about in 2002?

HOLLYWOOD CELEBRITY Pamela Anderson's announcement that she has hepatitis C was a major talking point at this recent conference. Unlike similar announcements of HIV infection, Ms Anderson has not positioned herself as a celebrity campaigner — there is no princess or pop star championing the rights of people with hepatitis C or demanding extra funding for research or services.

The participation of people from the affected communities provided opportunity for elaboration and reflection on research from the perspective of those primarily affected by hepatitis C. People with hepatitis C spoke commonly of feelings of shame, low self-esteem and self-worth that arose as a result of their interactions with some healthcare professionals. They claimed that internalising outcomes minimised opportunities for care and support from social networks and had implications for people's access to healthcare services.

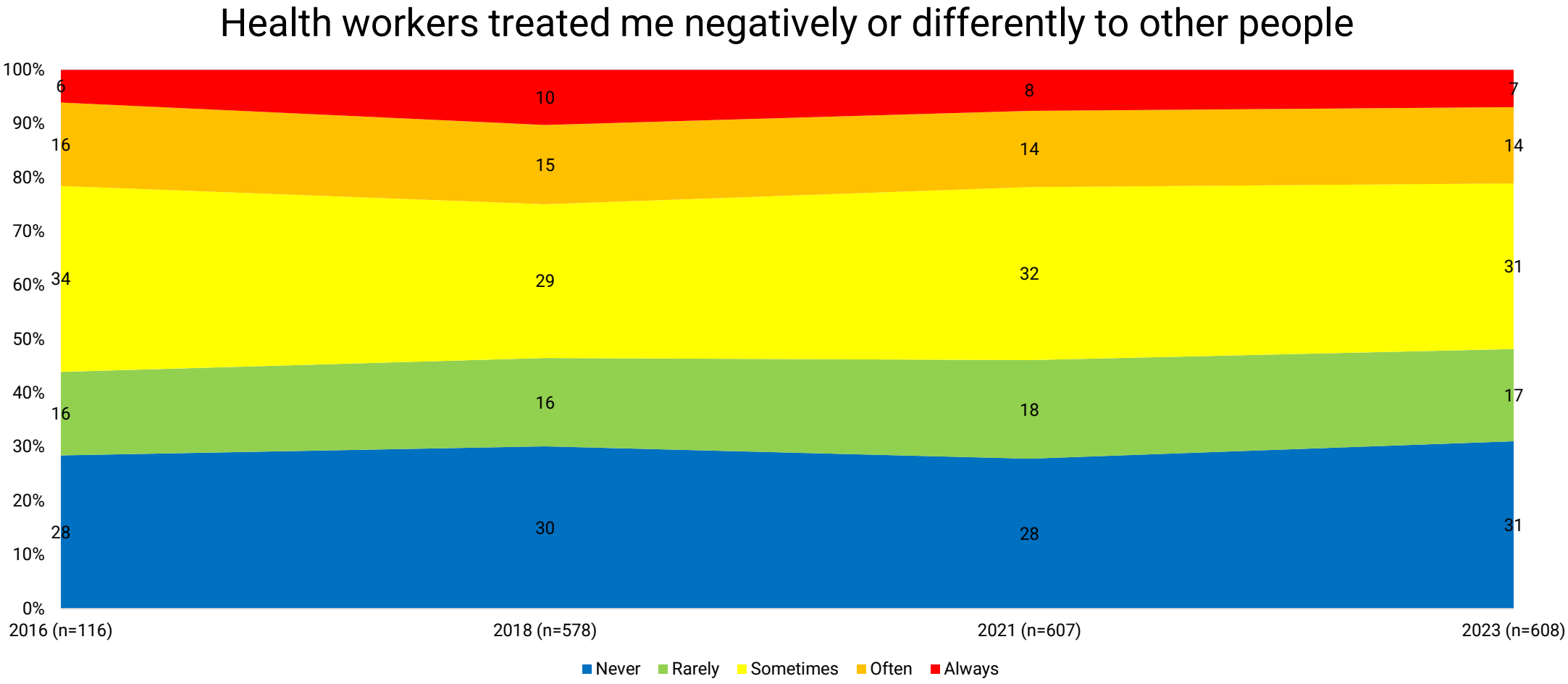
Not much has changed in 2 decades

Where is the outrage?

Presentations discussed both institutional and interpersonal discrimination against people with hepatitis C. The relatively low level of community and government concern regarding this epidemic was alluded to in several presentations, suggesting a form of systemic discrimination.

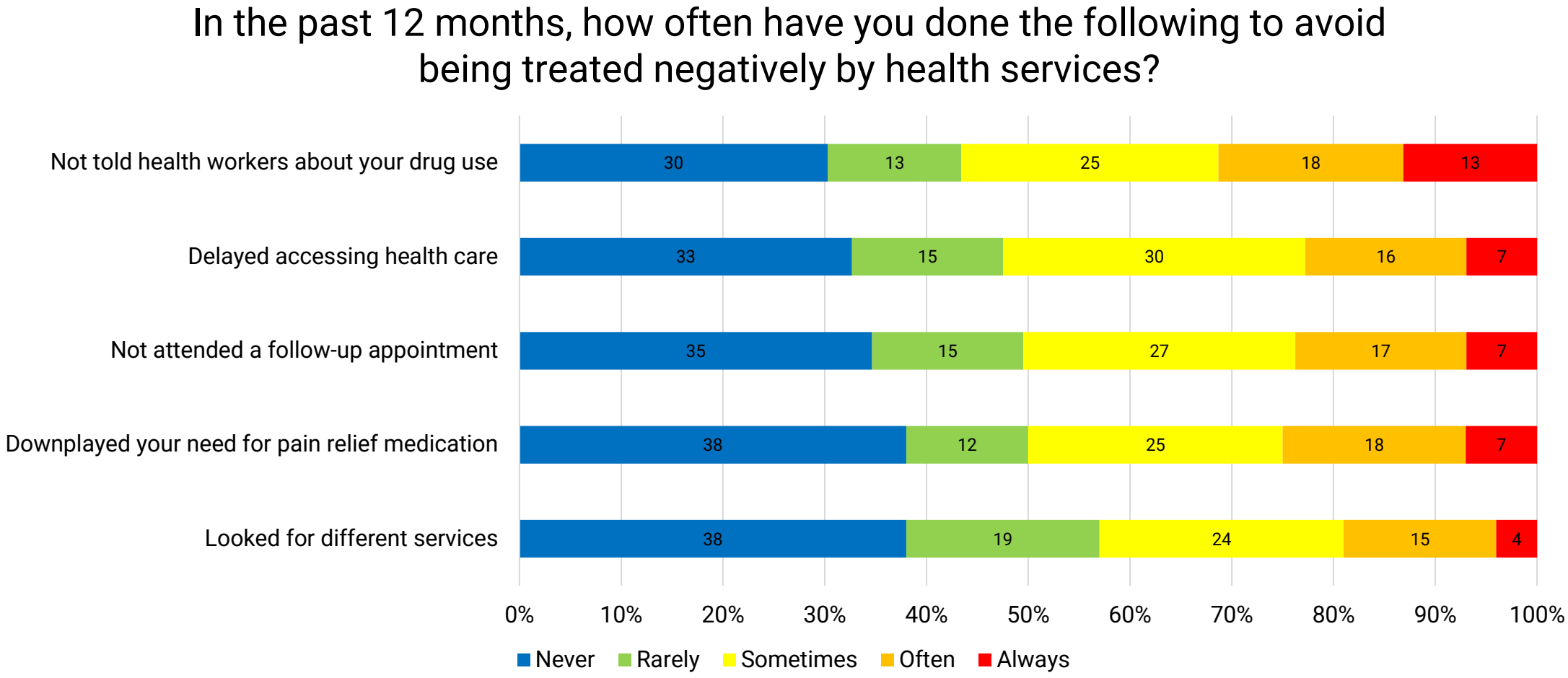
UNSW SYDNEY

People who inject drugs



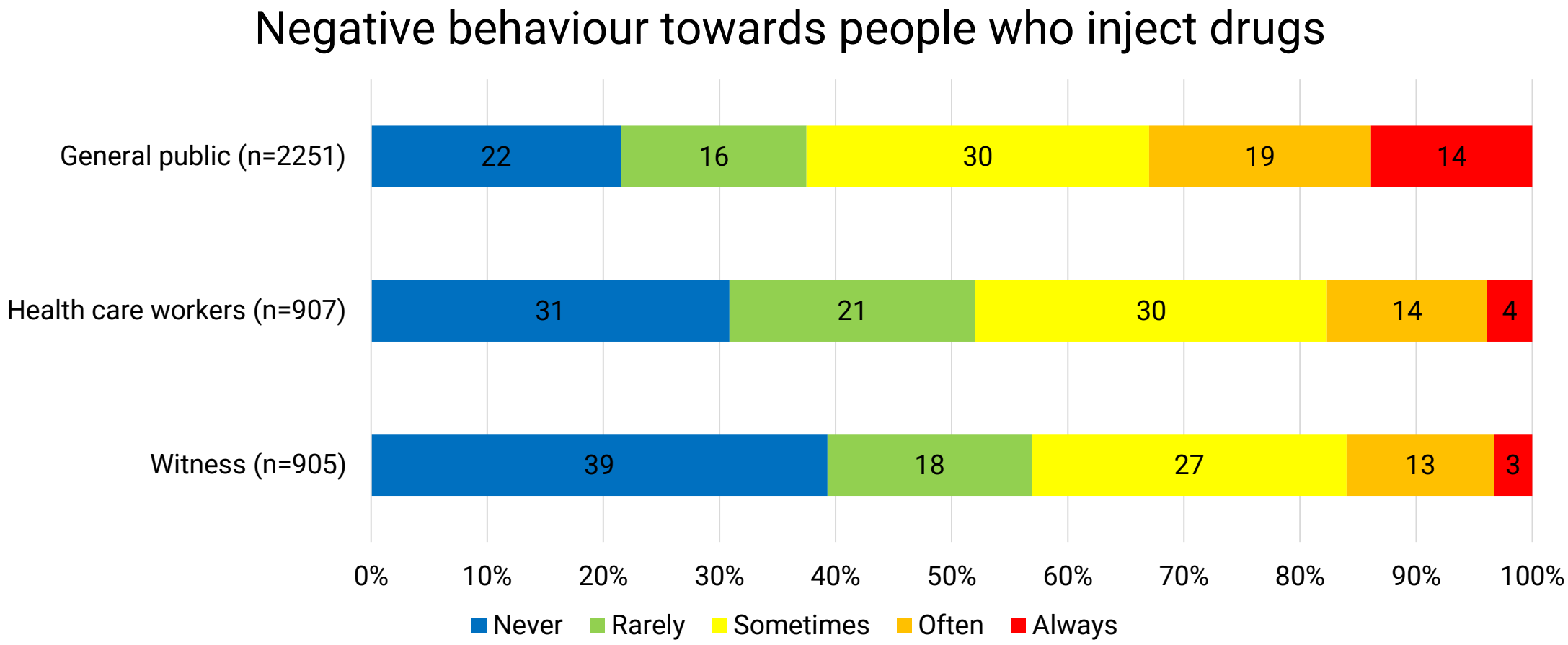
CSRH UNSW Stigma Indicators

People who inject drugs



CSRH UNSW Stigma Indicators

People who inject drugs



CSRH UNSW Stigma Indicators

First principles…

We seem to have some momentum, some focus on stigma

What do we need to know to create change?

Just like we need to understand and use:

antibody, PCR/RNA, POCT, SVR, models of care, cascades of care…

we need to understand and use precise knowledge for stigma action

What is stigma? Goffman (1963)

Defining stigma

A person experiences stigma when they are treated differently, or expect to be treated differently, because of some attribute that marks them as inferior

"… bad, or dangerous, or weak" (p.3)

Image source (CC): https://pxhere.com/en/photo/913653?utm_content=shareClip&utm_medium=referral&utm_source=pxhere

UNSW SYDNEY

What does stigma look like?

- Physical avoidance
- Reduced engagement
- Speaking in a manner that implies social distance
- Inappropriate engagement
- Ignoring / rejecting someone
- Unfair / unkind treatment
- Discrimination
- Facial / bodily expressions of fear / disgust
- Derogatory name calling
- Aggression / violence

UNSW SYDNEY

What makes up stigma?

The five components needed to produce stigma

1.	Distinguishing & labelling differences
2.	Associating human differences with negative attributes
3.	Separating “us” from “them”
4.	Status loss & discrimination
5.	Dependence on power

“In the extreme, the stigmatized person is thought to be so different from “us” as to be not really human. And again, in the extreme, all manner of horrific treatment of “them” becomes possible.”

Link, B., & Phelan, J. (2001). Conceptualizing stigma. *Annual Review of Sociology, 27, 363-385.*

UNSW SYDNEY

What is stigma power?: hidden in plain sight

Cultural/ambient stereotypes harm stigmatized groups even in absence of direct person-to-person discrimination

Buried in taken-for-granted aspects of culture, thereby hidden or "misrecognized" by those causing harm and by those being harmed

- Keeping people down - Stigma is mechanism for oppression and control
- Keeping people in - Society's desire to regulate behaviour through disapproval and penalties for being outside the status quo
- Keeping people away - When "in" fails -> social distance and discrimination

Ungar. (2021). Measuring Structural Stigma. In K. Dobson, *The Stigma of Mental Illness: Models and Methods of Stigma Reduction.* Oxford Uni Press.
Link & Phelan. (2014). Stigma power. *Social Science and Medicine*.
Morris et al (2024). Can 'justified disapproval' be separated from addiction stigma? An empirical focus is required. In press

UNSW SYDNEY

Where does stigma come from?

The six dimensions of stigma

Concealability	Its ability to be hidden or controlled
Course	Its persistence, outcomes, and patterns of change
Disruptiveness	How it inhibits or interferes with social interaction
Aesthetic qualities	Extent to which it repels or upsets others
Origin	How it arose, and extent of personal responsibility in this
Peril	How dangerous a threat it poses

Jones et al (1984). *Social stigma: The psychology of marked relationships. W. H. Freeman.*

UNSW SYDNEY

Where does stigma come from?

Origin – blame

Peril – infectious; physical threat

Aesthetic – smell, sight

The six dimensions of stigma

Concealability	Its ability to be hidden or controlled
Course	Its persistence, outcomes, and patterns of change
Disruptiveness	How it inhibits or interferes with social interaction
Aesthetic qualities	Extent to which it repels or upsets others
Origin	How it arose, and extent of personal responsibility in this
Peril	How dangerous a threat it poses

Jones et al (1984). *Social stigma: The psychology of marked relationships. W. H. Freeman.*

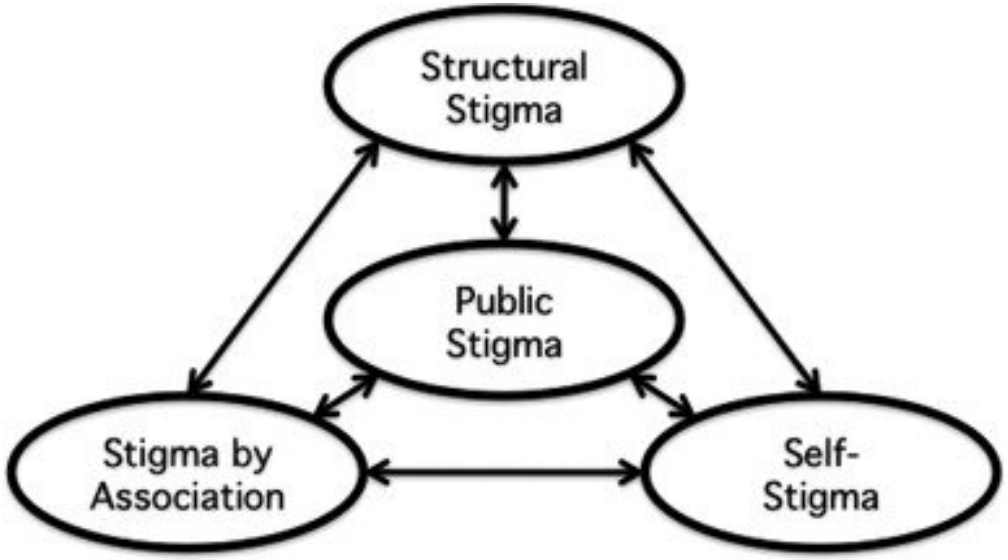
UNSW SYDNEY

Classifications of stigma

1. Public/Interpersonal stigma
Experiencing negative attitudes and behaviours
e.g. a black person in a store is observed closely by a shop attendant, but other white customers are not

2. Stigma by association
Experiencing secondary stigma because of a perceived connection to a person who is the object of primary stigma
e.g. the mother of a child with ADHD may experience judgment about her parenting

3. Structural stigma
Rules, practices, & customs that reproduce inequality
e.g. child protection practices that conflate poverty or kinship care with child neglect



4. Internalised/Self-stigma:
Applying negative labels and feelings to oneself and/or to others who share the same stigmatised attribute
e.g. "I ruined my life the first time I took drugs, and I'm to blame for what's happened to me"

FIGURE 1 Four types of stigma
Pryor, J.B. & Reeder, G.D. (2011). HIV-related stigma. In J.C. Hall, B.J. Hall & C.J. Cockerell (Eds.), *HIV/AIDS in the post-HAART era: Manifestations, treatment, and epidemiology* (pp.790–806). Shelton. https://www.researchgate.net/publication/235349425_Stigma_Advances_in_Theory_and_Research/figures?lo=1

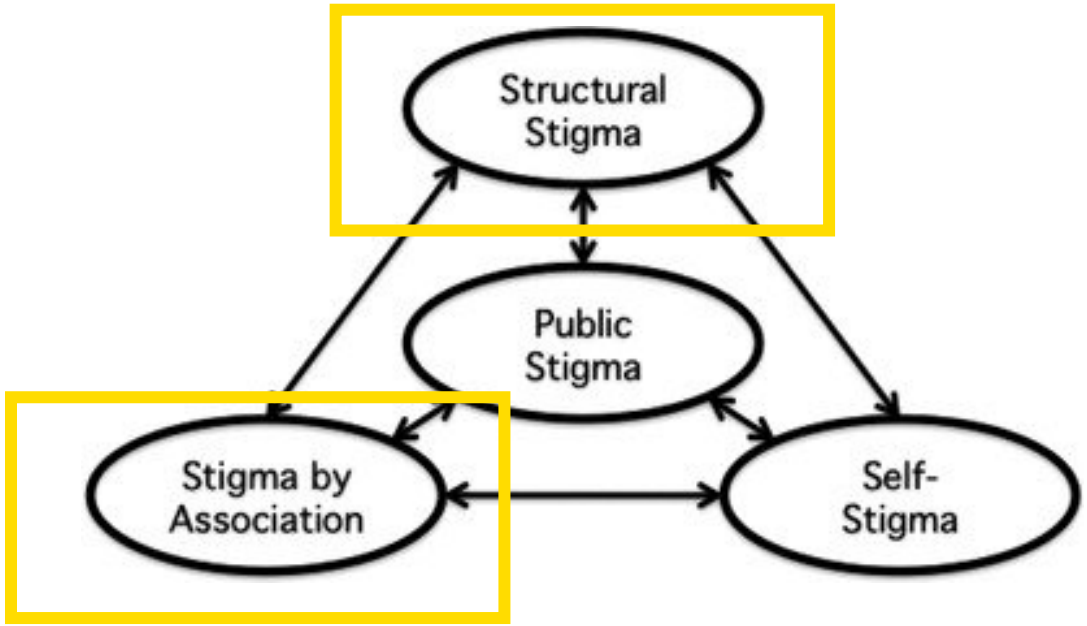
UNSW SYDNEY

Classifications of stigma

1. Public/Interpersonal stigma
Experiencing negative attitudes and behaviours
e.g. a black person in a store is observed closely by a shop attendant, but other white customers are not

2. Stigma by association
Experiencing secondary stigma because of a perceived connection to a person who is the object of primary stigma
e.g. the mother of a child with ADHD may experience judgment about her parenting

3. Structural stigma
Rules, practices, & customs that reproduce inequality
e.g. child protection practices that conflate poverty or kinship care with child neglect

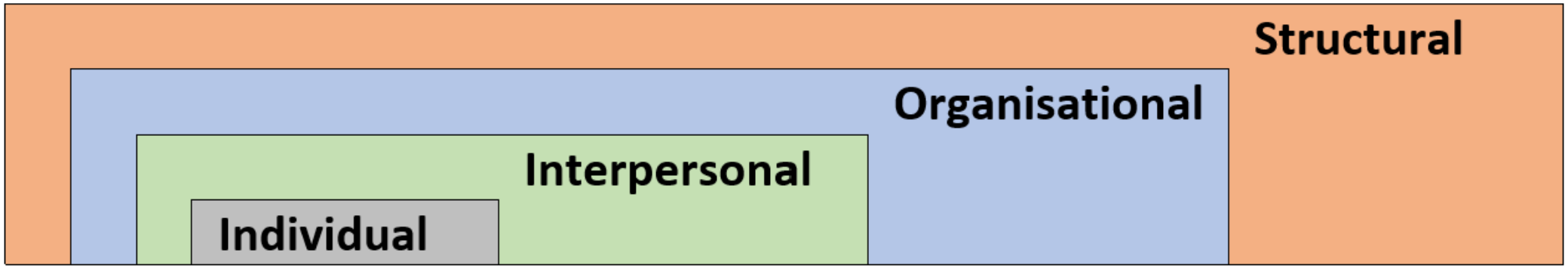


4. Internalised/Self-stigma:
Applying negative labels and feelings to oneself and/or to others who share the same stigmatised attribute
e.g. "I ruined my life the first time I took drugs, and I'm to blame for what's happened to me"

FIGURE 1 Four types of stigma
Pryor, J.B. & Reeder, G.D. (2011). HIV-related stigma. In J.C. Hall, B.J. Hall & C.J. Cockerell (Eds.), *HIV/AIDS in the post-HAART era: Manifestations, treatment, and epidemiology* (pp.790–806). Shelton. https://www.researchgate.net/publication/235349425_Stigma_Advances_in_Theory_and_Research/figures?lo=1

UNSW SYDNEY

Structural stigma



Rules, practices, & customs that reproduce inequality

Understand structural as shaping all other levels

Nyblade, L., Mingkwan, P., & Stockton, M. A. (2021). Stigma reduction: an essential ingredient to ending AIDS by 2030. *The Lancet HIV, 8(2), e106-e113.*

UNSW SYDNEY

Structural stigma in health

Societal norms rooted in the design, operation, delivery, and evaluation of health services

- the health bureaucrat, or the policy writer, or the person that's writing the legislation or designing the clinical service. They come from a very moralistic perspective (Participant 21).

Health services built on assumptions that do not match and work to keep out the people supposed to be assisted

Extra work to access care for people who deviate from normative assumptions

- “chisel away to find the door into a system” (Participant 2)

Treloar, C., Holland, A., Brener, L., Broady, T., & Cama, E. (under review). Tracing structural stigma in health care towards people with blood borne viruses and sexually transmissible infections: stigma power, societal norms and hidden processes.

Structural stigma in health

Societal norms as stigma governance in hidden, taken for granted processes in health care: “hidden within the system, within the language” (Participant 23)

- we are providing care for you, but somewhat reluctantly. Relationships and hidden assumptions that are in those environments which are about power and control, and who has influence is a is a really key issue … they’re influential in policy decisions and hidden biases and assumptions and judgmental attitudes that are seen in the division … and the allocation of resources (Participant 12)

Treloar, C., Holland, A., Brener, L., Broady, T., & Cama, E. (under review). Tracing structural stigma in health care towards people with blood borne viruses and sexually transmissible infections: stigma power, societal norms and hidden processes.

Stigma by association – health workers (1,2)

- Discrimination or prejudice experienced by individuals associated with people who are stigmatised
  - even though they do not possess the stigmatised attribute or identity themselves

- Negative attitudes people hold towards those who use AOD can also affect AOD workers
  - leading to lowered productivity and wellbeing

- Particularly significant as workers may have lived/living experience of AOD use, and identify strongly with their client group

1. Caruana et al "A huge, unwieldy barrier to push through on a daily basis": The effects of stigma on AOD workers and workplaces. *International Journal of Drug Policy, 2025 143, 104916.*
2. Treloar et al (2015). 'Doing the devil's work': emotional labour and stigma in expanding Needle and Syringe Programs. *Drugs: Education, Prevention, and Policy, 2015 22(5), 437-443.*

UNSW SYDNEY

Stigma by association – health workers (1,2)

"I feel like I have to justify to the public or family that people who use the service that I work for are deserving, good people and have the right to live their lives using drugs if they choose that. "

"I have become fairly adept at ignoring stigma. If people want to pointedly stigmatise me because of the work I do, then I am quite happy to disregard their opinions entirely."

"I know many peers who have chosen to "edit" their job title because they don't feel safe being identified as a peer worker in certain spaces.“

"Some other health professionals blame us for the challenging behaviours exhibited by our clients."

1. Caruana et al "A huge, unwieldy barrier to push through on a daily basis": The effects of stigma on AOD workers and workplaces. *International Journal of Drug Policy, 2025 143, 104916.*
2. Treloar et al (2015). ‘Doing the devil’s work’: emotional labour and stigma in expanding Needle and Syringe Programs. *Drugs: Education, Prevention, and Policy, 2015 22(5), 437-443.*

UNSW SYDNEY

“there’s 1000s of stigmas out there”

Broad range of conditions which attract stigma

93 identities, conditions and attributes reported as being stigmatised in a sample of US adults (1)

- most participants (>95%) indicated that they lived with at least one attribute
- 90% reported more than one, average of six.

Not feasible for health systems to respond to each (93) condition, identity, practices

A universal approach to stigma (and quality of care)

- assumes that all patients are concerned about exclusion or poor treatment
- on the basis of one or more conditions, practices, or identities (2)

autism
bipolar disorder
blind
criminal record
disability
drug use
facial scars
gender
HIV
Incontinence
living in public housing
low education
manual work
multiple tattoos
old age
overweight
psoriasis
race
sexuality
short stature
teen parent
unemployed
….

1. Pachankis et al. The Burden of Stigma on Health and Well-Being. Pers Soc Psychol Bull. 2018;44(4):451-74.
2. Treloar, Cama, Lancaster, Brener, Broady, Cogle, Donnell (2022). "A universal precautions approach to reducing stigma in health care: getting beyond HIV-specific stigma." Harm Reduction Journal 19(1): 74

UNSW SYDNEY

What are we doing about it?

Universal approach to stigma reduction in health care

Tackling Stigma Conference 2026

Stigma in Healthcare short course

Tackling Stigma in Healthcare network

Coming up:

Advocating for change to quality standards to explicitly reference stigma

Estimating the prevalence of stigma in Australian population

UNSW SYDNEY

Let’s tackle stigma together

Tackling Stigma IN HEALTHCARE

- Curated cross-sector research and resources
- Interviews with Stigma Champions
- Online events and webinars
- Monthly newsletter for inspiration and advice
- Conference every second year
- GET INVOLVED!

Sign up and we’ll be in touch with how you can nominate a champion

SHORT COURSE

Combating Stigma

Strategies for Inclusive Health Services

UNSW SYDNEY

CSRH

UNSW Centre for Social Research in Health

96% Course Satisfaction Rating

ONLINE LEARNING | 6 MODULES & LECTURES | 37.5 HOURS

LAUNCHING 07 OCTOBER 2025

SCAN ME!

CSRH UNSW Stigma Indicators

The Stigma-Free Standard

Tackling Stigma Network

Short course

Precise, informed analysis and action

c.treloar@unsw.edu.au