

Understanding Drug-Related Stigma

Tools for Better Practice and Social Change

Participant Workbook



**Harm Reduction Coalition
22 West 27th Street, 5th Floor
New York, NY 10001
(212) 213-6376
(212) 213-6582 (fax)**

www.harmreduction.org * hrc@harmreduction.org

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TRAINING AT-A-GLANCE – 3 HOURS

Module 1: Anonymous Survey and Introduction

Anonymous Survey Exercise
Participant and Trainer Introductions
Goals, Expectations and Guidelines
Quotes Discussion

Module 2: What is Stigma?

Basic Principles
Stigma Definition
Activity: *Forms of Stigma*

Module 3: Understanding Drug-Related Stigma

Elements of Drug-Related Stigma
Cycle and Reach of Drug-Related Stigma
Implications for Providers

- 10 minute BREAK -

Module 4: Exploring Labels and Language

Activity: *Video Critique*
Drug User Labels
Considering Language

Module 5: Dynamics of Stigma

Activity: *3D Exercise*

Module 6: Challenging Stigma, Creating Change

Individual-Level Change
Staff- and Community-Level Change

Module 7: Closing and Evaluations

Learning review
Evaluations

UNDERSTANDING DRUG-RELATED STIGMA AND DISCRIMINATION

Tools for Better Practice
and Social Change



Harm Reduction Coalition

2010

Introductions

- Name
- Organization
- How do you interact with drug users?

Goals

- Identify and explore the reach of drug-related stigma.
- Name strategies for confronting drug-related stigma.
- Promote productive service provision that avoids stigmatizing people who use drugs.

Training Guidelines

- Step up, Step Back
- Non-Judgment
- Talk *with* each other, not *at* each other
- Agree to disagree
- Confidentiality

A few basic principles...

- Drug use exists along a continuum
 - Abstinence is one of many possible goals*
 - Meet people "where they are at"*
- Drug-related harm can not be assumed
 - Drugs can meet important needs*
- Drug users are more than their drug use

What is stigma?

A **social process** which can reinforce relations of **power** and **control**.

Leads to **status loss** and **discrimination** for the stigmatized.

- Link and Phelan

ACTIVITY: Forms of Stigma

Stigma from individuals

Institutional stigma

Self-stigma (internalized)

Stigma by association

Key Elements of Drug-Related Stigma

Blame and moral judgment

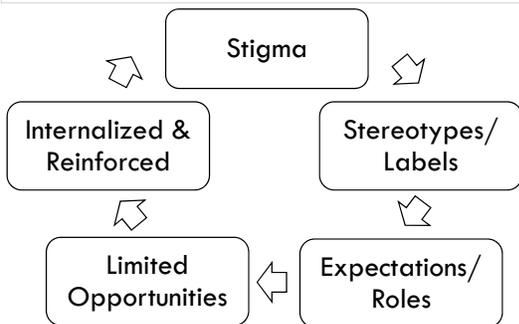
Criminalize

Pathologize

Patronize

Fear and Isolate

Cycle of Drug-Related Stigma



Implications for Providers

- Willingness to access services
- Relationships and trust
 - Assumptions
- Participant risk and behaviors
- Participant self-worth
- Funding

Break!

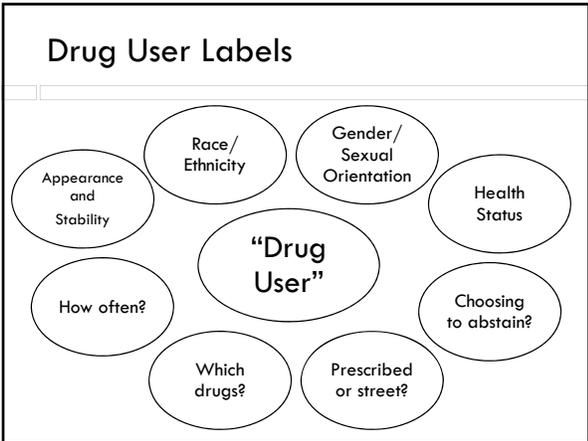
- 10 minute break -

Video: Labels and Language

Purpose: *Explore labels and language associated with drugs/drug use and their relationship to stigma*

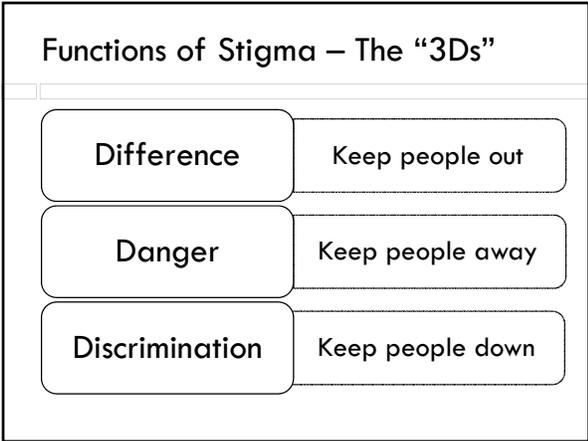
Pay attention to:

- Labels & Language
- Themes that you see in your work with clients



Language

Junkies, Dope Fiends
 Crack-heads, Crack Babies
 Drug Addicts, Drug Abusers
 Drug Users, People Who Use Drugs
 Drug Use, Drug Abuse, Drug Misuse
 Clean and Dirty
 Relapse vs. Lapse



Activity: Dynamics of Stigma

Purpose: *To explore different dynamics and consequences of stigma*

Keep in mind the the 3-Ds:

- ▣ *Difference (Keeping people out)*
- ▣ *Danger (Keeping people away)*
- ▣ *Discrimination (Keeping people down)*

Round 1

Brainstorm ways that your institution stigmatizes drug users

*Think about behaviors/actions
AND
Why it happens
(3Ds/Beliefs)*

Round 2

Brainstorm ways that drug users may respond to the stigmatizing behaviors from round 1

*Name behaviors/actions
AND
Ways stigma may be internalized*

Round 3

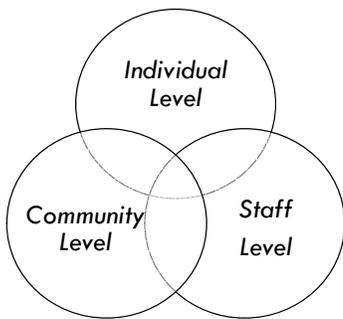
List 3 strategies/alternatives to challenge the stigmatizing behaviors you have discussed.

Either from the perspective of the institution

OR

As a provider helping a client

Challenging Stigma, Creating Change



Individual Level

Language

Honesty

Relationships

Disclosure and dialogue

Education and personal development

Staff and Community Level

Staff Level

- Training and education
- Outlets for feedback
- Assessment of practices
- Hiring Drug Users

Community Level

- Participant Advisory Boards
- Awareness Campaigns
- Policy and advocacy
- Events

Release Campaign



ANONYMOUS SURVEY

Consider the following statement. Either in your head or on paper mark the box that most accurately reflects your response to the statements below.

Please do not put your name on this paper.

There are no right or wrong answers and these papers will not be collected.

Statement	Strongly Agree	Agree	Disagree	Strongly Disagree
Although I don't necessarily agree with them, sometimes I have prejudiced feelings (like gut reactions or spontaneous thoughts) toward drug users that I don't feel I can prevent.				
I understand the experience of being stigmatized as a drug user.				
Sometimes I am uncomfortable around people who are very different from me.				
It is not appropriate for me to talk about my drug and alcohol use with clients.				
I trust drug users just as much as I trust non-drug users.				
If a woman is pregnant, she has a responsibility to stop taking drugs.				
Drug users have a difficult time practicing safe sex consistently.				
Drug users have meaningful participation in developing policies and programs at my organization.				
I know how to avoid language that stigmatizes drug users.				
Although it is hard to admit, I sometimes judge people who cannot stop using drugs.				

Adapted from *Using Harm Reduction to Address Sexual Risk with Drug Users and Their Partners*, HIV Education and Training Programs, NYSDOH AIDS Institute, by Joanna Berton Martinez, August 2009.

Some of the statements on this exercise were borrowed from Project Implicit and their Implicit Association Tests, <https://implicit.harvard.edu/implicit/>

QUOTES

Anyway, no drug, not even alcohol, causes the fundamental ills of society. If we're looking for the source of our troubles, we shouldn't test people for drugs, we should test them for stupidity, ignorance, greed and love of power.

P. J. O'Rourke, American political satirist, journalist, writer and author

I always got along with all types of people - popular people as well as drug addicts. - Amy Sedaris, American actress, author and comedian

I used to have a drug problem, now I make enough money.

David Lee Roth, American rock vocalist, songwriter, actor, author, and former radio personality, best known for Van Halen

Let me be clear about this. I don't have a drug problem. I have a police problem. - Keith Richards, English guitarist, songwriter, singer, record producer and a founding member of The Rolling Stones

People always want to ask me about my drug problem - I never had a drug problem; I had a self-esteem problem! - Gloria Gaynor, American singer, best-known for the disco era hits

"You cannot solve a problem from the same consciousness that created it. You must learn to see the world anew." -Albert Einstein, theoretical physicist, philosopher and author

It is no measure of health to be well adjusted to a profoundly sick society.

Jiddu Krishnamurti, an Indian writer and speaker on philosophical and spiritual issues

Society has always seemed to demand a little more from human beings than it will get in practice. - George Orwell, an English author and journalist, best known for the novels Nineteen Eighty-Four and Animal Farm

All the people like us are we, and everyone else is They. - Rudyard Kipling, a British author and poet

A man is but the product of his thoughts what he thinks, he becomes.

Mohandas Gandhi, pre-eminent political and spiritual leader of India during the Indian independence movement

There's so much talk about the drug generation and songs about drugs. That's stupid. They aren't songs about drugs; they're about life. - Cass Elliot, noted American singer, best remembered as Mama Cass of the pop quartet The Mamas & the Papas

The most potent weapon of the oppressor is the mind of the oppressed.

- Steven Biko, a political activist and writer, is regarded as the father of the Black Consciousness movement in the Union of South Africa

"Marijuana is taken by '.....musicians. And I'm not speaking about good musicians, but the jazz type...'

~ Harry J. Anslinger, Federal Bureau of Narcotics, 1948

"All people have the right to beautiful and radiant things" -Emma Goldman, an anarchist known for her political activism, writing and speeches

"Fear is a disease that eats away at logic and makes man inhuman." – Marion Anderson, an American contralto and one of the most celebrated singers of the twentieth century

"Prejudice is the child of ignorance." – William Hazlitt, an English writer, remembered for his humanistic essays and literary criticism, and as a grammarian and philosopher

No man is good enough to govern another man without that other's consent. - *Abraham Lincoln*, served as the 16th President of the United States

The trouble with people is not that they don't know, but that they know so much that ain't so. — *Josh Billings*, the pen name of humorist born Henry Wheeler Shaw

A junkie is someone who uses their body to tell society that something is wrong." ~ Stella Adler, an American actress and an acclaimed acting teacher

"Our national drug is alcohol. We tend to regard the use any other drug with special horror." ~ William S. Burroughs, an American novelist, poet, essayist, painter and spoken word performer

"Of course drugs were fun. And that's what's so stupid about anti-drug campaigns: they don't admit that. I can't say I feel particularly scarred or lessened by my experimentation with drugs. They've gotten a very bad name." ~ Anjelica Huston, an American actress

The basic thing nobody asks is why do people take drugs of any sort? Why do we have these accessories to normal living to live? I mean, is there something wrong with society that's making us so pressurized, that we cannot live without guarding ourselves against it? - John Lennon, an English singer-songwriter who rose to worldwide fame as one of the founding members of The Beatles

The more you can increase fear of drugs and crime, welfare mothers, immigrants and aliens, the more you control all the people. - Noam Chomsky, an American linguist, philosopher, cognitive scientist, and political activist

I think it's too bad that everybody's decided to turn on drugs, I don't think drugs are the problem. Crime is the problem. Cops are the problem. Money's the problem. But drugs are just drugs. - Jerry Garcia, an American musician best known for his lead guitar work, singing and songwriting with the band the Grateful Dead

Run for office? No. I've slept with too many women, I've done too many drugs, and I've been to too many parties. - George Clooney, an American actor, film director, producer, and screenwriter

As parents, we need to talk to young people about drugs and make sure they understand that drugs are dangerous, addictive substances that can ruin their lives and harm their communities. - John Walters, former Director of the White House Office of National Drug Control Policy (ONDCP)

I think hard drugs are disgusting. But I must say, I think marijuana is pretty lightweight. - Linda McCartney, an American photographer, musician and animal rights activist

If they took all the drugs, nicotine, alcohol and caffeine off the market for six days, they'd have to bring out the tanks to control you. - Dick Gregory, an American comedian, social activist, social critic, writer, and entrepreneur

It's so easy for a kid to join a gang, to do drugs... we should make it that easy to be involved in football and academics. - Snoop Dogg, an American entertainer, rapper, record producer and actor

Drugs made me feel more normal. - Carrie Fisher, an American novelist, screenwriter and actress

The purpose of random testing is not to catch, punish, or expose students who use drugs, but to save their lives and discover abuse problems early so that students can grow up and learn in a drug-free environment. - John Walters, former Director of the White House Office of National Drug Control Policy (ONDCP)

I'm in favor of legalizing drugs. According to my values system, if people want to kill themselves, they have every right to do so. Most of the harm that comes from drugs is because they are illegal. - Milton Friedman, an American economist, statistician, and a recipient of the Nobel Memorial Prize in Economics

There is only one reason why men become addicted to drugs - they are weak men. Only strong men are cured, and they cure themselves. Martin H. Fischer, was a German-born American physician and author

I'm already so ashamed of being a junkie. Now I have hep C, and I feel as if that announces to everyone that I'm a junkie. - Marcus R., from The First Year: Hepatitis C

In my hep C support group, people would talk about how they got the disease. There was this hierarchy in which people who got the disease through transfusion were 'good people' and people who got the disease through drugs were the 'bad people' who 'deserved' hep C. - Janice H., from The First Year: Hepatitis C

I am a successful guy. I have a great, well-paying job as a consultant. I am married with two kids. I have everything I've always wanted. I also have hep C. I messed around with drugs once or twice when I was younger. I wish I hadn't. Usually I lie about how I contracted hep C...say I don't know. I still feel like people are suspicious of me. As if I don't deserve everything I have now. - Bart M., from The First Year: Hepatitis C

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Research paper

Injecting drug users: A stigmatised and stigmatising population

Lesley Simmonds*, Ross Coomber¹

School of Law and Social Science, University of Plymouth, Drake Circus, Plymouth PL4 8AA, United Kingdom

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Abstract

Background: This paper considers the way that social stigma impacts both *on* injecting drug user (IDU) populations and operates *within* them and the consequences this has for prevention and harm reduction amongst IDUs.

Methods: The research from which this paper is drawn was a city case study, itself part of a larger national study to evaluate the efficacy of needle exchanges throughout England and Wales. Not initially part of the issues being explored, the interviews consistently pointed to concerns of stigma, and in this sense the theme was emergent from the qualitative process itself.

Results: The primary findings relating to this issue were: IDUs concern for being recognised or ‘seen’ as IDUs affected service uptake and/or their interaction with services; ‘normal’ IDUs moreover tended to stigmatise those IDUs they believed to be ‘worse’ than them – primarily the homeless – despite the fact that their own behaviour was often less than ‘responsible’ itself. In these ways ‘stigma’, whether being accepted or expressed by these different groups militated against the ‘harm reductive’ goals of Safer Injecting Services.

Conclusion: It is concluded that much can be done to reduce stigma related to IDU and drug use in general and that this may result in improved service efficacy and a reduction in associated drug related harms. It is also concluded that many IDUs seek to enhance their own self-esteem and reinforce their own sense as ‘responsible members of society’ rather than the outsiders they often feel themselves to be by attributing stigmatised behaviours on other ‘lesser’ IDUs. This practice may also contribute to them militating against their own guilt regarding their own risky behaviours, however in so doing the goal of harm reduction may be further undermined.

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Keywords: Stigma; IDU; Needle exchange; Harm reduction

Background

In recent years ‘stigma’ has been discussed in relation to various groups including those experiencing mental health problems (Angermeyer & Matschinger, 1994; Corrigan & Penn, 1999; Phelan, Link, Stueve, & Pescosolido, 2000), disability (Green, Davis, Karshmer, Marsh, & Straight, 2005) and a recorded criminal past (Cooke, 2004). As regards illicit drug use, injecting drug users and those experiencing HIV and Hepatitis it has been suggested that the attribution of, and internalisation of stigma can reduce the effectiveness of prevention and harm reduction activities: that the stigmatisation of client populations affects how they are treated and that the internalisation of stigma by the

client (or *potential* client populations) prevents them from accessing or fully utilising the services on offer (Fitzgerald, McDonald, & Klugman, 2004; National Aids Trust, 2003).

Traditional concepts of stigma were concerned with those considered to have a ‘spoiled’ public identity (Foster, 1971) and, via the ‘looking glass self’ (Cooley, 1964, p. 184) how those stigmatised tended to internalise aspects of that spoiled identity. Stigma for Goffman (1963) relates to ‘an attribute that is deeply discrediting’ to the individual; and similarly for Schur (1971) it is a label that is applied (and accepted) that signifies that the individual deviates from that which society has deemed to be ‘normal’. Society thus responds to the attribute with ‘... interpersonal or collective reactions that serve to ‘isolate’ ‘treat’, ‘correct’, or ‘punish’ individuals engaged in such behaviour’ (Schur, 1971, p. 24). Stigma is also a means of exerting ‘social control’ (Lemert, 1972) and/or reinforcing one’s own more righteous, or less discrediting position over those undergoing stigmatisation. Stigma

* Corresponding author. Tel.: +44 1752 233229.

E-mail addresses: lsimmonds@plymouth.ac.uk (L. Simmonds), rcoomber@plymouth.ac.uk (R. Coomber).

¹ Tel.: +44 1752 233218.

does not ‘sit alone’ in its discrimination and Jones et al. (1984) for example argued that the drug use of those of low socio-economic status is more likely to be stigmatised than that of the rich and famous. Historical examples of working class drug use and the development of drug control appears to bear this out (along with that of ethnicity) to some extent (Bean, 1974; Berridge & Edwards, 1987; Coomber, 2006; Musto, 1987).

Although traditional views on stigma continue to influence current thinking (albeit often without the ‘baggage’ of social control theory) more recent discussions reinforce the dynamic nature of the process/es of stigmatisation (Link & Phelan, 2001) through a combination of labelling, stereotyping, separation, status loss and discrimination. Stigma, and the extent to which it is successfully attributed and accepted, should be understood from the unequal (social) power relations from within the context it operates. Link and Phelan note how earlier approaches viewed stigma as a mark or attribution within the person which focused attention upon the stigmatised individual. By considering stigma as ‘discrimination’ the focus is directed at those who produce rejection and exclusion (Sayce, 1998). The incorporation and use of terms such as discrimination when discussing stigma can then lead to different understandings of who is responsible for the problem of stigma, and the actions that may be taken (Sayce, 1998).

Herek (1986), Herek and Capitanio (1998) and Herek, Capitanio, and Widaman (2002) discuss stigma as being both instrumental and symbolic; possibly at one and the same time. Instrumental stigma concerns an evaluation of a given situation whereby individuals may refuse to shake the hand of an HIV/AIDS sufferer in order to protect him/herself from harm or to protect community resources. More recently Herek, Widaman, and Capitanio (2005) discuss how this stigma may be instrumentally attached to those who are assumed to present a risk to society by virtue of lifestyle; for example gay men. They may then be discriminated against.

Stigma may also be symbolic, as in when a moral judgement is made. For example HIV/AIDS sufferers may be viewed as blameworthy as IDUs, unlike those ‘innocently infected’ by blood transfusions (Herek & Capitanio, 1998). Individuals then affirm their own self-concept by being able to distance themselves from ‘the problem’ and feeling justified in treating the blameworthy less advantageously.

The effects of stigma on drug users

The effects of stigma can be wide-ranging. In the public policy and health sphere the stigmatisation of specific populations may also result in the view that certain populations are less ‘worthy’ and therefore ‘less eligible’ or less ‘deserving’ of services than other groups. Fitzgerald et al. (2004) for example discuss how pain limitation for IDUs is less of a priority or indeed support services when there are other more

deserving groups within the context of scarce resources. After all IDUs may be judged as having ‘chosen’ or voluntarily succumbed to the ill-effects of drug use.

The work of Fitzgerald et al. (2004) on stigma as applied to injecting drug users has particular resonance with our work, producing strong parallels as shall become evident later. In their study of how social stigma affects young drug users (IDUs) in small town Australia, Fitzgerald et al. (2004) considered the impact of drug use upon a young person’s identity. In this small town context, drug users (IDUs) quickly become ‘known’ as such. They underwent a ‘social transformation’; an extreme identity transformation, whereby they become publicly acknowledged as users (IDUs). One outcome of this process is their acceptance into using networks. Once ‘known’ as a user; many become excluded from broader social worlds, including employment opportunities (Fitzgerald et al., 2004). In contrast Fitzgerald et al. report that some users in larger places manage to maintain a dual existence, maintaining separate friendship groups amongst users and non-users. However it was much harder to conceal one’s identity in the smaller towns and new users had to quickly choose which world they wished to inhabit.

One important outcome highlighted by Fitzgerald et al. was how stigmatisation appeared to increase the likelihood of IDUs rejecting services such as Safer Injecting Services, even where this was provided by an outreach van that provided a relatively secure means of protecting their identity. Users in these circumstances reported being reluctant to arrange for the outreach service to call to their homes. They were reluctant also to buy needles from a local pharmacy as pharmacists were viewed with high levels of suspicion and as part of a network of surveillance. Indeed one recommendation that Fitzgerald et al. make (point 3.3) (2004, p. 56) is the review of practices whereby pharmacists assemble databases on IDUs’ consumption of over the counter remedies and so perform a ‘policing role’ (Sheridan et al., 2000).

Social stigma is ubiquitous (Dovidio, Kawakami, & Gaertner, 2000). Its almost universal existence suggests a ‘functional’ value or utility for the stigmatising individual him/herself, for the group from which he or she comes, for the society, or for all of these (Crocker, Major, & Steele, 1998, p. 508). Stigma can enhance the self-esteem of the stigmatising individual through processes of ‘downward comparison’ (Wills, 1981). In the ‘active’ state stigmatisers ‘create’ the disadvantage of others through discrimination (Dovidio et al., 2000). Stigmatisation may motivate inter-group comparisons. The stigmatiser, who views him/herself belonging to the in-group may feel a raised sense of self-esteem (Tajfel & Turner, 1985). In this way the development of a positive social identity (Tajfel & Turner, 1979) rests upon a process of stereotyping other groups who are judged by the attributes that the ‘in-group’ value.

Such work has resonance with a further important issue raised by Fitzgerald et al. (2004)—that of stigmatisation *within* the injecting drug user population. In their study they noted how non infected IDUs often passed moral judgements

upon those with Hepatitis C, viewing them as ‘not caring’, having ‘less morals’ and for being ‘irresponsible’ (48). In this case the in-group was made up of those without Hepatitis C.

That stigmatisation operates *within* drug using groups was commented on as early as the 1950s and 1960s where researchers referred to what they saw as the ‘propensity by drug users [sic] to derogate other drug users [sic]’ (Garfinkel, 1956, p. 420), in an attempt to raise their own status. Other early research by Sutter (1966) identified a hierarchy of injectors, facilitating one group’s ability to feel superior to another. More recently it has been noted that it is not uncommon for heroin addicted individuals to distinguish themselves from the ‘out of control dope fiend’; distancing themselves in order to remove themselves from a stigmatised category (Furst, Johnson, Dunlap, & Curtis, 1999).

Methodology

This paper is based upon research undertaken in 2005, on the barriers to effective provision of Safer Injecting Services (SIS) in a city in the far South West of England. The research was a case study off-shoot from a national needs assessment of SIS facilities in the UK, undertaken by the National Treatment Agency (NTA). The primary method of data collection used a qualitative interview for both SIS providers (community pharmacists) and injecting drug users using the service, as well as for other key persons involved with the delivery and organisation of services within the city and beyond.

SIS in the city consisted of 13 pharmacy outlets—many of which were little more than conventional ‘needle-exchanges’ (providing little more than free needles to those registered and greater/lesser degrees of flexibility around the exchange element). A primary ‘hub’ SIS provided a comprehensive Safer Injecting Service and a mobile (call-out) outreach service. Safer Injecting Services of the type provided by the ‘hub’ studied in this research include the provision of injecting support and advice; the provision of other ‘paraphernalia’ such as citric acid, swabs and the like; health checks and the return of used needles.

Interviews were undertaken with all 12 pharmacists providing needles (one pharmacist owned two outlets). Four respondents had also provided other injecting paraphernalia, with a fifth reporting that whilst she had done so in the past, she was no longer supportive of this. Four Key Personnel were interviewed. These included members of the local Drug and Alcohol Action Team, the manager of the primary ‘hub’ SIS, and the manager of the mobile (call out) outreach service.

Ninety-one injecting drug users were interviewed in total. Six IDUs were users of the outreach service as they lived in outlying (rural towns) areas. Four IDUs were steroid injectors recruited from gyms within the city; they used the hub service. At the time of the research there were approximately 2000 IDUs in Plymouth; however of these only 850 were registered with the SIS. On an average week some 450 IDUs use the

SIS; however this figure may be subject to both over and undercounting as our research uncovered.

Recruitment

Seventeen (19%) IDUs were recruited from the hub SIS (including the 4 steroid injectors); 6 from the outreach service and 68 (75%) from the 13 participating pharmacies. The hub service provided researchers with rooms for interviewing, and staff approached IDUs initially to ask if they were willing to take part in the research. Outreach staff asked users beforehand if they would be willing to be interviewed and interviews took place ‘on location’. In pharmacies researchers were allowed to attend on days when pharmacists believed there would be more IDU ‘traffic’. After being introduced to the IDU (either by the receptionist/assistant or the pharmacist) and gaining agreement to be interviewed, the researcher either used an available room at the pharmacy for private interviews, used other local premises, or, very occasionally the researcher’s car. Very few IDUs declined the opportunity to take part in the research and all respondents received a £5 reciprocal payment for their time.

Sample characteristics

The mean age of IDUs interviewed was 32 years. Sixteen percent were between 18 and 25 years of age. Fifty percent were between 26 and 34 and 33% were over 35 years of age. Almost three quarters of the sample was male (73%). The sample reflected the largely White English population resident in the West of England with 96% (87) self-referring as ‘White British’. Three IDUs referred themselves as being ‘White Irish’, ‘White Scottish’ and of ‘dual heritage’, respectively.

The sample was a relatively experienced one, as injecting drug users and in using needle exchanges/SISs. The mean length of time that the main sample had used a needle exchange was 7.7 years whilst those using the outreach service had on average 10 years service use and the steroid users only 3 years.

A minority of the sample reported being in employment: nine (10%) IDUs said they were employed full time and two part-time. Three of the four steroid injectors were employed. Six IDUs (7%) reported being homeless, although it was clear that more lived in relatively unstable conditions.

Emergent themes

We did not specifically question pharmacists or drug users about the issue of ‘stigma’. However, in talking to pharmacists, comments that we interpreted as ‘stigma’ arose when we asked whether their staff or the local community opposed the running of needle exchanges. We also found that some

pharmacists stigmatised IDUs en masse, assuming them to be intent upon shoplifting for example. This occurred when we asked for their perceptions of problems that may arise for them in running a needle exchange.

When we talked to IDUs the issue of stigma arose, or comments that we interpreted as such, when we asked for their perceptions of problems arising for them in using the needle exchange; whether initially or at the time of the research. This was a common point at which IDUs, if they were going to talk about feeling stigmatised, actually did so.

Not all IDUs expressed feelings of being judged negatively by pharmacists, their staff and the community at large. Clearly, it may be that some users either were not sensitive to judgements being made or if they were they could not verbalise their sensitivity.

We found also that IDUs stigmatised others within the IDU population. This occurred when IDUs were asked whether they themselves shared needles or knew people who shared. In these ways the issue of stigma flowed from the more open ended responses that were made by both pharmacists and IDUs, and from the thematic analysis and ongoing reflective process that we, as researchers, engaged in as the study developed.

Findings

Stigma from the needle exchanges: what pharmacists had to say

A number of community SIS (three pharmacies) were provided by 'independent' pharmacists, that is those who owned their own businesses; however the majority were part of a regional or national chain ('non-independent'). We found 'independent' pharmacists to be more unconditionally supportive of the goal of harm reduction; that is they saw the benefits of providing the SIS even though difficulties arose in so doing. They tended to view the needs of IDUs as no less than the 'ordinary' customer and were less likely to stigmatise IDUs, tending to offer a professional but friendly service, for example calling users by name and/or offering medical advice.

In 'non-independent' venues pharmacists were more likely to be 'conditionally' supportive of harm reduction; for example they did not wish to go beyond providing the bare essentials (clean needles versus other drug using paraphernalia) and providing IDUs 'behaved' themselves. In addition this approach tended to trickle down to shopfloor staff. In these pharmacies shopfloor staff were also likely to be less tolerant and less supportive of harm reduction per se. Thus in one venue, shopfloor staff questioned IDUs' eligibility for support given their 'welfare dependence'. They also called for a 'three strikes and you're out' approach to users viewed as abusing treatment programmes by continuing to use street drugs. This resonated with the earlier controlling/policing role that community pharmacists had adopted (Matheson,

Bond, & Mollinson, 1999; Sheridan et al., 2000) and indicates more limited support for harm reduction.

However, pharmacists and their staff did not always fall neatly into groupings of those who were more or less tolerant. Pharmacists who appeared 'less tolerant' were not consistently so, whilst those initially perceived by researchers as fully supportive of IDUs and 'harm reduction' were at times negative and stigmatising.

Some pharmacists viewed IDUs as 'undesirable, scary and undeserving' and likely to be 'dodgy' and/or shoplifters. They feared losing 'general customers' who may be frightened by IDUs, viewing the former's needs as legitimate and as 'priority'. IDUs were viewed as overly demanding if they requested other drugs paraphernalia such as citric acid or sterile swabs, thus notions of 'less eligibility' arose (Fitzgerald et al., 2004). They also discussed pharmacists who chose not to run SIS, assuming this was a moral stance or a rational judgement given their own customers' reactions to IDUs. The extent to which such stigmatisation was discriminatory was raised, a point which Link and Phelan (2001) discuss.

Even where pharmacists appreciated the embarrassment and fear of recognition that IDUs experienced (Fitzgerald et al., 2004), they still expressed negative views. They discussed their staff feeling 'threatened', 'scared', morally judgemental and resentful of wasting resources on the undeserving. They also discussed staff fears concerning potential infection. Even where pharmacists themselves were supportive of SIS, their staff may not share those views, or indeed locums who from time to time support local pharmacies.

Stigma from needle exchanges: what IDUs had to say

Clearly, in talking to IDUs it became obvious that they did pick up on stigma from pharmacists and their support staff.

... you know they think you're a thief and you know you can see sometimes when people notice and like people working in chemists ... you know it was like a look of shock as if to say ... they keep an eye on you, you know, embarrassing. (41-year-old male IDU)

This type of comment mirrors evidence collected from pharmacists. In addition, users said that it was not always the pharmacists themselves who stigmatised them, but their staff. This was clearly a community pharmacy issue as it did not occur within the dedicated drugs agency operating in the area. IDUs spoke of stigma arising in both urban and rural pharmacies, with the fear of stigma being greater for those living in smaller communities. Even in the city, some users would not use particular pharmacies where they felt too uncomfortable, fearing a lack of discretion on the part of staff.

... they don't smile at you or nothing, know what I mean, ... if you're in there with other people and that, customers,

you don't know what they're going to say and you feel uncomfortable. (24-year-old female IDU)

However one IDU noted how on using the SIS a few times, that the sense of stigma reduced.

... once they've seen your face a few times, they're more relaxed and you can have a general chat about the day and it's not a problem. (33-year-old male IDU)

The hub SIS and its outreach service was viewed as being non-judgemental, in contrast to community pharmacies where 'helpfulness' was concerned.

I'd say that there's people in the outreach that are basically a lot more understanding and helpful. It seems more of a chore for the people in the chemist. (37-year-old male IDU)

Stigma: from other health and related professionals

IDUs identified stigma from other professionals, such as Social Services. One young female IDU felt judged as being a bad mother. She felt the need to 'prove herself' in order to displace the label and regain custody of her children. This labelling of women as 'bad' mothers' resonates with [Thetford's \(2004\)](#) work on mothers with Hepatitis C.

Two IDUs felt stigmatised by the National Health Service.

... I've even tried A & E at weekends. They won't give them to you. They ostracise you because you are a junkie. (36-year-old male IDU)

Steroid users recognised the potential for stigma in using anabolic steroids. They were sceptical about developments for gyms locally to provide clean needles.

... there would be a lot of gyms that won't want to do that because big fitness health clubs are not going to advertise the fact they allow steroid people to use their gyms but a lot of smaller ones would ... (25-year-old male ISU)

Stigma: from the community

A number of pharmacists explained how local residents were opposed to needle exchanges, and how they complained.

Oh people come in and ask to see me quietly and say that I'm encouraging drug use ... that the exchange doesn't work ... and they are going to report me to the police ... the local councillor. (Pharmacist 10)

Both pharmacists and IDUs described stigma from general pharmacy customers. Pharmacists felt customers resented IDUs being given needles freely, when those suffering from diabetes are charged. Users were viewed as less deserv-

ing because their need resulted from 'addictive life choices' rather than the perils of 'random' health failure. Approximately half of the pharmacists (7 out of 12) stated that 'general' customers did not like IDUs using the pharmacy.

Some can get verbal about it ... they actually talk in the shop ... you get some people that you can tell they are not happy with the situation. (Pharmacist 3)

IDUs were aware of stigma from general customers and the lack of privacy when using the SIS was a problem. Users were concerned about being labelled as criminals and being ostracised by their local community, and effectively moved on.

... you should be able to go get them [clean needles] without people knowing because some people are malicious and they like, will try and get you kicked out of your property or something. (24-year-old female IDU)

Users often devised coping strategies, such as waiting until the pharmacy was empty.

Yeah, yeah I go out the shop and have a fag ... (26-year-old female IDU)

Stigma within the IDU population

Here we discuss IDUs' own sense of stigma, resulting from their feelings of 'wrong-doing' or 'deviance', and from the verbal and non-verbal judgements of other customers and staff. The sense of stigma was particularly evident for injecting users of anabolic steroids, and for IDUs living in outlying areas. For both groups, being recognised was a particular problem, as it was anyway for those living in the urban environment. This research therefore challenges the commonsense view of IDUs as people who have little regard for what others may think about their behaviour.

Approximately half of the sample (41 out of 85 transcribed interviews) felt stigmatised when using SIS, particularly for the first time. For some, this sense of stigma continues.

The general sense of stigma and fear of recognition

A substantial theme was the general sense of stigma, shame or embarrassment at being an injecting drug user and in accessing SIS. Steroid injectors were particularly concerned at what others may think of them, they did not wish to be 'mistaken' for example as a 'junkie'.

The fear of being recognised was particularly worrying for IDUs living in outlying areas, as communities tend to be closer knit. This resonated with [Fitzgerald et al., 2004](#)). The outreach services users who we spoke to were extremely reluctant to use pharmacies in their own areas, even if SIS provision were to be made available.

... I wouldn't like to use the chemist out here. It'd be around the village in no time ... It's bad enough me going in there for my prescription. ... I just like to keep my anonymity and you can do that in a big place. (31-year-old female IDU)

Stigma: hierarchies within the IDU population

Here we discuss how stigma flows hierarchically through the IDU population. We do this by looking at the perceived behaviour of particular types of IDU. Thus users who perceive themselves to behave 'responsibly', judge and stigmatise those who they perceive do not, drawing upon the notion of attribution (Baskind & Birbeck, 2005).

Responsible vs. irresponsible behaviour

The homeless IDU was viewed as being at the bottom of the pile due to 'irresponsibly' sharing and disposing of needles. The main reason 'responsible' IDUs gave for sharing needles was laziness; or users not caring enough about themselves to access clean needles and feeling 'worthless'. The implication was that this would lead to risky behaviour. By implication, those who claimed not to share experienced a greater sense of self-esteem which was underpinned by passing such judgements.

It's either laziness or yeah ... or it's just ... not being able to wait and when we walk half a mile to get some more. If it was a choice of a like use a dirty needle and have the drug now or wait half an hour and walk half a mile. A lot of people don't wait. (33-year-old male IDU)

Sharing was viewed as something that is done by 'dirty', lazy people who had 'given up'—nothing like themselves. Again, homeless people were identified as more likely to share or dispose of needles irresponsibly.

... if they are off the drugs they're going to want a dig there and then do you know what I mean? Like if it's not clean they don't care and I need my drugs kind of thing ... (32-year-old female IDU)

... they'll [the homeless] inject on the streets and they'll just won't even bother to pack up their pin and throw it on the floor. (19-year-old female IDU)

This judgement was based upon a view of 'what homeless people are like', with no account taken of the barriers they face in using SIS. For those resident in hostels, ownership of any drug paraphernalia, including the Sharps Bins used for the safe return of used needles to the SIS, was grounds for eviction. Pharmacists were also reluctant to receive used needles that were not contained in this way (Coomber & Simmonds, 2005), again with little awareness for the obstacles that homeless people face. In addition, a number of homeless IDUs

thought they were more likely to be stopped by the police anyway, and so were wary of the evidential implications of being found in possession of a Sharps Bin, or 'sin bin' as they are more colloquially known.

Negative judgements of the homeless were promoted, even though respondents may themselves have shared needles at an earlier stage, or indeed continued to do so in some form or another (irregularly or accidentally since). For some, sharing with a partner was not considered as 'real' sharing. IDUs reporting sharing with a current partner (albeit occasionally) still castigated those who share, particularly the homeless who 'don't care'.

One user, who herself had been quick to judge homeless people as more likely to behave irresponsibly, realised that the system for re-using needles which she and her partner had adopted was potentially flawed.

... that that'll be right underneath the tin and I'll choose one of the top ones. You know when they say How did you realise? Actually I was stupid with it all really. It's only when you actually say it out loud that you think, because in your head you think Oh it's alright, it's Ok, well I know that's mine – but when you're explaining to someone like if someone was explaining to me I'd think I'd sit there like ah what you doing, you know, it'll raise our awareness of it, what we're doing like ... (32-year-old female IDU)

We found evidence that being homeless was not necessarily a function of sharing or of disposing of needles irresponsibly.

... well every time I use a needle I'll always clean it after I've used it so if I ever run out I'll just go back and use one of the ones that I have used before. (36-year-old homeless male IDU)

The respondent was scathing of users who shared needles. Another homeless IDU told us how he always returned his dirty needles, even though he was living in a car park.

I've been given a sin bin by ... so I fill that up and take it back. (29-year-old male IDU)

IDUs admitted disposing of needles in an unsafe manner, even though they were not homeless. One IDU was reluctant to return needles to the pharmacy. He described how he disposed of them, but also noted how pharmacies in other areas encouraged returns.

... every person I know that uses this needle exchange I have never seen one bring any needles back and I'm not going to be the first one to ask ... I get rid of them on my own. I put them in – I don't know if I am doing wrong – the recycle plastic – but it's got a danger thing on the actual sin bin. ... but in London you can not get any needles without

bringing your old ones along. And I think that's a good idea. (35-year-old male IDU)

Although 'normal' (non-sharers and/or non-homeless) IDUs were judgemental towards sharers and/or homeless IDUs, this did not mean that they themselves always behaved responsibly. Some admitted to sharing needles in both the past and present. This was the case for steroid injectors who were particularly keen to distance themselves from IDUs who use street drugs such as heroin.

Steroid users vs. 'junkies'

Two broad issues were clear in talking to steroid users. Firstly they feel 'different' from other injecting drug users and are anxious not to be misconstrued as a 'junkie', either by health professionals or their non-injecting peers. Secondly they view the drugs they use as creating this difference. They do not experience 'dependence' and 'withdrawal', unlike heroin users; thus, in their view they are not driven to share needles or to commit crime to feed their habit. In these ways steroid users were able to resist the label of junkie, perceiving themselves to be 'ordinary' or 'normal' people'. In this sense they managed a 'dual existence', as Fitzgerald et al. (2004) discussed in their study of IDUs in small town Australia.

I was actually quite chuffed when they asked are you here for steroids are you a steroid user by any chance, so that kind of cheered me up a bit that he knew I was there for steroids. . . . I thought he knows that I'm doing that then and I'm not a smackhead or anything. . . . I wanted him to know . . . know that I was just an ordinary normal person and haven't got problems. (29-year-old male ISU)

Steroid users felt quite different because of the type of drug involved. They would not therefore need to share needles.

I don't think anybody who does steroids shares needles. . . . when you're a completely high druggie, you'll share anything because you don't care. But steroid users they just want the injection they are quite happy to wait an extra day if they have to. . . . If you are a hard drug user who's injecting heroin, you probably couldn't give two shits whether or not you are going to use the same needle . . . because you're on a high and you're just having another fix . . . (25-year-old male ISU)

Discussion

This research reports the real effects of stigma from professionals and the public, in terms of service uptake and IDUs 'qualitative' experience. However an equally important finding, in our view, was that IDUs stigmatised other (in their view) 'lesser' IDUs. Although this was evident from the steroid injecting drug user who chose to separate their

behaviour from that of the 'junkie' heroin IDU, in terms of an aggregated impact on risky behaviour, it is the 'normal' IDU who looked down on the homeless and other 'lesser' IDUs that presented the most problematic form of stigma. Here, supposedly responsible IDUs (not engaging in risky behaviours such as needle sharing) condemned risky behaviour as likely to be carried out by lesser 'others'—the lazy, the homeless and those that simply 'don't care'. The real issue here is that stigma is being used as a mechanism (as it often is) to displace acknowledgement of their own risky behaviour (which *was* evident) by focussing on the behaviour of others—others not like them but worse in definable ways (Wills, 1981). By doing this they often ignored the risky behaviour they themselves practised because there were IDUs 'out there' who were far worse, doing far worse things—in comparison they had little or less to be concerned about! The operationalisation of stigma against other IDUs was thus, ironically, working against this population in the sense that they could be less scrupulous about their own behaviour and thus put themselves at greater risk.

This research then shows how stigma operates negatively and impacts both against and within the IDU population. Further, our findings concerning this phenomenon support (albeit in a different context) what others (e.g. Fitzgerald et al., 2004) have also reported in relation to injecting drug users.

We found that some IDUs were able to maintain a dual existence in hiding their drug use from their local community (Fitzgerald et al., 2004). Those with young families viewed this as imperative. They didn't want their children to be exposed to drug use in daily life, or by the research process. Steroid users particularly maintained dual lives as 'normal' guys who are also injecting drug users. Their drive to reject any label as to being a 'junkie' or 'smackhead' was very strong (Monaghan, 1999; Monaghan, Bloor, Dobash, & Dobash, 2000).

The embarrassment and shame that IDUs reported drew strong parallels with Cooley's (1964) conception of the looking glass self; respondents sensed negative judgements from pharmacists and other customers which they tended to accept (or internalise). Even steroid users experienced this on beginning to inject, viewing injecting as 'something that hard drug users do'. We also discovered the double jeopardy that certain drug users face; mothers who use, or homeless people who use drugs. Indeed the latter have little means by which to hide either their homeless or drug injecting identities.

Homeless people were at an unfortunate disadvantage in relation to being stigmatised, not only by professionals but by other IDUs. They were less likely to be able to return their needles to pharmacies and, by virtue of dress standards, were more likely to be thought of as 'homeless and up to no good'. They were also more likely to be identified as 'irresponsible' by other IDUs, for example sharing and discarding needles unsafely. This was so even though non-homeless respondents had often – at some point – shared needles and certainly other paraphernalia. IDUs perceiving themselves to be responsible (the non-homeless/non-sharers), were also found to dispose

of needles unsafely, some quite regularly. This attribution was used by those who perceived themselves to be responsible (supposed non-sharers and safe disposers of needles) as a means of distancing themselves from ‘the irresponsible’ (Furst et al., 1999).

We also view this as their way of minimising the extent of their deviancy or difference by removing themselves from a heavily stigmatised category (Furst et al., 1999) and they were therefore at pains to deny being a needle sharer and the connotations that this may hold. The stigma attributed may also draw upon the notion of ingroups and outgroups (Tajfel & Turner, 1979), such that non-homeless and steroid users could feel an enhanced sense of self-esteem, both individually and collectively (Dovidio et al., 2000) at the cost of those they stigmatise.

Stigma raises a range of negative implications for individuals and their sense of well being, in terms of low self-esteem and motivation. Indeed we would also strongly suspect that receiving a continually negative judgement, one that does not separate the whole person from activities in which they engage, cannot aid or drive an individual away from drug use. In addition it may increase the risk environment in which they are located (Rhodes, Singer, Bourgois, Friedman, & Strathdee, 2005).

Stigma therefore holds very real negative implications for harm reduction policy, as IDUs may feel too embarrassed to use the needle exchange service due to the reactions of professionals and the public. They may completely reject the service; delay using or as Scambler (1989) noted, take steps to avoid enactments of stigma. At worst this may mean not accessing clean needles with the greater likelihood of risky sharing ensuing. We were concerned that IDUs in outlying areas felt even more at risk of such stigma, within smaller, close knit communities. Even if a service had been available, they may still be reluctant to use them. At the same time they were sensitive to the stigma expressed towards them within city centre pharmacies.

The effects of stigma on IDU populations are sufficiently far-reaching for health care providers and others whose remit it is to reduce the harms emanating from injecting drug use, to seriously consider its impact, its production and how best to address the problems it causes. This research has shown that stigma has many facets and can impact upon individuals and groups differentially. Those types of stigma that fit with conventional understanding of the concept – where so-called ‘normal’ members of society look down on others – were found to be prevalent, to varying degrees, amongst most of the pharmacy outlets but absent from the hub service whose very *raison d’être* is harm reduction.

The relatively independent community pharmacy services often employed staff who lived locally and who often had little, if any, sympathy with harm reduction philosophy and practice. Even where pharmacists were more wedded to harm reduction activity, when it came to IDUs they often felt that the provision of other injecting paraphernalia was a ‘step too far’ for this ‘undeserving’ population. The outcomes of this

felt stigma, in real terms for IDUs, was for many an initial delay in accessing the service; the tendency to move between service providers (and thus interruption in provision); a belief (borne out by our outreach sample) that non-service users avoided needle exchanges through fear of being recognised and the (negative) consequences that could follow-on from this in their community. Each of these issues was in turn exacerbated by the structural conditions within which the pharmacies (as opposed to the hub and outreach service) operated their needle exchanges: usually sited in full view of the public and other IDUs.

What can be done?

Reducing some types and levels of stigma for SIS users may not be as difficult as first appears. One of the findings from the original research (Coomber & Simmonds, 2005) was that IDUs found using the same shopfloor as general pharmacy customers embarrassing. This was particularly true for those based in outlying (e.g. small town) areas. The hub service by contrast suffered from relatively few problems regarding user fear of recognition or labelling.

A preferred situation would be for the hub service to have many more small satellite SIS bases spread around in relatively discrete accommodation. IDUs would not meet other members of the public, but would also avoid other IDUs as well. Given the resource driven nature of this proposal, a more practical response – at least in the short term – would be for some pharmacies to be encouraged to alter their premises/activities. IDUs could be accommodated with little contact with other customers/IDUs. Some pharmacies in the UK for example have one door for SIS customers and the ‘normal’ shop door for everyone else. This is a start, although for pharmacies on busy streets the use of separate entrances may signal even more clearly who is an IDU. In the longer run, thought (and resources) are required to provide accessible SISs that address both the structural–physical setting (buildings; location; procedures for giving needles and other injecting paraphernalia and receiving needles, etc.) that encourage stigma as well as the psycho-social environment (staff attitudes; restrictive policies determined by pharmacy/staff prejudice).

The attitudes of staff and pharmacists can be addressed – in part at least – by more training to promote the realisation that harm reduction activity is not primarily about the IDU, but that it is a broader Public Health issue. Indeed an encouraging attitude towards IDUs has a wider pay-off for them, their families and their community. Most pharmacists have rudimentary training in such issues, with little training for staff. Training such as this could highlight the danger of age old judgements as to ‘eligibility’ (Fitzgerald et al., 2004), particularly relating to supplying other drug paraphernalia or viewing IDUs’ need for their service as illegitimate in contrast to those who are ‘really ill’. Staff who are resistant should, in the medium term, be asked to re-assess their commitment to

the pharmacy. Alternatively the hub service or the DAAT may consider relocating the SIS. Progressive pharmacy SISs also need to seek ways to communicate to IDUs that they were welcome and will not be treated poorly. In areas where there is little pharmacy uptake and/or where it is combined with a less than welcoming attitude the strategic aim for the local DAAT should be the establishment of appropriate services rather than simply accepting that some areas are ‘difficult’. A further alternative to hub satellites is an increase of confidential outreach activity and possibly the provision of vending machines to supply injecting equipment/paraphernalia in secure areas, giving 24/7 availability.

More ‘specialist groups’ such as steroid users perceive stigma from non-injectors such as the other gym users (Monaghan, 1999). They also fear being recognised when using the SIS, indeed none of our sample used community pharmacies and were fairly reticent about attending the dedicated Safer Injecting Service where we interviewed them. The idea of gyms providing more by way of a needle exchange has been mooted, and perhaps the time is ripe for this to be driven forward.

Reducing stigma from ‘normal’ IDUs onto ‘lesser’ IDUs is less necessary (though desirable) to help moderate risky behaviour that is otherwise being ignored as falling outside or peripheral to (that which is perceived as) the more serious risk of straight-forward needle sharing. Harm reduction intervention needs to focus—and be successful in getting its message across that sharing of paraphernalia; allowing access to stick bins; sharing with partners, however occasionally, all represent serious, short and long term, risky behaviour that cannot be separated from more overt forms of needle sharing.

The IDUs interviewed testified to feeling stigmatised by professionals and the public alike, resulting in their involvement in risky behaviour. The fact that they did not pick up on judgements from within the injecting population, for example homeless IDUs, reinforces the view that stigma is located within power relations (Link & Phelan, 2001). However whilst the more explicitly expressed stigma is dangerous, so is that which operates less visibly (that is from IDU to IDU). The stigma reported in this research, from whatever source, has negative implications for IDUs themselves but also, as noted, for the community as a whole.

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Stigma and its public health implications

Bruce G Link, Jo C Phelan

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Department of Epidemiology
(Prof B G Link PhD) and
Department of Sociomedical
Sciences (J C Phelan PhD),
Mailman School of Public
Health, New York, NY 10032,
USA

Correspondence to:
Prof Bruce G Link
bgl1@columbia.edu

The publication of Erving Goffman's *Stigma: Notes on the Management of Spoiled Identity* in 1963 generated a profusion of research on the nature, sources, and consequences of stigma—albeit with considerable variation on how stigma was defined. In our conceptualisation, stigma is the result of a process in which a series of five interrelated components combine to generate stigma. In the first component, people identify and label human differences. Although most human differences are socially irrelevant, differences such as skin colour, IQ, and sexual preferences are highly salient in many social contexts. The point is that there is a social selection process determining which differences are deemed relevant and consequential, and which are not. Medical conditions vary dramatically in the extent to which they are socially significant. Compare hypertension, bone fractures, and melanoma, for example, with incontinence, AIDS, and schizophrenia.

The second component of stigma involves the process of stereotyping in which the labelled person is linked to undesirable characteristics. In a third component the group doing the labelling separates “them”—the stigmatised group—from “us”. In the fourth component, stigmatised people experience discrimination and loss of status. We reason that when people are labelled, set apart, and linked to undesirable characteristics, a rationale is constructed for devaluing, rejecting, and excluding them.

Finally, there can be no stigmatisation without the fifth component of stigma, the exercise of power. The essential role of power is clear in situations where low-power groups attempt a reverse stigmatisation. For example, patients being treated for mental illness may label their clinicians as pill pushers—a cold, paternalistic, and arrogant “them” to be despised and avoided. Nevertheless, the patients lack the social, cultural, economic, and political power to translate their negativity into any significant consequences for the staff. The staff, in such circumstances, are hardly a stigmatised group.

Major forms of discrimination

We characterise three major forms of discrimination, which can have varying degrees of severity. Direct discrimination occurs when A engages in overt rejection of B's job application, refuses to rent B an apartment, and so on. Structural discrimination is more subtle. An example would be white employers who rely on job recommendations from their white colleagues, who in turn are more likely to recommend white candidates. There is no direct denial of a job to a person of colour, yet discrimination has clearly

occurred. Another example of structural discrimination is evident when treatment facilities for stigmatised diseases like schizophrenia are located in isolated settings or poor or dangerous neighbourhoods.

An insidious form of discrimination occurs when stigmatised individuals realise that a negative label has been applied to them and that other people are likely to view them as less trustworthy and intelligent, and more dangerous and incompetent.^{1,2} According to this modified labelling theory, people who have been hospitalised for mental illnesses may act less confidently and more defensively with others, or may simply avoid a threatening contact altogether. The result may be strained and uncomfortable social interactions,³ more constricted social networks,¹ a compromised quality of life,⁴ low self-esteem,⁵ depressive symptoms,⁶ unemployment, and loss of income.^{7,8}

Stigma processes and life chances

Stigma processes have a dramatic and probably under-recognised effect on the distribution of life chances such as employment opportunities, housing, and access to medical care. We believe that under-recognition occurs because attempts to measure the impact of stigma have generally restricted analysis to one circumstance (eg, AIDS, obesity, race, or mental illness) and examined only one outcome (eg, earnings, self esteem, housing, or social interactions). If all stigmatised conditions were considered together and all outcomes examined we believe that stigma would be shown to have an enormous impact on people's lives. To exemplify one part of this point we analysed nationally representative data from the USA, in which multiple stigmatising factors were taken into consideration in relation to self-esteem, and found that stigma could explain a full 20% of the variance beyond the effects of age, sex, and years of education.

Stigma and stress

The extent to which a stigmatised person is denied the good things in life and suffers more of the bad things has been posited as a source of chronic stress, with consequent negative effects on mental and physical health.⁹ Stress is also associated with the constant threat of being stigmatised. The social epidemiologist Sherman James suggests that such fear sometimes generates harmful health outcomes.¹⁰ An example would be the career woman who works extremely hard and under great pressure to show that she is as good as any man at the top. Such coping efforts can come at the cost of hypertension and other health problems.

The stress associated with stigma can be particularly difficult for those with disease-associated stigma. Not only are they at risk to develop other stress-related illnesses, but the clinical course of the stigmatised illness itself may be worsened and other outcomes affected, such as the ability to work or lead a normal social life. Indeed, the fear of being labelled with the disease may cause individuals to delay or avoid seeking treatment altogether, while those already labelled may decide to distance themselves from the label, forgoing treatment or becoming noncompliant. When either of these processes operate, people suffer the consequences—tragically, including death. Even when patients are willing, stigma can discourage care-seeking. The presence of barbed wires, guards, locked wards, and body searches in treatment facilities for the mentally ill could understandably discourage a would-be patient. More broadly, if a stigmatised illness has received less attention and fewer research and treatment dollars, the effectiveness of treatments may lag behind treatments for other less stigmatised diseases.

Stress is by no means the only factor exacerbating the health problems that stigmatised individuals face. We have proposed¹¹ that some social conditions are intrinsically related to health because they affect an individual's exposure to disease risks and protective factors. Thus, throughout history, socioeconomic status has had a robust association with disease and death: people with greater resources of knowledge, money, power, prestige, and social connections are generally better able to avoid risks and to adopt protective strategies. As stigma places people at a substantial social disadvantage with respect to these resources, it increases their exposure to risks and limits access to

protective factors, potentially adding to their burden of disease or disability.

Conflict of interest statement

We declare that we have no conflict of interest.

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Stigma and the law

Scott Burris

There are three broad areas where law affects the operation of stigma in society. Law can be a means of preventing or remedying the enactment of stigma as violence, discrimination, or other harm; it can be a medium through which stigma is created, enforced, or disputed; and it can play a role in structuring individual resistance to stigma. For the individual with a stigmatised health condition, acceptance of society's views and self-stigmatisation may lead to concealment to avoid discrimination. But an anti-stigma activism is also possible. For many stigmatised diseases (epilepsy, for example¹), the consequences of concealment may often be more severe than those of resistance. In both cases the individual faces status loss and discrimination, but, depending on the nature and incidence of enacted stigma, people who adopt resistance strategies may actually face

less stigma, experience less social harm, and be better able to cope with any discrimination. At the same time they avoid the life-long hidden distress and unhappiness experienced by people who conceal.

Legal protection against the enactment of stigma

Law is most commonly seen as a tool for blunting the effects of stigma by protecting health information and prohibiting discrimination based on a health condition. Legal protection can deter harmful conduct and can provide recompense when harm has been done. But law is limited. It addresses behaviour, but does not necessarily change the attitudes that produce the behaviour. Moreover, most enacted stigma is not forbidden by law, and many of the effects of stigma will

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 Temple University Beasley
 School of Law, Philadelphia,
 PA 19122, USA (Prof S Burris JD)
 scott.burris@temple.edu

Many syringe exchanges and other harm reduction programs talk about having a non-judgmental attitude, but what does it mean? For some, it means meeting drug users “where they’re at.” For others, it means creating a safe place to talk about personal issues. For some people involved in 12-step recovery, it can be summed up as “live and let live.” Non-judgmental can apply to other issues besides drug use, including HIV status, family and relationship issues, literacy and much more. But there are times and situations where a non-judgmental attitude can be about life and death.

American society sends a powerful message of shame and exclusion to drug users, an extra dose on top of the familiar helping served to all of us. Many of us create public personalities that hide difference (or divert attention), affirming the shame. Some shaming is rooted in racism, sexism, homophobia or classism. Syringe exchange staff and volunteers are placed in a difficult position, because shame is a built-in part of our culture: none of us are immune to its power, and all of us shame others in various ways. Sometimes when shame isn’t offered, we seek it out. But there are certain kinds of shaming that must be challenged in order for syringe exchange programs to make and maintain effective contact with drug users.

Here are some basic shaming scenarios:

1. A dedicated outreach worker has gotten a participant into a detox program. A few days later, that participant shows up at the needle exchange program, obviously still using. The outreach worker expresses anger that the participant wasted his time.
2. A participant shows up late (or early) for needle exchange. When the participant says she wasn’t able to come at the official time, a volunteer accuses the participant of trying to “get over.”
3. A sex worker participant says she doesn’t always use condoms with her johns. Instead of talking with the participant about the circumstance around this, the outreach worker tells her she should “know better.”

These scenarios raise a lot of issues about participant/provider relations. But I would like to focus on three things in this discussion: ethical questions, proper boundaries and the role of 12 Step Recovery in working with active users.

HOW ABOUT SOME SHAME WITH THOSE SYRINGES?

by Donald Grove

ETHICAL ISSUES

1. The whole community benefits when an injector uses sterile syringes and prevents the spread of deadly infections. If an injector is uncomfortable using your program, it isn’t just that injector who suffers, it is the whole community.
2. You must understand why you are doing this work. Are you doing it for yourself or for the people who use the program?

It is perfectly allowable to do the work for yourself. That is a normal thing for many people. They do the work because it is fulfilling for them. Many people with a history of drug use place strong value on “giving back” by working with drug users.

But drug users aren’t coming to the program to make an outreach worker’s life fulfilling. They are coming because they need sterile syringes, treatment, health care and other forms of support. Ultimately, if they feel they will be treated shamefully, many will not come. There are other places an outreach worker can go to seek fulfillment, but there probably isn’t any other place the participant can go. The real priority needs to be on making sure the participant can use the program comfortably, because he/she is the one without options.

It is unethical to offer something to someone in need, then shame them for needing it. This is not “giving back,” and it doesn’t benefit the participant or his/her community.

3. Does a shaming message provide useful support to the participant?

Although staff and volunteers may have a personal investment in advocating abstinence, they should also remember that these messages are *everywhere*. Drug users are often stereotyped as ignorant of the message of abstinence. But they are extremely aware of it. Drug users are closed out of most services, hunted by police and publicly derided by politicians, preachers, teachers, children and practically everyone else, including other drug users.

It is undeniable that chronic drug use has many harms, and abstinence is a goal that many drug users strive for. A participant’s life may be devastated by drug use, but an outreach worker has to consider that the participant may know this already, and carry shame for it. Most of the participants I know have been in and out of treatment and recovery more than once, and already have very strong feelings of shame about the problems their drug use creates for themselves and their families. You cannot protect a person from shame they already feel, but it is completely unethical to remind someone of their wound by rubbing salt in it.

Remember, you offer access to treatment and rehabilitation, but you ALSO offer access to sterile syringes. Just because the participant is using drugs does NOT mean they are ignorant of the message of abstinence, and they NEED those sterile syringes either way!

BOUNDARIES

Boundaries are a normal part of life, and everyone is entitled to them. This goes for *participants* of the program as well as staff.

There is a popular belief that whatever a drug user gets is what they deserve. Drug users face closed doors most places they go. If they get attitude from the needle exchange program too, then they really don't have any place to go. Is that really what they need?

These closed doors are usually presented as “boundaries” by the provider. “We can't provide services if we have users coming in here, nodding out, ripping us off, creating problems.” This may be true for some services. But the problem is that many providers also tack on the following part: “It's good for those users to close them out. It teaches them about right and wrong. It requires them to act responsibly.”

Consider the drug user who has been in and out of prison. This person has lived in a heavily restricted setting, intended to foster the deepest social concepts of responsibility. Consider the homeless drug user, whose ability to survive may already hinge on very careful control of one or two meager resources. Consider the sex working drug user, who must weigh a program's version of responsibility against the conditions they face in their struggle to support themselves and their children. All of these people have important responsibilities already in place, before the program comes with its own message of responsibility through restricted access.

The bottom line is this: we are all entitled to boundaries, but we should not claim our boundaries are in place to benefit the participant. Using boundaries to reinforce “responsibility” is a fallacy. It denies the genuine personal importance of boundaries, while claiming to address a preconceived notion of a drug users' social capacity. Can we pick and choose who gets HIV and who gets a clean needle based on using boundaries that “teach responsibility”? People who want to enforce boundaries in this way really shouldn't be working in a needle exchange.

RECOVERY

People in recovery need to take care of themselves, and need to give a lot of consideration to their process of healing. I'm only guessing, but it is likely that more than half the people working at syringe exchange programs are in recovery, or have spent time working a recovery program. The 12 steps were created by users themselves, rather than clinicians, and 12 step groups speak directly to issues in a way that many users can understand. Nevertheless, as with any spiritual movement, human nature can distort the message.

The message of the 12 steps is not one of shame, but *some* people in recovery treat drug users very arrogantly and shamingly. It's a question of human nature. It takes many years of devoted effort to develop an attitude of grace and humility. In working with other drug users to prevent HIV and bring them into services, many people in recovery are confronted by their own shame. Some people re-examine their attitudes and learn a different approach to talking with drug users, but for some this is too difficult, and maintaining recovery becomes confused with shaming active users. In all cases, a person must do what is right for themselves, but this may mean avoiding needle exchange work.

According to the 12 steps, it is the grace of a higher power, combined with fellowship with other addicts, that supports a member in not using drugs. The shaming message is not coming from that place, and shaming other drug users won't help them get clean. Put bluntly, you are not a higher power yourself, and your contempt for active users will not support them. It's a spiritual program, and people get the message of recovery because they have souls, not because they are treated like no-good junkies.

The 12 steps teach that all people in recovery share their disease with all active users. As someone in recovery, the most valuable thing you can offer an active user is empathy and understanding—not shame. You don't know more than they do and you aren't better than they are. You only know what they know, that's why you're an addict! Reach out and share about what recovery has done for you, and leave the shaming to people outside the fellowship. If your message to others about recovery is shaming, your recovery may be at risk, and you should consider where you will get services if your disease becomes active.

Your recovery is IMPORTANT. Your boundaries are IMPORTANT. Taking care of yourself, and making your needs a priority is the first step to health and sanity! But those ARE NOT the same thing as what the needle exchange participant needs. Drug injectors need access to health care, sterile syringes, housing, support, legal advocacy and more. Who offers it, and how it is offered can make the difference between life and death.

Donald Grove has done both above- and underground syringe exchange since 1990. He currently is Technical Resources Coordinator at the Harm Reduction Coalition.

Can we pick and choose who gets HIV and who gets a clean needle based on using boundaries that “teach responsibility”? People who want to enforce boundaries in this way really shouldn't be working in a needle exchange.

LOOK IN THE MIRROR!

LOOK IN THE MIRROR!

BY ROSE LEASE

I hope that this conference is the beginning of a long beautiful relationship between you and harm reduction, because harm reduction means understanding for us all, no matter whether we're black or white, gay or straight, junkie or no junkie, alcoholic or no alcoholic, crack smoker, whatever. Harm reduction is for all of us.

I don't want to explain to you what harm reduction is, I don't want to preach to you about what it is but I can tell you it fucking works. I mean I've been there, I'm still there, I'm still fighting for my own sanity, and with the help of my friends I am incorporating this thing called harm reduction in my life and without it, I wouldn't be able to stand here and talk to you. Without it I probably wouldn't be standing anywhere.

I'm not going to pull any punches with you and if I offend you please forgive me, but AIDS is a very offending thing. I am HIV positive. I am a recovering junkie, and I still drink and I still smoke pot, so you know what, two out of three ain't bad. I don't want to spend a lot of time talking about the shit in our lives, and there's a lot of it. You know the kind of things, like copping, like praying that you don't get busted by anybody. Praying on your way to get the drugs. Praying on the way back home and praying the kids aren't there so you can get high. Then you got your relationships, whether it's your boyfriend or your girlfriend, or your insincere friends, you know, people that like to try to keep you down there, instead of building you up. Then you got family and friends who are "worried about you" but all they can do is talk about you like a damn dog and put you down. And after you went through all that stuff about the relationships and your boyfriend or your girl-

friend and your family, and you're worried about everything, you get in the bathroom and you either blow your damn shot or you got beat. It's like a merry-go-round that's not fun to ride anymore.

You know what I tell my so-called friends, "You kiss my ass, because I'm not here to prove myself to anyone but my God and myself, and then you people come next." I have a 24-year-old son, and I look at it like this. He can't live for me, he can't die for me, and I can't do it for him either, so if he doesn't like the way I

"and what I learned was that I need to love myself, like myself, need myself and, most of all, respect this person named Rose"

am, guess what, grow up, get a job, move out. We need to learn to tell people, and this is a form of harm reduction, "this is it, this is where it stops." Because if you don't do it, then you're standing out there on that street corner at 4:00 in the morning looking for a bag of dope or a bag of crack, and that's because we have not learned that the easiest form of harm reduction is just to say "no more."

If it wasn't for harm reduction and my friends who help me incorporate it into my life, I wouldn't be able to be here. I wouldn't be able to share what I've learned since I met this thing called harm reduction, and what I learned was that I need to love myself, like myself, need myself and, most of all, respect this person named Rose or nobody else was

going to respect me. I can now walk up the street with my head held high, and it's not because I quit getting high. I think what helped me the most was that I realized that Rose is worth loving, and if Rose doesn't love Rose then I can't ask anybody out there to give me anything. And as a woman, that's the hardest thing. We can give our love to everybody else but ourselves. So you have to stop doing that, because if we don't love us first, then we can't expect our boyfriend or our girlfriend to love us. We can't expect them to respect us because we're not giving it here first. You can't give something out there that you're not giving in here. That's what harm reduction does. I hear politicians ask, "what the hell is harm reduction?" Look in the mirror. It's you. It's how you treat yourself. It's how you wake up in morning, even if you're dope sick, even if you have AIDS, even if you don't think you want to finish the rest of that damn day, you got to wake up and go, "hell yeah, I'm here and I want to do the best that I can." And it doesn't matter if you're getting high or not, it's just doing the best that you can for you to protect yourself, because nobody's going to do it for you.

I'm hoping that today will be one that will always be in our memories, that every time that you start getting down on yourselves or you get down on your clients or your participants, that you remember that we're all one step away from death and that doesn't matter if we're getting high or we have the virus or what, we're just one step away from dying and the point is, that if we don't start loving and caring, ain't nobody going to give a shit whether you're dead or not. Like I said, if I offended you, too bad. Life can be very offending, AIDS can be a very vicious thing. I hope we can learn to stop hurting people, stop judging people and start showing what harm reduction is about. May the Lord bless you all and keep you safe no matter what you perceive him or her to be.

This text is based on Rose Lease's key note speech at the conference. Rose Lease is 38 and hoping for a miracle.



YOU CAN LEAVE THAT BAGGAGE AT THE DOOR, MISS THING

BY HEATHER EDNEY

This article is based on a presentation Heather gave to the Fifth Annual Women & HIV Conference that took place in San Francisco in January 1997.

When I have been asked to speak about my experience as an injection drug user who identifies as a femme who predominantly gets fucked by butches, sometimes fucks men, and engages in other activities that could be construed as “high risk,” I’m never really sure what angle to come at it from. While I feel that my personal experience is valuable, it is only one woman’s experience and is not inclusive of the injection drug-using community or femme dykes within the lesbian community. In fact, my experience is specific in that I

have access to resources that many injection drug users do not—a new syringe every time I shoot up, for instance. This is one of the benefits of having worked with and directed a needle exchange program for the past six years. I also have access to economic resources and I’m white, all of which set the context for my particular experience, but are not what’s necessarily essential about it. Because I was asked to speak *specifically* about my personal experience and feel compelled to meet the needs of the conference organizers, I will do that but with a few stipulations.

First, I do not perceive myself as a vector for HIV transmission to the lesbian community because I shoot drugs and fuck men. And I ask that for the duration of this presentation that you put that idea aside and hear what I have to say on this topic. Second, I ask that you understand how difficult it is to disclose information that is very private, very intimate, and potentially damaging if heard by the wrong person due to the illegality of drug use and the ways in which segments of the lesbian community stigmatize femmes who fuck men. Finally, I ask that you consider the political ramifications of what it *really* means to have someone speak on a panel because of the behavior(s) they engage in.

Some of you may be wondering why I’m spending so much time asking you to consider these issues, but I am doing this for a reason. It’s because I’ve presented on this same topic in the past, on several different occasions, and each time I’ve been verbally beaten down or made to feel fucked up for being a whore because I talked about multiple sex partners, some of whom were HIV+, and because I have been told on more than one occasion after the presentation is over that I will never be anything as long as I continue to stick a needle in my arm. I don’t want that to happen today. I don’t want to leave this room terrified that you have more on me than I have on you.

Instead, I want to share my experience with you because that is what I was asked to do and unless we can speak openly about our experiences, we will continue to operate under assumptions that are not necessarily accurate and which are alienating and dangerous to me and women like me, assumptions

that do not support us, as part of a larger community, in addressing the complexity of our risk for HIV. I am not asking you to agree with me. I am not asking you to change your mind about what you think about anything I present. But if you think what I am about to say is fucked up, please don’t put that on me: it is not my responsibility to take on your feelings of discomfort surrounding these issues.

I started using drugs when I was about fifteen years old. At approximately the same time, I started having sex with women, but it was always violent sex. Also at this time, I started having sex with men, and with them, it was also in the context of violence.

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Since then, there has not been a point in my life when I have not used drugs. The way I have sex is similar to my drug use in that it is oftentimes dangerous and oftentimes unsafe. The way in which I have sex is similar to my drug use in another way in that I am always moving along the continuum of what is safe and what is unsafe in regards to the violence associated with fucking. I have been strung out on amphetamine, crack, heroin, morphine, Valium,

CONTINUED ON PAGE 31

MISS THING

CONTINUED FROM PAGE 10

Percocet, Percodan, Vicidan, and Dexedrine. It wasn't until I started volunteering with the Santa Cruz Needle Exchange and working with the Harm Reduction Coalition that I learned how to use drugs and maintain a life where I could be productive and still be strung out. I'm not saying that this can happen for everyone who uses drugs. But because of the exposure I have had to other drug users who are also trying to negotiate the fine line between being strung out and controlling their use, I feel I have figured out a way to negotiate this line in my own life. This does not mean that I have a handle on my drug use. Sometimes I don't. Sometimes I have a very difficult time with my drug use, just like sometimes I don't have safe sex and sometimes I engage in "violent" sex.* I'm not always safe even though I know how to be safe. I have access to all of that information as a health educator and am surrounded by other women who claim to follow all the rules.

Because we have access to this information, we are *not* supposed to overdose, get the virus, miscalculate the amount of coke we shoot up and have a heart attack or a stroke, nod out in a meeting, or let our girlfriend choke us until our eyes roll back in our head and we get real dizzy and black out but it feels so good so we don't stop her. But generally we don't talk about this, especially in the lesbian community. Someone might mention an overdose, but 'she deserved it anyway because she shouldn't have been putting that poison in her body, and it was just a matter of time because everyone knows that drugs will kill you and aren't you glad you didn't fuck her?'

And we don't talk about how in the queer community we fuck with no latex, whether it's a girl with a strap-on or a man you know is HIV+. Because a real lesbian would never fuck one of us whores like that, even though you stare at us down on the street and fuck us in staircases, alleyways, and at parties in the bathrooms in houses full of "real" lesbians. You fuck us all right, just as long as we promise not to tell. And when one of us *does* test positive or overdoses, we are largely forced to be silent because if we're not, we will be accused

of being a junkie or a whore, and whether or not it's true, no one wants to be told that about themselves—especially since they've probably been told that their whole lives and believe that about themselves anyway.

For every experience I have like this, there is another woman participating in this behavior(s) with me. We are not a subculture in the lesbian community. We are as much a part of it as you believe you are. But we are invisible because we have no other option than to keep quiet about what we do. Or we do it alone, in isolation. Or with people who couldn't give a fuck if we live or die. Or we hide our track marks from our girlfriends as long as we can and lie and pretend to be outraged when we hear about another woman in the community who trades sex with a man for drugs or money or food or a place to stay, or because there is nothing better around to fuck.

Most people don't lie unless they are put in a position where they are forced to lie. A lot fewer of us will get the virus if we don't have to lie about what we do. And I promise you that you'll be much more effective if you do not judge your friends and lovers because of the drugs they use, the people they have sex with, or the type of sex they engage in that may not be considered "safe" in the queer community. Instead, my suggestion would be to offer support, or find a place where they can get that support, as it is identified and defined by *them*.

I'm not always safe even though I know how to be safe.

Heather Edney is the Director of the Santa Cruz Needle Exchange Project.

"True Stories by Girl Junkies" is a magazine put together by a group of women at the Santa Cruz Needle Exchange that contains interviews, stories, poetry, artwork, and safer injecting tips by women who shoot drugs ranging in age, sexual identification, and ethnicity. It is available from the Santa Cruz Needle Exchange Project by calling (408) 429-9489.

*I use the term 'violent sex' instead of 'sado-masochism' or 'S/M' because to me the latter implies a community-defined and -supported set of rituals and structured experiences, and the type of sex I'm talking about does not include these characteristics.

HARM REDUCTION COALITION T-SHIRTS ARE STILL AVAILABLE!

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how does stigma affect HIV prevention and treatment?

what is HIV/AIDS stigma?

HIV/AIDS-related stigma is a complex concept that refers to prejudice, discounting, discrediting and discrimination directed at persons perceived to have AIDS or HIV, as well as their partners, friends, families and communities.^{1,2}

HIV/AIDS stigma often reinforces existing social inequalities based on gender, race, ethnicity, class, sexuality and culture. Stigma against many populations disproportionately affected by HIV has been present for a long time in the US. HIV has compounded the stigma of homosexuality, drug use, poverty, sex work and racial minority status.³

HIV/AIDS stigma is a problem in the US and throughout the world. Stigma has been expressed in a variety of ways, including: 1) ostracism, rejection and avoidance of people living with AIDS; 2) discrimination against people living with AIDS by their families, health care professionals, communities and governments; 3) mandatory HIV testing of individuals without prior informed consent or confidentiality protections; 4) quarantine of persons who are HIV infected; and 5) violence against persons who are perceived to have AIDS, be infected with HIV or belong to "high risk groups."¹

how can stigma affect prevention?

HIV/AIDS stigma adds to the stress experienced by HIV+ persons. In addition, it leads to challenges for HIV prevention efforts.

HIV testing. *Fear of negative social consequences of a positive HIV test result can deter some persons from getting tested. A study of men and women in seven cities in the US found that stigma was associated with a decreased likelihood of being tested for HIV.⁴ People who are HIV+ but haven't tested and don't know they are HIV+ are less likely to try to prevent transmitting HIV to others.⁵*

Safer behaviors. Some HIV+ persons may fear that disclosing their HIV status or using condoms may bring partner rejection, limit sexual opportunities or increase risk for physical and sexual violence. A study of rural men who have sex with men (MSM), found that men who thought health care providers in their community were intolerant of HIV+ persons, also reported more high-risk sexual behaviors.⁶

Prevention programs. *Stigma surrounding HIV, homosexuality, commercial sex work and drug use make it difficult for HIV prevention services to be offered in a variety of settings. While it is widely accepted that HIV prevention should be integrated into a broader health and community context, many community venues such as churches, businesses, jails, prisons and schools have resisted incorporating frank discussions of HIV.⁷*

how can stigma affect treatment?

HIV/AIDS stigma can also negatively affect the health and well being of HIV+ persons.

Treatment. *HIV+ persons may not seek treatment or delay going to doctors due to real or perceived discrimination against them. A national study of HIV+ adults found that 36% reported experiencing discrimination by a health care provider, including 8% who had been refused medical service.⁸*

Support. Some HIV+ persons don't have an adequate support network because they fear that friends or family will abandon them or suffer the same stigma they do. One study of Asian and Pacific Islanders (API) living with HIV found high levels of internalized stigma. APIs avoided seeking support because they were afraid of disclosure and saw themselves as unworthy of getting support.⁹

Adherence. *Experiences of social rejection, disapproval and discrimination related to HIV may decrease the motivation of HIV+ persons to stay healthy. A study of HIV+ men and women found that those who had experienced stigma were also more likely to miss HIV clinic appointments and lapse in adherence to their medication.¹⁰*

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what's being done?

Stigma-reduction programs and trainings take place throughout the US and the world. However, it is difficult to measure the effectiveness of programs. As a result, there are few published studies of effective stigma-reduction programs. Most programs use multiple components to address stigma including education, skills building and contact with HIV+ persons on individual and community-wide levels.¹¹

*A school-based program for inner-city high school students in Texas, featured HIV+ speakers to decrease negative attitudes towards HIV/AIDS. The speakers were popular with students and teachers and had a positive impact on attitudes in the short term. Combining HIV+ speakers with a multicomponent HIV prevention and education program produced a greater impact.*¹²

The South Carolina HIV/AIDS Council (SCHAC) instituted an anti-stigma program with three components. First, SCHAC held legislative town hall meetings focused on HIV issues within rural counties. Second, they produced an educational play on the realities of HIV stigma for communities and their local leaders. Third, SCHAC created a statewide marketing campaign to address HIV/AIDS stigma using public service announcements, posters and editorials.¹³

*The New York State Department of Health AIDS Institute (AI) has used multi-level interventions to prevent HIV-related stigma and discrimination. On a policy level, the AI has worked to pass laws and enact policies to protect the rights of HIV+ persons and persons perceived to be HIV+, including confidentiality laws and naming HIV/AIDS in the existing anti-discrimination law. They also provide forums and advisory councils for policy discussions, and set up an office for discrimination issues to handle complaints. On a program level, the AI provides diversity and confidentiality training for healthcare providers, leadership training for HIV+ persons and social marketing approaches for community-wide education and awareness.*¹⁴

what needs to be done?

Knowledge about HIV prevention, transmission and care can offset the stigma that is caused by misinformation and ignorance. Education programs are still needed in many areas and populations, and will continue to be needed for successive generations of young people.⁵

*Stigma exists not simply within individual actions, but within broad social and cultural contexts that need to be addressed in stigma-reduction programs. Organizations and communities must tackle the values, norms and moral judgments that contribute to the stigmatization of HIV+ persons by engaging faith-based organizations, key institutions and opinion leaders that help shape and reinforce societal values.*¹⁵ *Policymakers need to consider the potential consequences of laws to make sure they don't inadvertently increase HIV/AIDS-related stigma.*

HIV+ persons must be involved in designing, running and evaluating stigma reduction programs. One approach is to train and support HIV+ persons to organize to advocate for themselves.¹⁶ Prevention, coping and adherence programs for HIV+ persons should directly address stigma and its effect on HIV+ persons' health and well being.

Programs can also offer cultural competency, confidentiality and awareness training for healthcare workers, counselors and staff at social service organizations including drug treatment, housing, mental health services. Training is especially important in areas where stigma is high, such as rural areas and organizations where there may be few HIV+ clients.

HIV/AIDS-related stigma is unlikely to go away any time soon.¹⁶ While research is being conducted nationally and internationally,¹⁷ more research is needed to measure the effects of stigma and understand what types of interventions work best for which communities. Promising stigma awareness and reduction programs need to be evaluated and published so that effective programs can be widely replicated.

PREPARED BY MARIA EKSTRAND PHD, CAPS AND THE NATIONAL AIDS FUND

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SC HIV/AIDS Council
*www.schivaidsCouncil.org/

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*All websites accessed May 2006



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ABSTRACT

In light of increasing cross-communication and possible coalescence of conceptual models of stigma and prejudice, we reviewed 18 key models in order to explore commonalities and possible distinctions between prejudice and stigma. We arrive at two conclusions. First, the two sets of models have much in common (representing “one animal”); most differences are a matter of focus and emphasis. Second, one important distinction is in the type of human characteristics that are the primary focus of models of prejudice (race) and stigma (deviant behavior and identities, and disease and disabilities). This led us to develop a typology of three functions of stigma and prejudice: exploitation and domination (keeping people down); norm enforcement (keeping people in); and disease avoidance (keeping people away). We argue that attention to these functions will enhance our understanding of stigma and prejudice and our ability to reduce them.

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“Ethnic prejudice is an antipathy based upon a faulty and inflexible generalization. It may be felt or expressed. It may be directed toward a group as a whole, or toward an individual because he is a member of that group” (Allport, 1954: 9).

“Stigma... is the situation of the individual who is disqualified from full social acceptance” (Goffman, 1963: preface). The stigmatized individual is “reduced in our minds from a whole and usual person to a tainted, discounted one” (Goffman, 1963: 3).

So are the terms “prejudice” and “stigma” defined by the authors who gave life to each – Allport publishing *The Nature of Prejudice* in 1954 and Goffman *Stigma: Notes on*

the Management of Spoiled Identity in 1963. Since then, largely separate literatures have developed around the two concepts. However, there is evidence that these literatures have begun to coalesce. Increased attention by prejudice researchers to the targets of prejudice in the 1990s (Crocker & Garcia, 2006) brought greater overlap to work on stigma and prejudice. The concepts of stigma, prejudice, and discrimination increasingly are used by the same authors in the same texts (e.g., Heatherton, Kleck, Hebl, & Hull, 2000; Levin & Van Laar, 2006). In 2006, the National Institute of Mental Health brought together prejudice and stigma researchers to address the problem of mental-illness stigma. This special issue, and the conference that led to it, also aim to bring together concepts and research identified with stigma, prejudice and discrimination. However, to our knowledge, no one has systematically compared conceptual models of prejudice and stigma.¹ Such a comparison seems worthwhile and timely.

Sometimes entirely separate literatures develop around essentially identical constructs (Merton, 1973). If this is the

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* Corresponding author. Mailman School of Public Health, Columbia University, 722 West 168th Street, 16th Floor, New York, NY 10032, USA.

E-mail address: jcp13@columbia.edu (J.C. Phelan).

¹ Some of the works we review are theories, while others are not. We use the term “conceptual model” as an inclusive term that accurately describes all the contributions.

case for stigma and prejudice, scholars may borrow freely across the literatures, vastly expanding the theoretical, methodological and empirical resources relevant to both areas. If there are some essential differences between models of prejudice and stigma, a comparison of the two may sharpen our understanding of the sets of models, and it may reveal something about a broader conceptual space in which they both reside. In this case, borrowing would not be precluded but may be more targeted.

Are the parallel lives of stigma and prejudice a consequence of the application of different terms by luminaries in different fields to describe basically the same processes, or are there more fundamental differences in the processes that have been labeled “stigma” and “prejudice?”

Methods

To address this question, we reviewed 18 key conceptual models in the domains of stigma and prejudice, summarized in Appendix 1. Because prejudice often deals with race, and because prejudice and racism are recognized as closely related concepts (Dovidio, 2001; Jones, 1997), we included racism models in the prejudice category. We included models we judged to be particularly widely known or influential or to make unique contributions to conceptualizing stigma or prejudice; four of these were added at the suggestion of peer reviewers. Clearly, this set of 18 models is not exhaustive. Other models that we did not include because of space limitations are those of Adorno, Frenkel-Brunswick, Levison, and Sanford (1950), Brewer (1979), Greenwald and Banaji (1995), Jost and Banaji (1994), Macrae, Milne, and Bodenhouse (1994), Neuberg, Smith, and Asher (2000), Sidanius and Pratto (1999), Sears (1988), Smith (1984), and contributions to the edited collection by Levin and Van Laar (2006).

We analyzed the conceptual models in three ways. First, we coded each along the following dimensions: (1) what are the model's key constructs? (2) Where does the model focus its attention (e.g., on stigmatizing or prejudiced individuals, referred to hereafter as “perpetrators”); on individuals who are the object of stigma or prejudice (referred to hereafter as “targets”); on interactions between perpetrators and targets; and/or in social structures? If the focus is on individuals, what processes does the model focus on (e.g., cognitive, emotional, behavioral)? (3) To what human characteristics does the model claim to apply? (4) Are stigma/prejudice processes viewed as normal or pathological? As processes that are common across individuals or that vary between individuals?

Second, we compared each pair of models searching for contradictions or incompatibilities – cases in which the models make different predictions. Third, we asked whether human characteristics were interchangeable in the model (i.e., could characteristics other than the ones explicitly addressed be “plugged in” to the model?).

This analysis could potentially support several different conclusions: models of stigma and prejudice are parallel (i.e., describe the same phenomena in different terms) or complementary (i.e., describe different parts of one overarching process) – both “one-animal” conclusions; or they may be contradictory (i.e., make conflicting

predictions) or disconnected (i.e., describe distinct and unrelated processes) – both “two-animal” conclusions.

Results

Focus of analysis: mapping the terrain of stigma and prejudice

First, we compared the phenomena addressed by the models of prejudice and stigma. We began by enumerating the constructs central to each separate model and fitting each into the conceptual map shown in Fig. 1. As in open coding of text, we believed this bottom-up approach would allow the identification of overlapping and non-overlapping areas of focus in models of stigma and prejudice. Fig. 1 thus contains but is more extensive than the distinct models from which it was built.

Each box names a construct and lists the models that include the construct. We did not indicate specific causal relationships between constructs; therefore, Fig. 1 is not a causal model. However, we do intend the figure to represent a rough progression of causal effects from left to right. Above the dotted line are processes pertaining to perpetrators of stigma and prejudice. Below are processes pertaining to targets. On the dotted line are processes engaged in by both groups.

In Column 1 are basic sources or functions of stigma and prejudice and of responses to stigma and prejudice. Above the line are power differences, which Link and Phelan (2001) consider necessary for one group to effectively stigmatize another; desire for power and economic gain (e.g., the profit motives undergirding U.S. slavery, Feagin, 2000); social groups' desire for order and conformity, implicated by Goffman's identification of norms as the cause of stigma; and evolutionary pressures, which Kurzman and Leary (2001) cite as the source of all stigmatization. Below the line are core social goals (Fiske, 2004) that stigma and prejudice threaten and that influence targets' coping strategies (Swim & Thomas, 2006). Broad or local cultural values influence what characteristics are most likely to be targeted for stigma and prejudice and which social values are most threatened for targets (Yang et al., 2007).

In Column 2 are intergroup competition, which we view as following from economic and power desires; categories and labels, emphasized as the cognitive bedrock for prejudice and stigma in most of our models; and norms (Goffman, 1963).

In Column 3 are a range of cognitive and emotional processes generated by the forces in Columns 1 and 2. These processes are most often included as they refer to perpetrators, but some models also attend to these processes in targets.

In Column 4 are three ways in which processes in previous columns get translated into behavior and other concrete outcomes that affect targets. Structural discrimination refers to structured practices that can operate independently of prejudiced attitudes, for example, built environments that impede the functioning of people with physical disabilities. Discriminatory behavior can occur outside interactions, for example, when an employer discards a job application disclosing a history of psychiatric hospitalization. Finally, the forces in previous columns,

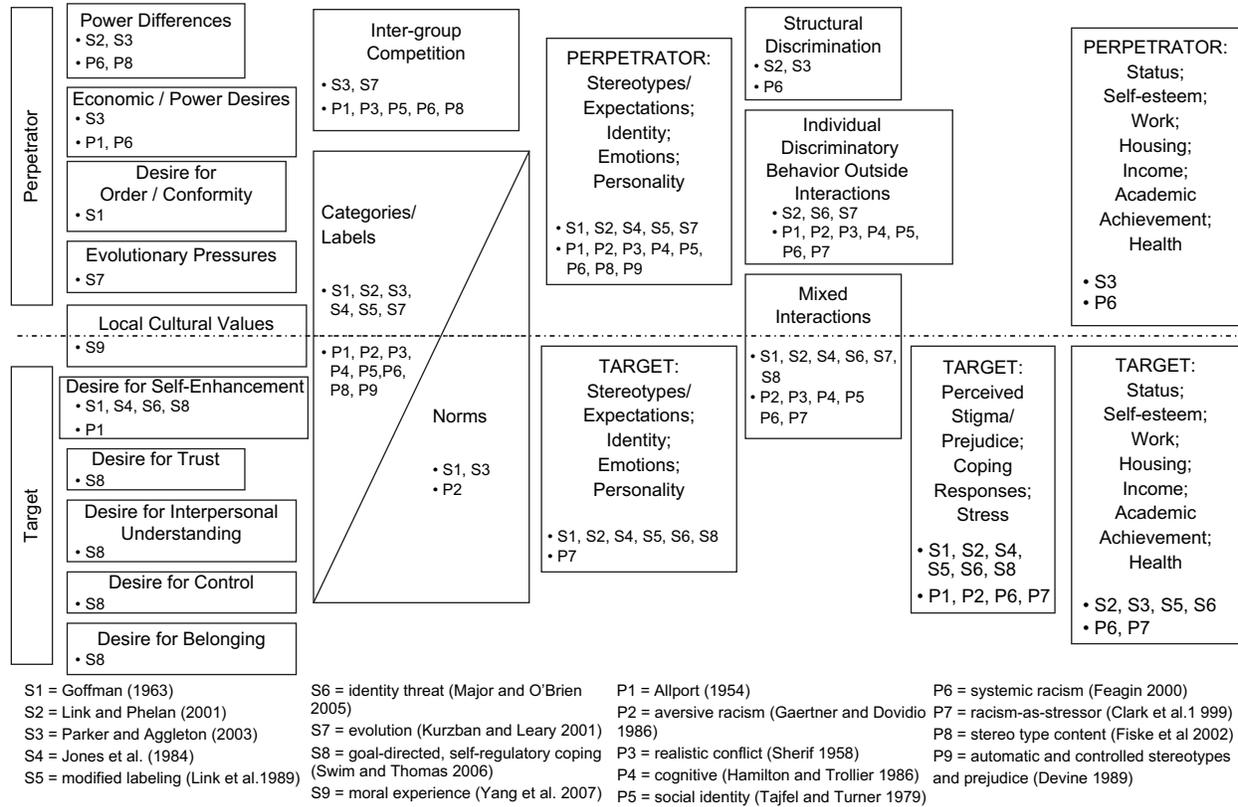


Fig. 1. Factors involved in stigma and prejudice.

working through both perpetrators and targets, shape the processes that unfold in “mixed interactions” (Goffman, 1963) between perpetrators and targets.

In Column 5 are targets’ responses to discrimination and problematic interactions with perpetrators, including perceptions of stigma or prejudice, stress and coping. These in turn affect targets’ life outcomes, such as status, self-esteem, work, housing, academic achievement, and health, as described in Column 6. Column 6 also includes such outcomes for perpetrators, because as suggested by models emphasizing conflict and domination (Feagin, 2000; Parker & Aggleton, 2003), when targets lose in terms of outcomes such as work, housing, and income, perpetrators gain.

Fig. 1 reveals considerable variation between models in terms of the processes they focus on. Stigma models place somewhat more emphasis on targets, particularly in terms of stereotypes/expectations, identity and emotions (Column 3). Prejudice models pay more attention to these processes in perpetrators, as well as to individual discriminatory behavior outside interactions. These differences reflect the contrasting foci in the two seminal works on prejudice and stigma: Allport (1954) clearly focused on the perpetrator, while Goffman (1963) focused more on the target. However, Fig. 1 reveals no clear fault line between stigma and prejudice models and in fact shows considerable overlap in focus.

Finally, the concept of prejudice refers specifically to perpetrators’ attitudes, and thus might appear narrower in scope than the concept of stigma. However, Fig. 1 shows that, when

we consider explanatory models of prejudice that include not only the construct itself but also its causes and consequences, the scope of prejudice and stigma models is similar.

Contradictory predictions

Next we compared pairs of models in search of contradictory predictions. We identified two points of contention. The first concerns the impact of stigma or prejudice on psychological well-being of targets. Based on the situational nature of stigma and the importance of coping, the identity threat models of Crocker, Major, and Steele (1998) and Major and O'Brien (2005) argue that targets of stigma and prejudice are not necessarily as psychologically harmed as most models suggest. The second concerns evolutionary vs. social/psychological processes. Kurzban and Leary's (2001) evolutionary model does not deny that social processes may play a part, but argues that evolutionary processes actually explain most stigmatization. Social and psychological models of prejudice and stigma generally do not mention evolutionary factors. Neither of these disagreements represents a schism between prejudice and stigma models. Both identity threat and evolutionary models identify themselves with stigma, and the models from which they differ include both stigma and prejudice models. Overall, our review of the separate models leads us to conclude that differences of focus indicate complementarity rather than contradiction.

Normality/common processes vs. psychopathology/individual variation

Next we considered whether models view stigma or prejudice as being rooted in normal processes that work similarly across individuals or whether they focus on individual differences or psychopathology. In general, stigma models emphasize that stigma is rooted in normal processes common across individuals. Goffman expresses this most eloquently “stigma management is a general feature of society...the stigmatized and the normal have the same mental make-up, and that necessarily is the standard one in our society; he who can play one of these roles...has exactly the required equipment for playing out the other” (Goffman, 1963: 130–131).

Most of the prejudice models also emphasize normal processes that are common across individuals. Tajfel attributed out-group discrimination to “a generic norm of out-group behavior” that is “extraordinarily easy to trigger off” (Tajfel, 1970: 102). Feagin (2000) emphasizes that racism is rooted in the system rather than in individuals. Although Allport attends to prejudice as a normal process (Chapter 2 is titled “The normality of prejudgement”), his stands out among the models we reviewed in also emphasizing individual variation and psychopathology (i.e., prejudiced vs. tolerant personalities). Notably, we find nothing in models emphasizing common processes that deny a role for individual variations. For example, while emphasizing the roots of prejudice in common processes, Sherif notes “there is good reason to believe that some people growing up in unfortunate life-circumstances may become more intense in their prejudices and hostilities” (Sherif, 1958: 350). Likewise, Allport (1954) clearly does not deny the role of the more universal processes. Thus, we do not see this as a dividing line between stigma and prejudice.

Interchangeability of characteristics that are the object of stigma and prejudice

To this point, our analysis suggests variations in conceptual models that do not align with a stigma/prejudice distinction. However, our last device for detecting differences between models uncovered a distinction we think is significant. We asked whether a given model could be applied to characteristics other than those the model explicitly addresses. In other words, are characteristics that are the object of stigma or prejudice interchangeable?

All but one of the stigma models is comprehensive in terms of the characteristics they address (The exception is Link et al.’s modified labeling theory, which applies specifically to mental illness; however, the model should be applicable to any stigmatized characteristic about which cultural attitudes are learned before the stigmatized label is acquired). For example, Goffman’s tribal stigmas, blemishes of individual character, and abominations of the body appear to cover every imaginable form of stigma or prejudice. Similarly, several of the prejudice models are not tied to particular in- and out-groups, and social identity theory is based in research showing that arbitrarily identified characteristics can serve as the basis of discrimination (Tajfel, 1970). However, other prejudice models are more

restrictive. Allport focuses on nationality, race, religion and ethnicity, and the racism models focus specifically on race. For some of these more restricted models, it is easy to imagine substituting other human characteristics for race. For example, Clark, Anderson, Clark, and Williams’s (1999) analysis of the stressful consequences of discrimination should apply to any characteristic that is the target of stigma or prejudice. However, in other cases, this substitution does not make sense. This is most clear for Allport (1954) and for Feagin’s (2000) systemic racism model. Although much of Allport’s analysis could apply to characteristics such as mental illness or sexual deviance, a key statement is this: “In every society on earth the child is regarded as a member of his parents’ groups. He belongs to the same race, stock, family tradition, religion, caste, and occupational status” (Allport, 1954: 31). The same cannot be said for most illnesses and disabilities and deviations such as non-normative sexualities that may be targeted for stigma or prejudice. These may be more common in some families than others, but they are not shared by families in the same way that race, religion and caste are. We believe this distinction between what we call “group” characteristics (those shared by family members) and “individual” characteristics (those that occur more sporadically within families) is a significant distinction uncovered by our examination of models of prejudice and stigma.

This distinction is reinforced by an examination of the human characteristics which have been analyzed in terms of “stigma” and “prejudice” in published literature. We searched the titles of journal articles indexed in PsycInfo every five years from 1955 (the year after *The Nature of Prejudice* was published) to 2005, and we searched the articles to identify the human characteristics they analyzed.² Results are shown in Table 1.

In most cases (62%), “prejudice” is connected with race or ethnicity, followed by 11% for articles that deal with prejudice as a general phenomenon. In these cases, race or ethnicity would implicitly be considered a core characteristic of concern. In contrast, an overwhelming proportion of articles with “stigma” in the title – 92% – dealt with illness, disability or behavioral or identity deviance.³ Only 6% of stigma articles dealt with race, ethnicity or gender.

Why some characteristics become the target of stigma and prejudice and others do not

This distinction in the types of characteristics studied in the name of prejudice vs. stigma led us to another question: why do particular characteristics become the object of stigma and prejudice, and are there different reasons for

² These years were chosen as a sample of the 52 years between the publication of *The Nature of Prejudice* and the present. We located 162 articles with “stigma” in the title and 139 with “prejudice.” The number of relevant articles increased steadily over time; consequently, 46% of the articles were published in 2005, and 75% of the articles were published in 1995 or later.

³ We use “deviance” here not as a pejorative term but in the classical sociological sense of deviation from the norms of a particular social group. We include both deviant behavior and identity. For example, sexual deviation may be defined in terms of behavior or identity; both are objects of stigma and prejudice.

Table 1

Types of human characteristic with which “prejudice” and “stigma” are associated in journal articles^a

	Prejudice (N = 139) (%)	Stigma (N = 162) (%)
Race or ethnicity	62	4
Gender	7	2
Behavioral/identity deviance		
Sexual orientation	3	4
Other deviance	4	8
Illness/disability		
Mental illness	0	38
Substance use	0	4
HIV/AIDS	1	16
Other illness/disability	6	22
Other characteristic	6	0
Unspecified characteristic	11	2

^a Based on a search of PsycInfo for 1955, 1960, 1965, 1970, 1975, 1980, 1985, 1990, 1995, 2000 and 2005.

different characteristics? Many of the models we examined emphasize that the things we target with stigma and prejudice are socially constructed and vary dramatically across time and place. This is certainly an important aspect of stigma and prejudice. At the same time, the choice of particular human characteristics as targets of stigma and prejudice is not a random process. We believe the reasons that particular characteristics get selected may represent an important variation that was revealed by our comparison of stigma and prejudice models.

Above we discussed the association of prejudice with “group” and stigma with “individual” characteristics. We now make a further distinction between what we see as the two major types of characteristics addressed in the stigma literature – disease/disability and deviant behavior/identity. Based on these distinctions, we develop at a typology of functions of stigma and prejudice.⁴

We propose that there are three functions of stigma and prejudice (1) exploitation/domination, (2) enforcement of social norms and (3) avoidance of disease. We also refer to these as keeping people down; keeping people in; and keeping people away.

Exploitation and domination

Some groups must have less power and fewer resources for dominant groups to have more. Some groups provide labor that is exploited by others or perform unpleasant or dangerous tasks that others prefer to avoid. Ideologies develop to legitimate and help perpetuate these inequalities (Jost & Banaji, 1994; Marx & Engels, 1976). We argue that exploitation and domination, along with their corresponding ideologies, are one basic function of stigma and prejudice. Race is a clear example. Feagin describes how racism was “integral to the foundation of the United States” (Feagin, 2000: 2). “At the heart of the Constitution was protection of the property and wealth of the affluent bourgeoisie in the new nation” (Feagin, 2000: 10). Slavery was seen as an

⁴ We do not imply that a desirable end is served by stigma and prejudice by using the term “function”; we use the term rather to indicate the sources, reasons or motives for stigma and prejudice.

essential tool for maintaining this wealth, and discrimination was considered necessary. Ideologies that viewed African-Americans as inferior, less worthy, and dangerous (i.e., stereotypes) developed to legitimate the discrimination (Morone, 1997).

By this reasoning, we also consider stigma and prejudice against women, people of low socioeconomic status and ethnic minority groups to be rooted in exploitation and domination.

Enforcement of social norms

Societies also find it necessary to extract conformity with social norms. We propose that failure to comply with these norms, usually cast in terms of morality or character (Goffman, 1963; Morone, 1997), is a second ground for stigmatization and prejudice. Here, the function of stigma and prejudice may be to make the deviant conform and re-join the in-group, as in reintegrative shaming (Braithwaite, 1989), or it may be to clarify for other group members the boundaries of acceptable behavior and identity and the consequences for non-conformity (Erikson, 1966). In either case, the goal is to increase conformity with norms. This type of stigma and prejudice should only apply to behavior or identity perceived as voluntary. For example, although people with mental retardation may behave in deviant ways, we would not include mental retardation here, because the application of stigma and prejudice cannot be expected to change the behavior. Examples of this form of stigma and prejudice are numerous: non-normative sexual behavior or identities, such as homosexuality, polygamy or (in some contexts) extra-marital sex; political deviations; various forms of criminal behavior, such as theft, rape or murder; substance abuse; smoking; perhaps obesity and some mental illnesses such as depression.⁵ This function of stigma and prejudice is aligned with exploitation/domination in that the dominant group is influential in defining the unacceptable. However, it differs importantly in that the dominant group does not, in a significant way, profit from the labor of the deviants.

Avoidance of disease

A large set of characteristics remains to be explained in terms of stigma and prejudice function. In the review of journal articles (Table 1), we grouped these as illness and disability, and they constituted the largest set of articles with stigma in the title. Included here are mental illnesses, including mental retardation, and physical illnesses such as cancer, skin disorders and AIDS, physical disabilities and imperfections such as missing limbs, paralysis, blindness and deafness. Again, the dominant group does not profit from the labor of people with these characteristics – in fact, they have trouble getting jobs. Neither are we trying to control their behavior or set an example for others by subjecting them to stigma and prejudice. We find this form of stigma

⁵ Although there is disagreement about whether sexual orientations and identities are voluntary, we believe that stigma or prejudice against people with non-normative sexual orientations and identities are based on public perception that they are voluntary, and we, therefore, include them under norm-based stigma and prejudice.

and prejudice difficult to explain in purely social or psychological terms, and we turn to evolutionary psychology. *Kurzban and Leary (2001)* (also see *Neuberg et al., 2000*) argue that there are evolutionary pressures to avoid members of one's species who are infected by parasites. Parasites can lead to "deviations from the organism's normal (healthy) phenotype" (*Kurzban & Leary, 2001: 197*) such as asymmetry, marks, lesions and discoloration; coughing, sneezing and excretion of fluids; and behavioral anomalies due to damage to muscle-control systems. They argue that the advantage of avoiding disease "might have led to the evolution of systems that regard deviations from the local species-typical phenotype to be...unattractive;" that systems might develop wherein people would "desire to avoid...close proximity to potentially parasitized individuals;" and that "because of the possible cost of misses, the system should be biased toward false positives, and this bias might take the form of reacting to relatively scant evidence that someone is infested" (*Kurzban & Leary, 2001: 198*).

Aesthetics, one of *Jones et al.'s (1984)* six dimensions of stigmatized "marks," are particularly relevant here. An evolutionary explanation for disease avoidance is consistent with humans' aesthetic preference for facial symmetry (*Grammar & Thornhill, 1994*) which develops early in life and across cultures (*Johnson, Dziurawiec, Ellis, & Morton, 1991*) and with *Jones et al.'s* observation that physical anomalies seem to "automatically elicit 'primitive' affective responses in the beholder" "not mediated by labels or causal attributions" (*Jones et al., 1984: 226*). Consistent with *Kurzban and Leary's (2001)* argument that disgust should be the primary emotion associated with parasite-avoidance stigma is the plethora of words and phrases to describe affective reactions to physical deviance, including disgusting, nauseating, offensive, sickening, repelling, revolting, gross, makes you shudder, loathsome, and turns your stomach (*Jones et al., 1984*).

The evolutionary explanation applies most clearly to visible illnesses, deformities and deviations in physical movements. If "species-atypical phenotype" can be extended to illnesses that are not necessarily visible, such as cancer, and to psychological functioning that appears "diseased," such as psychosis, then the evolutionary model may apply broadly to our "illness and disability" category. However, this broad application depends critically on the strength of bias toward false positives, which is unknown. Because evidence to connect many stigmatized illnesses to parasite avoidance is lacking, the evolutionary explanation must be considered provisional.

According to this argument, the function of disease-avoidance stigma and prejudice is rooted in our evolutionary past rather than in current social pressures. People may indeed consciously avoid others because they appear to be infected. However, the strong emotional reactions involved in this type of stigma and prejudice, as well as its application to individuals who are not actually infected ("false positives"), are attributed to the disproportionate survival and procreation of individuals who exhibited extreme vigilance, resulting in exaggerated reactions in present-day humans. Thus, when we refer to the disease-avoidance function of stigma or prejudice, we are referring to its past, not current, function.

Relation to other functional explanations of stigma and prejudice

Some previous work has attempted to understand the functions of stigma or prejudice for individuals or groups. Proposed functions include coping with guilt and anxiety (*Allport, 1954*), self-esteem enhancement through downward comparisons (*Wills, 1981*), management of terror associated with awareness of one's mortality (*Solomon, Greenberg, & Pyszczynski, 1991*), simplification of information processing (*Allport, 1954; Hamilton & Trolhier, 1986*), competitive group advantage (*Allport, 1954; Feagin, 2000; Tajfel & Turner, 1979*) and system justification (*Corrigan, Watson, & Ottati, 2003; Jost & Banaji, 1994*). These explanations do not specify why particular groups are targeted for stigma or prejudice (*Stangor & Crandall, 2000*). Two functional explanations (*Kurzban & Leary, 2001; Stangor & Crandall, 2000*) are, like ours, both comprehensive (i.e., include all types of targets of stigma or prejudice) and specify why some characteristics are stigmatized and others not.⁶ Here we briefly delineate how our functional typology differs from these.

Stangor and Crandall (2000) argue that all stigmatization is rooted in perceived threat to the individual or culture, including intergroup conflict, health threats, physical features that denote threat, belief in a just world, and moral threats. Each of our three types of stigma and prejudice can be construed as threats (domination/exploitation defends against the threat of loss of power and economic advantage; norm enforcement defends against the threat of social disorder and harm to group members; and disease avoidance defends against the threat of infection). However, particularly for exploitation/domination, models that emphasize the role of power and status differences in stigma and prejudice (*Feagin, 2000; Fiske, Cuddy, Glick, & Xu, 2002; Link & Phelan, 2001; Parker & Aggleton, 2003*) provide a more accurate representation, we believe, of what is at stake for the perpetrators of this type of stigma and prejudice. Accordingly, the function of stigma and prejudice based on exploitation and domination is the desire to maintain advantage rather than the threat of losing advantage. Webster's dictionary includes words like "punishment," "injury," "trouble," "menace," and "danger" in defining "threat," words that aptly describe the situation of a subordinate group but would not be called into play to define the loss of a power advantage. Omitting the concept of exploitation/domination and subsuming it under the concept of threat, we believe, robs a functional schema of the very thing that marks group-based stigma and prejudice such as racism as distinct, and its inclusion provides an important niche for this type of prejudice and stigma in an inclusive model of stigma and prejudice.

Kurzban and Leary's (2001) functional schema strongly overlaps ours. They argue that stigma derives from three evolutionary pressures. Dyadic-cooperation adaptations result in avoidance of poor social exchange partners (people who are unpredictable, are resource-poor, or cheat). Coalition-exploitation adaptations lead to exclusion and

⁶ A similar evolutionary model was proposed by *Neuberg et al. (2000)*.

exploitation of social out-groups. Parasite-avoidance adaptations were described above. These correspond fairly closely to our functions of norm enforcement, exploitation/domination and disease avoidance, respectively.⁷ The major difference between Kurzban and Leary's (2001) and our explanations is that they argue for an evolutionary basis of all stigmatization, whereas we reserve the evolutionary explanation for disease avoidance. To the extent that behaviors adaptive in the past are currently adaptive, stigma and prejudice may be co-determined by biological vestiges of past adaptation pressures and by current social and psychological pressures (Neuberg et al., 2000). For example, social groups benefit now as in the distant past from dominating and exploiting other groups. Similarly, control of at least some types of deviant behavior serves group well-being now as in the past. In these cases, whatever evolutionary functions may have been served, they are strongly bolstered by current social functions. We believe these social functions are a more fruitful focus for understanding and, particularly, reducing stigma and prejudice. By contrast, as discussed above, we find disease-avoidance stigma and prejudice difficult to explain in terms of current functions. While it is functional to avoid someone with a serious infectious disease, it is difficult to discern the function of avoiding someone with a non-infectious disease or physical imperfection. It is the illogic of this avoidance as well as the strong and seemingly automatic emotional reactions to such individuals that lead us to call on evolutionary processes. It is currently impossible to determine to what extent stigma and prejudice may be attributable to evolutionary pressures and to what extent they may be due to current social/psychological pressures: all or none of these types of stigma may have evolutionary roots. More generally, data are not available to determine which of the three functional explanations we have compared – Kurzban and Leary's (2001) and Stangor and Crandall's (2000), or our own – has more validity. However, each is plausible and distinct enough from the others to warrant consideration and empirical testing.

Distinctions and commonalities in stigma/prejudice processes across the three functions

Our functional typology raises the question of whether the stigma/prejudice process varies depending on function. For example, the reasoning behind exploitation/domination-based stigma and prejudice suggests that intergroup competition, derogatory stereotyping, and discrimination in allocation of resources may be particularly prominent here (Feagin, 2000), and emotions of pity (Fiske et al., 2002) fear, or hate (Kurzban & Leary, 2001) may also be important. Attribution theory (Weiner, Perry, & Magnusson, 1988) and Kurzban and Leary's (2001) evolutionary model suggest that anger and punishment may be

prominent in stigma and prejudice based on norm enforcement. Kurzban and Leary (2001) and evidence about aesthetics in stigma (e.g., Jones et al., 1984) suggest that fear, disgust and avoidance may be prominent in stigma and prejudice based on disease avoidance. Targets' experiences and coping strategies may also vary according to function.

Nevertheless, we suggest that the social processes involved in enacting and maintaining stigma and prejudice are more alike than different once a human characteristic gets selected as a basis for stigma and prejudice. All involve categorization, labeling, stereotyping, negative emotions, interactional discomfort, social rejection and other forms of discrimination, status loss and other harmful effects on life chances of targets, as well as stigma management and coping. The experiences of different targeted groups may become "homogenized" by a confluence of these pressures. Morone (1997) describes how racial, ethnic and immigrant out-groups become stereotyped as posing moral and health threats to the majority. Here, stigma and prejudice rooted in exploitation/domination call into service the other two bases of stigma and prejudice: norm enforcement and disease avoidance. Similarly, although exploitation may not have been the original function of stigma and prejudice against people with depression or AIDS, those people are more vulnerable to exploitation as a result of the degraded social status attending all forms of stigma and prejudice. Finally, stigma and prejudice against some characteristics serve more than one function. For example, stigma and prejudice associated with HIV/AIDS is likely based on both norm enforcement and disease avoidance.

One area where distinctions based on function may be particularly important is the question of how to prevent or reduce stigma and prejudice. Some aspects of stigma and prejudice can be reduced without attention to function. Anti-discrimination laws have decreased discrimination and do not depend on a consideration of function. We argue, however, that stigma and prejudice reduction will be enhanced by attention to function. Subtle but significant anti-Black prejudice persists despite real changes effected by law (Gaertner & Dovidio, 1986). The continuing exploitation of African-Americans may help explain why racial prejudice has been so difficult to eradicate: continued exploitation requires continued justification. Modern legitimations are more subtle but remain powerful. Stigma and prejudice based on exploitation/domination may not be completely eliminated without changes to the power hierarchy (Parker & Aggleton, 2003). Similarly, stigma and prejudice based on norm enforcement may be difficult to eradicate without changes in social norms.

An evolutionary basis for stigma and prejudice based on disease avoidance may seem to argue against any possibility of reducing stigma or prejudice. But that is not necessarily so. Sex roles may also have some evolutionary base but can be altered. Disease-based stigma and prejudice may operate largely through automatic emotional reactions, and familiarity might reduce these reactions, just as desensitization through exposure can reduce evolutionarily based phobias. Accordingly, research suggests that personal

⁷ Both schemas also correspond closely to Goffman's (1963) three types of stigma – tribal-based stigmas, blemishes of individual character, and abominations of the body. Goffman, however, did not analyze these in terms of their functions.

contact is one of the most promising approaches to reducing stigma and prejudice associated with mental illness (Kolodziej & Johnson, 1996). Whether or not our particular schema of the functions of stigma and prejudice proves useful, we believe efforts to reduce stigma and prejudice will be enhanced by considering why the characteristic is the target of stigma and prejudice.

Conclusions: one animal or two?

Our analysis suggests some differences in emphasis and focus, but we conclude that models of prejudice and stigma describe a single animal. However, distinctions in the functions of stigma and prejudice led us to delineate three subtypes of this animal. We believe a useful distinction can be made between stigma and prejudice based on exploitation and domination (keeping people down), norm enforcement (keeping people in) and disease avoidance (keeping people away). This typology both distinguishes between and unites work in the stigma and prejudice traditions. Although these distinctions are diminishing, work in the prejudice tradition grew from concerns with social processes driven by exploitation and domination, such as racism, while work in the stigma tradition has been more concerned with processes driven by norm enforcement and disease avoidance. Our analysis suggests, however, that these processes are quite similar and are all part of the same animal.

What should we call this animal? Throughout this paper, we agnostically paired the terms “stigma” and “prejudice” as we investigated the relation between the corresponding sets of conceptual models. Going forward, we follow Dovidio, Major, and Crocker (2000) and others in using the term “stigma” when referring to a broader process including many components shown in Fig. 1 and “prejudice” to refer to attitudinal components of this process.

We believe our comparison of conceptual models of stigma and prejudice has proven fruitful in several ways. First, the strong congeniality and large degree of overlap we found between models of stigma and prejudice should encourage scholars to reach across stigma/prejudice lines when searching for theory, methods and empirical findings to guide their new endeavors. The conceptual map we generated (Fig. 1) may help scholars identify new constructs that are relevant to their current thinking and research. Finally, we hope that the distinction between stigma and prejudice based on exploitation/domination, norm enforcement and disease avoidance will be useful in understanding stigma and prejudice more fully and in reducing both.

Appendix 1. Brief synopses of conceptual schemes of prejudice and stigma

Prejudice models (arranged chronologically)

The Nature of Prejudice (Allport, 1954). “Ethnic prejudice is an antipathy based upon a faulty and inflexible generalization. It may be felt or expressed. It may be directed toward a group as a whole, or toward an individual because

he is a member of that group” (p. 9). “Prejudice is ultimately a problem of personality formation and development” (p. 41). A broad array of influences affect the development of prejudice, including cognitive, social structural, cultural and psychodynamic factors.

Realistic group conflict model (Sherif, 1958). Individuals brought together with common goals form “in-group” structures with hierarchical statuses and roles. If two in-groups are brought together under conditions of competition and group frustration, hostile attitudes and actions and social distance develop between groups.

Social identity theory (Tajfel & Turner, 1979). Individuals have multiple social identities corresponding to different group memberships. The salience of different identities varies according to context. When identity with a particular group is salient, self-esteem associated with membership in that group as well as in-group favoritism result. Prejudice results from the need for a positive social identity with an in-group.

Aversive prejudice/racism (Gaertner & Dovidio, 1986). “Aversive racism represents a particular type of ambivalence in which the conflict is between feelings and beliefs associated with a sincerely egalitarian value system and unacknowledged negative feelings and beliefs about blacks... The negative affect that aversive racists have for blacks is not hostility...[but] discomfort, uneasiness, disgust and sometimes fear” (Gaertner & Dovidio, 1986: pp. 62–63).

Cognitive perspective (Hamilton & Trolhier, 1986). Human information-processing systems inevitably result in the categorization of individuals into groups, which in turn inevitably results in stereotypes and in-group biases in attitudes and behavior.

Automatic and controlled components of stereotypes and prejudice (Devine, 1989). Knowledge of stereotypes is distinct from their endorsement (prejudice). Stereotypes are learned early in life and activated automatically. Prejudiced or non-prejudiced personal beliefs are acquired later, are under conscious control and can override responses based on stereotypes.

Racism as stressor (Clark et al., 1999). “The perception of an environmental stimulus as racist results in exaggerated psychological and physiological stress responses that are influenced by constitutional...sociodemographic...psychological and behavioral factors, and coping responses. Over time, these stress responses...influence health outcomes” (p. 806).

Systemic racism (Feagin, 2000; Feagin & McKinney, 2003). Racism has been a core aspect of American culture and society since the country’s founding. It is rooted in the dependence of the wealth of the new country’s elite on slavery and maintained by a racist ideology of white superiority and systematic life advantages for whites.

Stereotype content model (Fiske et al., 2002). “(a) 2 primary dimensions [of stereotype content] are competence and warmth, (b) frequent mixed clusters combine high warmth with low competence (paternalistic) or high competence with low warmth (envious), and (c) distinct emotions (pity, envy, admiration, contempt) differentiate the 4 competence-warmth combinations” (p. 878).

Stigma models (arranged chronologically)

Stigma: Notes on the Management of Spoiled Identity (Goffman, 1963). Stigma is “the situation of the individual who is disqualified from full social acceptance” (preface). The stigmatized individual is “reduced in our minds from a whole and usual person to a tainted, discounted one” (p. 3). Goffman emphasizes stigma as enacted in “mixed interactions” between stigmatized and non-stigmatized individuals and how stigmatized individuals manage those interactions.

Social Stigma: The Psychology of Marked Relationships (Jones et al., 1984). “The stigmatizing process involves engulfing categorizations accompanied by negative affect that is typically alloyed into ambivalence or rationalized through some version of a just-world hypothesis” (p. 296). Jones et al. identify six dimensions of stigmatizing “marks”: Concealability, course, disruptiveness, aesthetic qualities, origin and peril.

Modified labeling theory of mental disorders (Link, Cullen, Struening, Shrout, & Dohnrenwend, 1989). Socialization leads to beliefs about how most people treat mental patients. When individuals enter psychiatric treatment, these beliefs become personally relevant. The more patients believe they will be devalued and discriminated against, the more they feel threatened by interacting with others. They may employ coping strategies that can have negative consequences for social support networks, jobs and self-esteem.

Identity threat models (Crocker et al., 1998; Major & O'Brien, 2005; Steele & Aronson, 1995). Possessing a stigmatized identity increases exposure to potentially stressful, identity threatening situations. Collective representations (e.g., beliefs about prejudice), situational cues, and personal characteristics affect appraisals of the significance of those situations for well-being. Responses to identity threat can be involuntary (e.g., emotional) or voluntary (i.e., coping efforts). These responses can affect outcomes such as self-esteem, academic achievement and health.

“Conceptualizing stigma” (Link & Phelan, 2001). Stigma occurs when elements of labeling, stereotyping, cognitive separation into categories of “us” and “them,” status loss, and discrimination co-occur in a power situation that allows these components to unfold.

Evolutionary model (Kurzban & Leary, 2001). “Phenomena... under the rubric of stigma involve a set of distinct psychological systems designed by natural selection to solve specific problems associated with sociality... Human beings possess cognitive adaptations designed to cause them to avoid poor social exchange partners, join cooperative groups (for purposes of between-group competition and exploitation) and avoid contact with those differentially likely to carry communicable pathogens” (p. 187).

“HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action” (Parker & Aggleton, 2003). “Stigma plays a key role in producing and reproducing relations of power and control. It causes some groups to be devalued and others to feel... they are superior. Ultimately... stigma is linked to the workings of social inequality” (p. 16).

Goal-directed, self-regulatory coping (Swim & Thomas, 2006). Discrimination threatens core social goals of self-enhancement, trust, understanding, control and belonging. The weighting of these goals, as well as appraisal of one's ability to engage in responses and the ability of a response to address goals, influence choice of coping responses by targets of discrimination.

Moral experience and stigma (Yang et al., 2007). “Moral experience, or what is most at stake for actors in a local social world” shapes the stigma process for stigmatizers and stigmatized. “Stigma exerts its core effects by threatening the loss of what really matters and what is threatened.” (p. 1524).

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WELCOME

NO ADMITTANCE

PULL

PUSH

EXIT

ENTER

A DOG AND PONY SHOW?

Users in the Harm Reduction Movement

BY PAUL CHERASHORE

At the First National Harm Reduction Conference in 1996, when HRC was looking for someone to speak about “the politics and complexity of being an active user in the harm reduction movement,” the list of potential speakers was quite short. The list for this presentation today, on essentially the same topic, was equally short. Not the kind of short list where you’ve whittled down a longer list of 20-30 or so names to a handful. The kind where you start off with three or four, scratch off a couple and then you have your short list—maybe one or two names.

I was the speaker in 1996, and here I am again.

CONTINUED ON PAGE 4

A DOG AND PONY SHOW?

USERS IN THE HARM REDUCTION MOVEMENT

BY PAUL CHERASHORE

When it comes to the state of harm reduction in 1998, with regards to the personal drug use of our comrades and the (lack of) willingness to come forward and speak openly about it, things aren't much different than they were in 1996. I only hope that people will be banging down HRC's doors to speak on this issue in the year 2000. Not very likely, is it? Well, how about settling for just a real "short list". If we want to face a different picture in the new millennium we will have to work together—on ourselves and on our movement—to create an environment considerably more hospitable to the users in our midst.

Last time around I was vague when speaking about my personal life. I was a newcomer to harm reduction, and I was feeling my way around. Over the last few years, though, I've been gradually opening up about my own use. Not because I want to, but because I've felt compelled to do so, both politically and personally.

I had kept my drug use in the closet for 13 years until it just became unbearable to continue doing so, as it was impacting negatively on my mental health and overall happiness (or lack thereof). Because I had used for much of my adult life, and because I had sold drugs to support my habit, I had a lot to hide. My drug use, though, was an integral part of my life, and concealing it had major negative personal consequences for me. In effect, I was forced to fragment myself into very different private and public personas. We

all do this to a degree, but I had to carry this charade much further. I couldn't talk openly about my life; when the subject did turn to me I found myself constantly on guard, watching my words, often lying, usually through omission, but sometimes blatantly. I wasn't comfortable living this lie, and it wasn't healthy. I wound up withdrawing further into my drug use.

Four years ago I reached a point where I'd finally had enough and could

We are cultivated because as users we lend legitimacy to programs that crave just that. And we bring a point of view that is desperately needed, the "privilege of experience." The downside of such a relationship is that our continued use is often necessary to fulfill our part in the bargain.

no longer keep up my charade. At that time I couldn't conceive of being open about my current drug use. Although I had been exposed to harm reduction, I hadn't been introduced to the concept of user empowerment. (Some users come to that idea naturally, but in the U.S. most

of us are introduced to it.) I saw that if I really wanted to live a whole existence I would have to put my drug use into the past. Only then, after giving in to the system and stopping using, could I talk about my life at twelve step meetings. So, after having used dope for over 12 years without a substantial break, I finally did what I thought I couldn't. I was excited to be drug free and wanted to tell my story. Unfortunately I was still in the middle of a methadone detox, so in the "rooms" I was not considered to be clean, and consequently not permitted to speak to the group. Of course in *my* mind I *was* clean, and couldn't wait to tell the world.

It's interesting how ex-users have these forums for talking about their substance use. It's ok to talk about your past use, especially when you're remorseful. The past is a great psychic divide, especially when it comes to drug use. People will forgive and forget the most horrible things that are over and done with. But the same person talking about those same activities in the present tense will get flayed alive. The active user who is not apologetic for his/her sins will not receive forgiveness or redemption. In our society 12 step rooms are the places ex-users go to tell their stories. When I found myself unable to "confess my sins" in the rooms I made the mistake of going outside of the established boundaries and talking about my drug use at any old time I felt like it. It was just such a liberating feeling to no longer be hiding such a big part of myself. Of course losing the job I happened to hold at the time wasn't so liberating, nor was being rejected by erstwhile friends who pretended that nothing had changed between us. (Nothing had, except for the fact that I was being more honest about my life, and I had made the mistake of assuming that the honesty would prevail over bigotry.)

It was during this period that I began making use of the facilities of the Lower East Side Harm Reduction Center. As I got more immersed in the harm reduction philosophy, I began to see there were alternatives—one could be forthright about one's current drug use. Eventually, for reasons too complicated to delve into here, I decided that altered states were preferable to sober ones, especially if one could be part of a community of

active users, and I resumed using.

As I began to get more involved with the harm reduction movement I felt the need once again to be open about my personal use. The more I spoke with other users, the more I realized how compelling personal disclosure could be. The act of speaking out about something that society would prefer to keep hidden is in itself a powerful statement of rebellion. One of the drug warriors' most successful strategies has been the intimidation that has kept most users silent in the face of incredible oppression; as we remain silent we are isolated and alienated from each other and from ourselves. When we speak up we see that we are not so different: that many others have common experiences and problems and have chosen similar methods of dealing with them, i.e. self medication. By lifting that veil of secrecy we feel better about the decisions we have made, and that in turn gives us additional strength to fight against oppressive drug policies and laws.

Some people come into the harm reduction movement as non-users or recreational users and became more active. Others come in as ex-users. I will speak about the difficulties encountered by those of us who come into the movement as known users, because that's what I know best.

I've always believed that expectations shape our lives to a much greater degree than we would like to acknowledge. What we believe to be free choice is often a combination of our opportunities, abilities, and experiences filtered through others' perceptions of those things. It's not that we don't have options. It's just that, for most of us, doors open for many of life's choices at a point where our own expectations intersect with the expectations held by those who happen to have influence and power over our lives. Because the equation is inherently unequal (the individual on one side, society on the other) the danger is that we will find ourselves living out our lives according to how other's perceive us to be, as opposed to who we really are—or what we want.

These expectations apply to people who come into the harm reduction movement as drug users. It will always be easier to remain identified as a user in the movement if you come in with that label,

and in some ways the expectation that you are a user encourages you to continue your drug use. You will have to struggle to step out of that role. I know that when I came into harm reduction there were individuals who believed I could be a user activist, and that was the path that was easiest for me to take. There were cer-

Too often we assume users are content to volunteer, or accept part-time menial positions. We expect them to work for free or a small stipend, and we expect them to be satisfied to be just given an opportunity to participate in the delivery of services to fellow users. We wouldn't ask that of any other disenfranchised group of people-why should we ask that of users?

tain perceptions that others had of me, and whether consciously or unconsciously, I responded to those perceptions. It would have been a hell of a lot harder for me to convince people I could be a grant writer or a treatment referral specialist. Of course, my willingness to be an open user and my particular political vision which saw coming out as a powerful political tool assisted me in going down that road. I am not saying users are victims of the movement's tendency to see us just as users, but that it is easy to fall into that trap -and we must be aware of this if we are to prevent it from happening.

My experience is not so different from those of many of the users who have eventually gotten paid jobs in this movement. We start out putting in our time—usually as volunteers, or on stipends. We are cultivated because as users we lend legitimacy to programs that crave just that.

And we bring a point of view that is desperately needed, the “privilege of experience.” The downside of such a relationship is that our continued use is often necessary to fulfill our part in the bargain. Because many times we lack skills and job experience, it is our drug history that has landed us employment. In fact, I've wondered at times what my value to the organization I work for would be if I were to stop my drug use.

As long as active users are at the margins of the movement situations like this will continue to develop, with dangerous precedents being created where users can feel obligated to meet others' expectations. This may mean using when they really would rather not, or, in a more likely scenario, feeling obligated to disclose their personal drug history when they would be better off not doing so. All harm reductionists need to be cognizant of the potential for such situations arising. Users, when encouraged to speak out about their personal lives for the benefit of the movement, need to stop and ask themselves, before jumping into these situations, “Is the benefit to myself and other users worth the personal risk? Am I doing this for myself and my fellow users, or am I doing this because some agency needs to trot out a pretty face for some dog and pony show?” And each of us, as fellow harm reductionists who may be needing a user for public display, must ask ourselves, “Am I doing the right thing here? Have I really taken into consideration the risks to which this individual may be exposed?”

It can be so easy to rationalize, “This is for the greater good...it can help to keep my program open, my exchange going, and that will save lives.” But what about the life of the person we've asked to speak out in public? We can all get caught up in the excitement of the moment when the opportunity arises for a program participant to speak in public (or to the media) about how needle exchange or harm reduction has saved his or her life. Because users are often so grateful to be treated with dignity and respect -something that everyone deserves but that drug users feel privileged to receive- they will sometimes go out on a limb in order to express their appreciation. Unfortunately we are not practicing



harm reduction when we put users on the spot like this, and we are usurping the very process we have asked them to publicly praise.

Before we ask a user to speak in public we need to make sure that we have outlined all of the potential risks and benefits, listed the alternatives, and set limits with which he or she will feel comfortable. I believe as a movement we need to practice harm reduction on this level if we are to do it on a grander scale. We need to remember that it's not just about the reduction of direct, obvious use-related risk, but also about improving the overall quality of user's lives.

Of course it would be far better if users in the movement were not as marginalized as they often are; users in posi-

tions of authority would be more likely to be sensitive to the issues their comrades face. We as a movement need to think about this; too often we assume users are content to volunteer, or accept part-time menial positions. We expect them to work for free or a small stipend, and we expect them to be satisfied to be just given an opportunity to participate in the delivery of services to fellow users. We wouldn't ask that of any other disenfranchised group of people—why should we ask that of users?

We must consciously make efforts to bring users aboard—especially as paid staff—not because they are users, but because they happen to be individuals with skills and abilities who can make a contribution to our programs—who also hap-

pen to use drugs. Bringing people on as harm reductionists first and users second will help pave the way towards creating programs that are partnerships with users; this will in turn lead to the demise of the barriers and hierarchies that naturally arise when your point of view is either that of a service provider or service recipient. Of course it's not enough to just say we're partners in this, we have to take concrete steps to make this a partnership. And that will only happen when we create an environment where we can go beyond the labels, and where it no longer matters whether you use or not. ■

Paul Cherashore has been involved in user activism since 1995. He currently works at the Harm Reduction Coalition.

The Junkie Bill of Rights

What is "Junkie-Apartheid?" Remember South Africa where the majority of people were segregated and controlled by the minority? That's what's happening to drug users here...We are segregated and persecuted...anybody who uses drugs is scared shitless these days and for good reason...our civil rights have vanished. To that end, I suggest the following dream list to keep in mind...Please feel free to add to this or subtract from it.

1. Decriminalization of All Drug Laws... hands off our bodies...like the abortion struggle, the principal is control over our bodies, not government control.

2. Clean Drugs With No Bullshit: Think about it...what other business is so unresponsive to consumers? Whatever happened to customer satisfaction? Would any other big business last this long while delivering such an inferior product? Demand testing of drugs for purity of content—not drug-testing of consumers!

3. Consumer-Controlled Junkie Services—detoxes where the client determines the method of treatment, rather than the

provider...demand availability of the latest technological advances in detox including electro-stimulation machines and electro-acupuncture to reduce withdrawal symptoms. The people should control their own technology. Harm reduction therapy...drug-management therapy...these services are supposedly for the client, yet they are controlled solely by the system of "Junkie-Apartheid".

4. Consumer-controlled Drug Maintenance: This means methadone clinics where the client determines the dosage and is not penalized for dirty urine, etc...demand the right to be treated with dignity...demand injectable methadone for shooters and heroin maintenance for those who prefer it (probably most of us).

5. Non-discrimination in health services: We all know too well what happens to drug-users in the health-care system...resulting in a well-founded reluctance to seek medical care...To most doctors, we're just drug-seeking scum...demand respect.

6. Housing for Drug-Users: It's nearly impossible to obtain any kind of decent housing for

known drug-users, leaving the only options shelters—which ain't nothin' but de facto prisons—or the alienation of the streets. As citizens of the richest country on the planet, demand respect.

7. Jobs for Junkies: IQ testing of drug-prisoners in San Quentin found their IQs higher than the national average, yet known users are not hired or summarily fired. Demand an end to drug-testing; replace it with competency-testing for the job itself.

We're talking basic civil rights here. We are a disenfranchised minority. Nobody will hand us our civil rights—we will have to fight for them, especially now when the battle lines are obvious. Let's stop bickering and think, dream, and organize for our collective future.

Above Manifesto is dedicated to Rod Sorge, who I pray is watching over us from a better place. Rod, we miss you more than we can say...you gave your life for this cause...I hope we're deserving of your sacrifice.

Vicki Jacobs has been doing needle exchange on the Lower East Side since 1991, and now works at the Lower East Side Harm Reduction Center.



Let's Get Real

Looking at the Lives of Pregnant Drug Users

BY SHEIGLA MURPHY AND PALOMA SALES

At the turn of the 21st century, social and economic arrangements in the United States continue to be predicated on the presumption that women assume primary responsibility for childbearing and rearing without the commitment of social resources. While increased access to social and welfare services, the institution of universal health care and guaranteed income for families with children could go a long way in ameliorating some of the problems women face, structural inequality would remain unchallenged. In order to effectively intervene in pregnant drug users' lives policies that redistribute responsibilities and resources for social reproduction must be a political priority. But until such major social redistribution policies are in place, what can harm reductionists do to help pregnant drug users with the struggles that characterize their daily lives?

Pregnancy, Drug Use and Violence Study

Attempting to answer this question, we interviewed 126 women regarding their experiences with pregnancy, violence and drug use, focusing on their survival strategies. Of the 126 women interviewed 79% qualified for a second qualitative interview because they had one or more incidents of physical (including sexual) or emotional abuse (25% of their pregnant days). All but five of our participants had experienced both types of abuse.¹ Our participants' life stories unfolded during tape-recorded interviews, as they related the violence and humiliation they endured at the hands of drug dealers, pimps, johns, other drug users and—most frequently—their intimate partners. Participants shared common problems with standing on their own two feet in a male-dominated world where women occupied the lowest rungs of the social hierarchy. In both illicit drug-using subcultures and conventional social worlds, our interviewees recounted that being a woman was a strike against them, being a pregnant woman was a second strike and being a drug-using pregnant woman was the third and final blow to their social standing. Nonetheless, interviewees kept going, day after day, beating after beating. Some were able to raise their children, even shelter them from their own drug use and violent experiences. Women's drug use both exposed them to violence and protected or helped them cope with violence. Drug use eased their pain or increased their endurance. The women we interviewed achieved a very human objective: survival.

Given women's primary responsibility for childbearing and rearing, the conflicting social roles of mother and drug user created an atmosphere of continuous tension for

our interviewees. They were under pressure to juggle their time and energy between the requisite responsibilities of motherhood—like making sure the house was clean, the kids were fed—with drug-related tasks, like selling their bodies or drugs, finding dealers and using. In addition to the ongoing juggling act, they had to deal with the risks of encountering violence during their associations with drug dealers, customers, pimps and johns. Worse yet, those who were involved in abusive intimate relationships had the added burden of having to do everything in their power to make their partners happy in the hopes of avoiding the next violent outburst. As mothers or mothers-to-be who used drugs, they lacked the respect of those around them. The violence they experienced was directly associated with the tension generated by their social roles as partners, mothers and drug users; their drug use was directly associated with the violence. The more violence they endured, the more they used drugs; the more drugs they used, the more violence they experienced. Like other investigators, we found our interviewees' violent experiences generally occurred within their drug-using circles of partners, relatives, drug sellers, drug users and other males. (Fagan 1994; Sterk 1999) The types of violence encountered by participants varied and sometimes overlapped. Most (91%) had experienced lifelong abuse beginning in childhood and continuing with their adult partners. The abuse they experienced can be categorized into two types: ambient and partner violence.

Ambient Violence

Theidon (1995) characterized ambient violence as emotional, verbal or physical abuse

resulting from exchanges with people in the streets (e.g., neighbors, drug dealers, johns, pimps). Ambient violence was an integral part of women's everyday lives, especially since a significant part of their lives involved the acquisition of drugs. The urgency and desperation to obtain drugs often cast women along the dangerous paths of dealing drugs or prostituting. Sterk (1999), studying women crack users in Atlanta, notes that “. . . as the women became cut off from mainstream society, their lives increasingly became entangled in the illicit drug-user subculture. They also reported feeling pressured to begin resorting to illegal routines to fund their drug use.” Thirty-eight percent of the interviewees were involved in illegal income-generating activities (e.g., prostitution, drug sales and theft).

In drug-using social worlds, masculine values, as well as differential physical prowess, relegated women to secondary roles, making them more likely to be dependent on dominant males. As both drug users and women, they were vulnerable to physical and emotional abuse. The repeated humiliation, abuse and rape women suffered at the hands of their partners, customers and men on the street were a direct result of women's lower positions of power in society. Twenty-year-old Jada² shared her experiences as a prostitute:

Well, I got raped on the streets about four times. Twice while I was pregnant . . . I didn't know whether I was in the wrong. I blame myself sometimes, how could I be stupid? And you know, I could have done something, but I really couldn't have done anything, 'cause I can't overpower a man. I've been tied up, burnt with cigarettes . . . humiliated, talked about . . . I been through a lot.

Monique is a twenty-four-year-old prostitute who generally works under her husband's watchful eye, though he's not always around to protect her:

. . . a guy in a van pulled out a knife on me and forced me into the van . . . My husband was home waiting on me . . . Three or four hours he had me in the van, . . . raped me in all kinds of ways . . . He was gonna rape me up the butt and I told him that I had to go to the bathroom first. . . and I told him I couldn't go to the bathroom with him looking at me so he turned around and as he turned around I saw the knife. I picked up the knife, stabbed him in the shoulder. And then, he, he grabbed the knife from me and cut my hand. The tendons of my fingers were torn, so I had to go to the hospital and get 'em tied together. And I got out of the van . . . and I was naked and on my way out of the van I grabbed my clothes and I grabbed his underwear and a towel with his semen on it. From that the police caught him. And with a stab wound and stuff he showed up at the hospital later on, so they caught him. And I was in the hospital for about a week, trying to get my fingers moving again.

She encountered another violent "john," even though her husband was supposed to be watching:

. . . I was walking up the street with my husband and he was on the other side a the street. Sometimes we do it like that so he watches me so I'm okay. He sees what kind of car I get into and makes sure he brings me back. I was walking up the street trying to catch a ride. And he force me into the alley and he raped me. My husband, he didn't know where I was at 'cause he didn't see him haul me into the alley. And then I came out and my husband chased him up the street with a knife. But he never caught him . . . I was about four months (pregnant).

Pregnancy often increased drug-using women's risk of violence. The procurement of drugs became more difficult because some dealers would not sell drugs to pregnant women. If the woman traded sex for drugs, her clientele decreased as her pregnancy became more obvious. Sandra, a twenty-year-old African-American, was asked if prostituting became more difficult during her pregnancy:

. . . back in the days, I could go out there and meet a guy, and get a hundred and fifty dollars. But now, these guys out here, they wanna give you thirty dollars. And thirty dollars is not enough to take care of me and two kids. I'm sorry, that's not even a week's worth of food.



MICHAEL WINIKOFF

As a woman's pregnancy became more noticeable her resources diminished, and she was more willing to take greater risks, like performing sexual acts for a lot less money (or drugs) than she normally would. A reduced pool of potential clients meant she could not be selective about whom she serviced, thereby increasing the risk of being picked up by customers she did not know. Whether she knew them or not, they were often angry with her for using and working while pregnant, and felt she deserved to be mistreated.

Women's accounts of the ambient violence they were subjected to were horrifying. Women's guilt and stigmatization were so internalized that they questioned the difference between sexual assault and treatment they deserved. But even more horrifying was that more frequently, the violence participants experienced was at the hands of people who were supposed to love them and protect them—their partners.

Partner Violence

In our sample, of those reporting physical abuse, 80% said it was perpetrated by their partner. Women characterized their abusive relationships as increasing attempts by their partners to expand their control. It was not necessary for the abuser to batter the woman on a regular basis. One severe beating was sufficient to keep the woman in a constant state of fear. The mere threat of another beating kept the woman "in-line." Abusers, as reported by the women in our study, diminished their self-esteem to the point where they believed they deserved the violence. Many remained silent and therefore protected partners from outside domestic violence interventions, especially from the police. Women's failure to report assaults was justified by their low expectations regarding interventions, the fear that others would discover their drug use and the belief that they deserved to be abused. The most frequent reason given for not reporting was fear of the

abuser. Jenny, a 22-year-old Latina, was asked if she ever thought about leaving her abusive partner:

. . . I'm really scared. If you could see this man, you would be scared too. He said, 'If you call, ever call the police on me, I'm gonna kill you.'

Thirty-nine-year-old Tracy suffered both verbal and physical abuse at the hands of her partner and father of her child, but did not report him to the police because he terrified her:

He beat me. Half the time I thought I would die! The way he treated me.

Kicked me, stomped me, threw me! . . . Being stomped in the face with a boot. Hit with bats! He had no mercy. As if I was trying to take something from him, and I was a stranger or something! No mercy. . . He would beat me, then rape me and dare me to get up and use the phone. If I tried to, he would just beat me again. He even kidnapped my son, so I wouldn't call the police on him! . . . When I would leave him he would find me and it was just the same thing. It was just being on a train, going nowhere! Over and over again. . . it went on for a good four years.

Sometimes partners would exercise control by withholding drugs or unilaterally deciding how money was spent. Marie, a white 43-year-old, talks about her struggle with her controlling partner:

. . . he would call me a dumb bitch and things really hurtful like that . . . and telling me I really fucked things up, you know, it's all my fault and, he'd get mad at me. . . he wants me to give him the money I make so that he can manage our money. He says that the only way that we're gonna ever have anything is if he's in control. Well, I have a real hard time with that. But then I would try to like, please him, and I would give it to him. And then he'd get—he'd start drinking and then he'd wanna buy some crack and he'd start smoking it up. I'd get mad, telling him he's spending too much money. . . he'd tell me, 'Fuck you. I'm not giving it to you!' and go out and blow a whole shit-load a money.

Not only did he control her money, but tortured her as well by withholding drugs from her:

. . . he'd buy the crack. And he would control it. He'd sit there and take his couple a hits. And I'd have to patiently wait for mine. And then I'd get mad. I'd say, 'Goddamn it, gimme a hit! Gimme the pipe!' And he'd ignore me. It was like this big control issue. To where he says (emphatic) when and how much and he would break me off a little piece . . . my money paid for it, but he's control-



Being a woman was a strike against them, being a pregnant woman was a second strike and being a drug-using pregnant woman was the third and final blow to their social standing.

ling it. I wanted to leave sometimes he wouldn't let me out a the room. And he would like restrain me on the bed and stuff. I would just freak out and make things worse because of my reaction. If I would have um, been calm and just let him have his little power play . . . everything would be fine.

Do drugs cause these women to remain in violent situations or does violence cause them to use drugs? Some espouse the opinion that these women chose to use drugs, chose to remain with their partners and therefore are responsible for finding themselves in violent situations. But from the participants' perspectives, they remained in dangerous situations precisely because they did not have choices.

Drug Use As a Survival Strategy

The women in our study used drugs as a resource to endure the myriad of problems they faced as women, drug users and victims of abuse. We found, like other investigators who studied abused women, women self-medicated with alcohol, illicit drugs and tobacco to cope with the abuse. (Campbell, et al., 1993; Lempert, 1997; McFarlane et al., 1996; Paltrow, 1998) Drug use made life more manageable by alleviating physical pain, while acting as an emotional analgesic as well. Drugs were also a source of recreation, a chance to have some "time out" or to party. Women provided drugs for their partners to keep them happy, hoping to ward off or postpone violent episodes. Drug use also gave them a sense of control, if only over their own consciousness, in circumstances where they had very little.

Drugs as Pain Relievers

Carla, a 26 year-old-crack and marijuana smoker, also used drugs to endure the pain from pregnancy and violence.

One 'a the reasons why I would use drugs is just not to feel the hardships. It's like, well medicate myself so I wouldn't have to go through all the problems that I was going through.

Drug intoxications temporarily masked the emotional and physical pain of abuse, diminishing daily hardships and suffering. Drug use produced euphoric feelings and

promoted a sense of well-being. Tracy, a 39-year-old crack user, found that her violent experiences intensified her insecurities. Getting high helped her feel better about herself and was a source of comfort.

It (abuse) brought my self esteem down, very low . . . He told me I was ugly and I was nothing, don't nobody want me. . . And I believed him because my mother wasn't there. . . what else was I to believe? And I just stayed in my own little world, and I guess that's when crack comforted me the most.

Violet, a 23 year-old-crack user, eased her pain from years of violence with years of drug use. When she was 14, her mother hit her in the back with a hammer; she suffered from back pain that continued through her twenties. Chronic pain, combined with the acute pain inflicted by her severely abusive partner, compelled her to seek the analgesic properties of street drugs.

Using Drugs to Create a Sense of Control

Using drugs gave women some agency over their own sense of happiness. Their living situations were characterized by meager finances, lack of suitable housing, food and care for children, social isolation and ambient/partner violence. With not much else to count on, drugs became a primary support system that they could manage. Drug use became the one thing they could depend on for fun or to make them feel good. Most aspects of their lives, such as poverty and violence, felt insurmountable and beyond their scope of control, but they could manipulate their intoxications. Thirty-year-old Denise used crack to take the place of her man, introducing some personal agency into her life. "The drugs is my man. My man can't beat me up! Ha. He can't do this, that and the other to me!" Drug use was a simple and immediate way to cope with daily hardships of poverty, abuse and poor health. For the 61 percent who were in abusive relationships at time of interview, their partners had chipped away at their personal autonomy. The ability to alter their own consciousness gave them a sense of mastery over at least one aspect of their lives.

Summary

Pregnant drug users suffer severe stigmatiza-

tion and degradation in a policy context that holds them solely responsible for the "bad product" of a drug-involved pregnancy. Clearly, study participants' needs were not being met by existing services. A third of the interviewees named police services, emergency rooms and doctors (respectively) as most helpful to them; however, it must be noted that these services are designed to provide temporary help. Model therapeutic communities, such as Amity's Center for Women and Children, in Tucson, Arizona, address the specific needs of drug-using pregnant women. (Stevens and Arbiter 1995) They have taken a holistic approach in helping women with child care, education, housing, prenatal care, drug treatment and domestic violence intervention. They have been funded by federal agencies, like National Institute on Drug Abuse and the Center for Substance Abuse Treatment, but more resources from state and local levels must be allocated to make these kinds of programs more widely available. But pregnant women cannot and should not have to wait for the requisite brick and mortar funding, particularly during an era characterized by workfare. Besides, therapeutic communities do not meet the needs of all women.

The needs of the women we interviewed were multilayered as well as overlapping, making available help inaccessible and insufficient. Their problems were treated individually, rather than holistically. Each service area focused on either women's drug use, pregnancy or violence, addressing only one problem at a time. Our participants were not only drug users. They were mothers, daughters, victims, poor, homeless, malnourished and stigmatized in conventional and illicit drug-using worlds. Drug use helped them to cope and to survive. It also caused them serious problems. They were demonized for their means of survival, but not given feasible or reasonable alternatives.

It is time to get real. To offer real harm reduction services to our most stigmatized drug-using population—pregnant women. Incremental changes must be rewarded and drug substitution and supplementation must be explored. Not just methadone instead of heroin, but, for example, medical marijuana to help a woman decrease or abstain from alcohol use. As harm reductionists we must offer alternatives to interventions that require a woman's immediate abstinence from all drug use. Help that is predicated on the immediate discontinuance of all drug use is not only cruel, it is unrealistic and inhumane. ■

Shegla Murphy and Paloma Sales are researchers for Community Health Works / Institute for Scientific Analysis, San Francisco, CA.



1 In this article we report selected findings from a National Institute on Drug Abuse (NIDA) funded study entitled, "An Ethnographic Study of Victimization, Pregnancy and Drug Use" (RO1 DA0982). The mean age for the entire sample was 29 with a range of 18 to 50 years of age. Only 35 (28%) had graduated from high school and 29 (23%) had some college. Ninety-two (73%) were married or in a relationship. Seventy-one (56%) were African-American, 32 (25%) were white, 16 (13%) Latina, 4 (3%) Native Americans, 1 (1%) Pacific Islander and 2 (2%) of mixed ethnicity. Twenty-four (19%) were self-reported primary heroin users, 36 (29%) were marijuana users, 51 (40%) were crack cocaine users, 9 (7%) were powder cocaine users and 6 (5%) were methamphetamine users. Over two-fifths of the sample (43%) reported that they had been homeless for three or more days in the six months prior to interview. Seventy-five percent of the women who had altercations with their partners reportedly experienced physical violence. Twenty-five (36%) were forcibly raped, 15 (21%) were kicked, 14 (20%) were threatened with a knife or gun, 11 (16%) were beaten with an object and 5 (7%) were injured by a knife or gun. For many of the women, these acts were repeated many times throughout their pregnancies. We must end the description of the sample with a very important caveat. We extended the data collection period by nine months in order to intensify our efforts to diversify the sample. We were not successful. We can only speculate that the honorarium we offered potential participants was not enough of an incentive for more pregnant drug users from other ethnic groups and social classes to come forward and share their painful violence experiences as victims. Thus, this distribution is not in any way meant to accurately depict the demographics of pregnant drug users; it may well be the result of the stigmatization of pregnant drug users as well as our recruiting strategies.

2 All the names used in this article are pseudonyms.

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Icon/I have a Dream BY AYA DELEON

Martin Luther King fought for justice, not just integration. Don't confuse the method of transportation with the destination. But corporations remember our heroes distortedly like black & white kids holding hands is all he ever stood for & completely forgets his opposition to the Viet Nam war & what's more

his ideas are intellectual property & if Gandhi can be an icon for apple computers, then everything in this nation is for sale. I can just imagine what advertisers would do with King's Letter from the Birmingham Jail.

Picture this: it gets bought by corporations in the prison industrial complex & they take it all out of context putting up billboards in the hood that say: "Hey young black men, MLK went to jail; if you're lucky, you can be next!"



Or imagine this one:

let's say the NBA buys his speech at the March on Washington talking about "I have a team...."

"I have a team so the sons of former slaves can sweat and toil up and down basketball courts like modern day cotton fields for the profit & amusement of the sons of former slave owners; it is deeply rooted in the american dream; I have a team."

Or perhaps it would be bought by developers talking about "I have a scheme.

I have a scheme that little white yuppies can live next to little black and brown boys and girls digging the convenience & flavor of their hood. & when the black & brown folks get moved out white yuppies will say in their newly acquired hipster slang Don't trip peeps, it's all to the good.

Yes, I have a scheme still deeply rooted in the american dream feeling like a déjà vu, except without the smallpox blankets & then developers can go to black church testimony meetings talking about I'm not here to testify I'm here to gentrify! Can I get a witness?"



Or maybe it would be bought by a multinational pharmaceutical conglomerate talking about "I have a cream..."

"I have a cream & even if the red hills of Georgia are nothing compared to the acne on your face, I have a cream.

A cream that guarantees that every pockmark will be exalted and every pimple made low, I have a cream.

I have a cream that fights against itching, anti-government bitching and encourages snitching.

I have a cream that is spermicidal, herbicidal, pesticidal, homicidal & genocidal, I have a cream today!

I have a cream that will turn little black boys into little white girls

& we sold some to michael jackson & he said White at last! White at last!

Thank God almighty, I'm white at last!"

Yes, people,

we must be very careful who we let control our past.



Aya deLeon is a trainer with the Harm Reduction Training Institute in Oakland, and a member of the San Francisco poetry slam team to the National Poetry Slam. For info on her poetry: micdmicd@yahoo.com.



Commentary

Strengthening drug policy and practice through ethics engagement: An old challenge for a new harm reduction

Kevin S. Irwin^{a,*}, Craig L. Fry^b

^a *Yale School of Public Health, Center for Interdisciplinary Research on AIDS, Suite 1B, Room 111, 40 Temple St.,
New Haven, CT 06510, United States*

^b *Turning Point Alcohol and Drug Centre Inc., and Department of Public Health, University of Melbourne, Australia*

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Abstract

Harm reduction proponents aim to identify and support policies and programmes that moderate or decrease the deleterious consequences of illicit drug use. While harm reduction is clearly a value-based response to drugs, for many, ‘ethics’ merely represent institutional research and professional practice regulations to be satisfied, subjective moral claims, or philosophy that is too abstract to offer tangible benefits in keeping with the pragmatism of harm reduction. In this paper we revisit the relationship between harm reduction and ethics, reframe ethics as a pragmatic concern for all of harm reduction, and argue that greater attention to the actual values and beliefs underpinning harm reduction can help to enhance policy, practice and research outcomes. Examples are given of early progress in this area to illustrate possible features of ethics engagement in harm reduction, and existing ethics materials are highlighted as suitable supporting resources for applied ethical decision-making in this field.

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Introduction

“Harm reduction... emphasises tolerance, respect for the personal choices of others and respect for human rights. It favours evidence over anecdote, courage over cowardice and doing what is right even if it seems to send out the “wrong message.” It means doing what has to be done to protect the public health in the face of opposition from all quarters because it is the right thing to do” [our emphasis] (O’Hare, 2006).

A working group was convened under the auspices of the International Harm Reduction Association (IHRA), to explore the place of ethics in the harm reduction field, first gathering at the annual meeting in Belfast in 2005, and again in Vancouver in 2006. A consensus was reached that the group should be guided by the strategy of engaging in the

applied ethical dimensions of harm reduction in relation to drug policies and practices (not just research), and strive to remain practical and accessible to the widest possible audience. Following the 2006 meeting, the newly established ‘Harm Reduction Ethics Committee’ (HR-EC) – now a special IHRA sub-committee – announced its mission of raising the profile of ethical issues in all areas of harm reduction including policy, service delivery, research and advocacy (IHRA, 2006).

The current “Coming of Age” special issue of IJDP provides a timely and important opportunity to reflect upon and imagine how a focus on ethics can contribute to harm reduction into the future. The aim of this paper is to consider how ethics engagement can help to strengthen harm reduction policy and practice. We outline in simple terms a general definition of ethics, suggest why we should consider ethics in harm reduction, and discuss where ethics sits and how it can serve harm reduction conceptually and practically, and the resources needed to achieve this. Our intended audience for this paper is programme managers, outreach workers,

* Corresponding author. Tel.: +1 203 764 4338; fax: +1 203 764 4353.
E-mail address: kevin.irwin@yale.edu (K.S. Irwin).

nurses, members of law enforcement, clinicians, academics, policy makers and all drug users (licit and illicit) who consider themselves “harm reductionists,” as well as those who remain skeptical. We aim to outline an ethics engagement approach that can be debated, further developed and where suitable, applied in a range of harm reduction settings.

Why should we talk about harm reduction ethics?

‘Ethics’ is widely accepted as “the set of rules, principles, values and ideals of a particular group of people” (Beauchamp & Steinbock, 1999: p. 4). However, while the ultimate object of ethics may concern standards of conduct for persons or groups, the content of these standards is fundamentally shaped by our interactions. Morality is inescapably a product of the way we think about our contact and associations with other persons and groups and (hopefully) the consideration of their viewpoints. Some moral relationships are immediately interpersonal (e.g. within families or friendships), and some exist through more distant connections (e.g. within professions, religion, cultural/national identity, environment). Ethics may be thought of as the values and beliefs we develop, define and clarify within the context of these relationships, our expectations and acknowledged responsibilities in these, and our understanding of the consequences of particular courses of action. Implicit in this definition of ethics is the important place of discussion about values and beliefs, without which ethical or moral positions could not be legitimately evaluated and revised.

Isn't harm reduction already ethical?

Drug policies and associated practices are courses of action that shape the social, economic and health consequences of mood altering substance use for individual drug users, their families and their communities. Proponents of harm reduction identify and support policies and programmes that attempt to moderate or decrease the deleterious consequences of drugs and drug use. Pat O’Hare’s recent definition of harm reduction cited above (O’Hare, 2006), affirms the intuition that most people who consider themselves ‘harm reductionists’ might already be convinced that their work is ethical, or at least the ‘right thing to do’. So why do we need to discuss ethics any further?

It has been suggested that harm reduction has come to emphasise technical skills, evidence and methods innovation in order to bypass, or ‘make no assumptions about’ (Erickson, Riley, Cheung, & O’Hare, 1997), the moral status of drug use, users and the state response (Fry, Treloar, & Maher, 2005; Hathaway, 2002). Some argue that this rhetorical ‘value neutrality’ is a strategically necessary stance for harm reduction that permits it to achieve its objectives in prohibitionist policy environments (Keane, 2003). In contrast, others claim “playing down values has hampered the movement. . . as reflected by the dissension over harm reduction policy in practice

and more general state of confusion as to harm reduction’s guiding principles” (Hathaway, 2002), and that a “morally detached” approach to harm reduction misses opportunities for ethical engagement as a tool for “improving new research, treatment, and policy” (Fry et al., 2005).

At first glance, taking the time to define and discuss the ethical bases of drug policy and practice may seem incompatible with the pragmatic aims of harm reduction in some settings. It is, admittedly, difficult to imagine what ethics dialogue achieves in an environment where the humane treatment of drug users in many regions is not a state priority. Indeed, protecting human rights is included in the mission of IHRA, yet pausing to reflect upon and describe the ethical underpinnings of our responses to the human rights abuses visited on drug users in some countries may seem a distraction and a luxury. At the harm reduction ‘coalface’ there appear to be more immediate and practical concerns tied up in the goal of working to prevent or ameliorate such abuses.

The language of ethics also probably generates uncertainty about its applied relevance to fields like harm reduction, particularly where it creates exclusive “discourse communities” (Porter, 1992) among philosophers and academics. The content of ethics may either be perceived as too obscure and difficult to penetrate, subjective and without foundation (or evidence), or simply not practical or functional enough for the variety of harm reduction settings occupied by people in immediate need.

Since its foundations in grassroots advocacy (Marlatt, 1996), harm reduction has become increasingly institutionalized (e.g. in drug policy in many countries, through numerous harm reduction organisations and research centres, and as evidenced in several articles in this Special Issue of IJDP) and professionalized (e.g. the establishment of IHRA, emergence of dedicated journals, and the development of certified training curricula). Harm reduction is exemplary of numerous elements of good public health practice (Stimson, 1998). Similar to public health, harm reduction is comprised of diverse professional and para-professional groups, each bringing their own distinct theories, methods and other traditions which influence approaches to policymaking, service delivery and clinical practices, programme development and evaluation, and the conduct of research generally.

While this diversity may be regarded as a strength of harm reduction, in no small part these factors have also made it difficult to conceptualise core harm reduction values and beliefs around which even a basic level of debate and dialogue can be achieved, much less an emerging consensus. This has left the relationship between harm reduction and ethics as mostly implied and taken for granted, perhaps creating an impression of widespread agreement about guiding principles and core values, or that empirical, clinical and political considerations are more pressing.

In spite of these reservations however, it is still possible to say that the overarching aim of harm reduction to situate drug use as a public health, rather than criminal issue, renders it a project with fundamentally ethical or value-laden ambitions.

In as much as health and disease are both value-based concepts (Fulford, 1989; Nordenfelt, 1987; Seedhouse, 1986), so too is harm reduction. In harm reduction, there simply *are* moral and ethical questions, and even those at the coalface are exposed to these (Solai, Dubois-Arber, Benninghoff, & Benaroyo, 2006).

However, these considerations have largely been ignored in mainstream harm reduction, certainly because of the uncertainties about the utility of ethics highlighted above, but also due to the implicit separation or dichotomy between ‘drug ethics’ and ‘drug politics’ (or policy) that has accompanied harm reductions growing institutionalization and claims to technical expertise. In essence, harm reduction has chosen to see the solution to drug law reform as coming from rational ‘objective’ science (evidence-based policy and practice), not moral claims which many in harm reduction see as abstract, foundationless, and responsible for the punitive judgments and responses to drug use in the first place. One consequence is that this has unnecessarily restricted the field to a similarly narrow and technical form of ethics (i.e. as an institutionalized regulatory device), and reinforced the view that ethics is an abstract art which has no place in an ‘evidence-based’ domain. Another (related) consequence has been the historical lack of applied resources available to harm reduction practitioners to help frame and respond to the ethical dilemmas they inevitably encounter.

To adjust this imbalance in harm reduction will require a reorientation to ethics, to define it as not just a normative regulatory mechanism (most familiar in the form of research ethics guidelines, institutional ethics committees, and professional codes), but also as a formative, practice-based resource that can have an applied utility for harm reduction policy and practice. To see this latter possibility more clearly, we must pay greater attention to identifying and discussing ethical challenges in harm reduction.

Significant ethical challenges

There is little doubt that the context, nature and focus of harm reduction work provides fertile conditions for the emergence of ethical dilemmas. Acknowledging that in many countries illicit drug use and dependence are highly stigmatized, often occurring in a politico-legal environment that creates tension between criminal justice and public health responses, Fry and colleagues have noted that “harm reduction professionals often engage with marginalized population groups where issues of poverty, unemployment, illness, mental health, disability and basic rights are core concerns.” Furthermore, they point out that significant ethical challenges also exist in relation to legislative and policy change (e.g. decisions affecting resource allocation) and recent innovations in research and service delivery in the field (e.g. visual ethnography, www-based surveys and counselling, heroin and injecting room trials) (Fry et al., 2005).

Indeed the research and evaluation effort that has helped to build harm reduction’s evidence base has always been

accomplished in this challenging political context. The criminalized status of drug users and their activities exacerbate the potential harm from legal and social risks of confidentiality breaches, as well as unpredictable ethical dilemmas that emerge during the process of conducting research (Buchanan et al., 2002). Despite multiple vulnerabilities, drug users are seldom afforded the special protections conferred upon other vulnerable populations (Fisher, 2004). Given the current view of and approach to ethics apparent in harm reduction it seems there will be cause for growing concern as research and evaluation efforts continue to discover new groups, utilize innovative methods, and develop novel health interventions.

Fry and colleagues have argued that the general lack of orientation towards ethics in harm reduction, and the specific inattention to these types of ethical challenges represents an area of susceptibility, heightening the potential for preventable ethical breaches, undermining the quality of innovative research and practice, and threatening consumer and public acceptance and funding (Fry, Madden, Brogan, & Loff, 2006).

Evidence and ethics

Despite these continuing ethical challenges, evidence of the benefits of the harm reduction approach in reducing drug-related morbidity and mortality in a multitude of settings has grown steadily over the last 20 years (Hunt, 2003; Van Den Brink & Haasen, 2006; Wodak & Cooney, 2006). And yet, in some of the jurisdictions that could most benefit, we see a continued reluctance to adopt ‘proven’ evidence-based harm reduction strategies that appears to be driven by a different, and explicit, moral view on the status of drug use, drug users, and the appropriate state response.

Evidence will always be contested in areas of controversial social policy, and this is likely to continue in harm reduction for the foreseeable future. One cannot evaluate harm reduction without evidence, yet equally one cannot produce evidence without making value-laden decisions about what to research and the methods to employ, which intervention or service to deliver, and how to interpret and report the information collected about these practices. The moral and empirical are intertwined, as the collection, delivery, and interpretation of evidence is also an ideologically driven and not entirely neutral endeavour (Bourdieu, 1991). Further, just as the concept of risk is ideologically loaded serving political and moral functions (Lupton, 1993), so too is the term harm.

In drug policy debates, harm reduction data competes with other forms of ‘evidence’ such as public opinion, lobby group interests, economic factors and partisan political standpoints. So too, different types and ‘standards’ of harm reduction evidence (i.e. ‘gold standard’, qualitative, quantitative, etc) compete for space not only in drug policy domains, but also in the areas of research funding and regulation and service delivery/practice. Evidence is necessary but not always sufficient for harm reduction to achieve its drug policy goals (Fry, Cvetkovski, & Cameron, 2006). There would be few who dis-

agree that contemporary harm reduction is an evidence-based public health response to drug use and its consequences, and that this should remain so. However, if harm reduction is also a humanitarian approach, with the familiar characteristics O'Hare proposes (O'Hare, 2006), then it should equally be able to articulate and debate the moral and ethical basis of harm reduction policy, research and practice (Fry et al., 2006a), and be actively committed to doing so. Ethical engagement is crucial to moving harm reduction forward. The goal is to make an already successful harm reduction even better. The question is, how are we to achieve this?

How can ethics serve harm reduction?

The ideologies that create and drive our harm reduction systems, policies and practices – even those that claim to be objective and evidence based – are fundamentally rooted in moral grounds. Disregard of this fact seems antithetical to a harm reduction committed to tolerance, respect for choice and rights, and doing what is right (O'Hare, 2006). Refusal to engage on ethical terms is limiting. As Fry and others have stated, “rather than evoking moralistic responses to drug use and drug users, engaging with harm reduction ethics can help to directly confront these. . . [and by making]. . . harm reduction values and ethics explicit. . . it can be a potent tool to make harm reduction better” (Fry et al., 2005: pp. 457–458). The relationship between harm reduction practice and ethics not only falls squarely within, but is also the precise location to address a number of the recurring tensions regarding the scope, aims and practice of harm reduction itself. Indeed, for many applied ethicists, the consideration of practice itself is what informs and imparts value to moral philosophy.

By failing to name and debate the values and beliefs underpinning harm reduction practice, or by taking agreement on these for granted, in the inevitable event of disputes over the scope, direction, focus, means and ends of harm reduction, we are left on uncertain ground. As we have noted earlier, disagreements about what harm reduction is, or should be, will not be resolved by reference to evidence alone, as differing drug policy outcomes within and between countries clearly demonstrates.

Approaches to ethical decision-making

There are a variety of approaches to ethical analysis from which we can draw the possible content of ‘ethics engagement’ (for an accessible overview see Carter, 2002). We briefly review some common frameworks for ethical decision-making and consider their application to harm reduction. These approaches can be defined according to whether they focus on actions (i.e. what we do, what we should do, and the consequences), those who perform the actions and what we might expect from them, or the situation in which actual or proposed actions occur (i.e. contextual, community or cultural issues).

Action-based approaches to ethics: Amongst the action-based approaches are examples that focus on universal principles, consequences and duties and rights. Biomedical principlism emerged from the post-WWII Anglo-American approach to ethics in response to human rights and medical research abuses, and developments in biotechnology and patient rights (Callahan & Jennings, 2002; Siggins, 2002). It has delivered a highly influential set of principles which define the boundaries of ethical practice with reference to: *autonomy* (the obligation to respect the actions of persons and valuing informed voluntary consent, confidentiality and privacy); *non-maleficence* (the obligation to minimise risks and harms); *beneficence* (obligations to ensure benefits outweigh risks); and *distributive justice* (obligations of fairness in the distribution of risks and benefits).

These principles have been influential in defining professional codes of ethics, and widely used as a starting point for ethical decision-making in clinical, public health and biomedical settings (Carter, 2002). Principlism has become a common international language of ethics (for better or worse) and an operational reality for many practitioners, evaluators and researchers, and currently underpins most international guidelines for human research (Beauchamp & Childress, 1994). Principlism is not without its critics, who caution that it tends to neglect emotional and personal factors, decontextualizes ethical issues or makes excessive universal claims (Campbell, 2003), and is neither the start nor the end of the process of ethical reflection (Harris, 2003).

Perhaps the most recognisable consequentialist approach to ethics is utilitarianism, in which actions are justified through outcomes, or consequences that produce the greatest good (Singer, 1979). To revisit the implied meaning of the term ‘harm reduction’, the focus on harms as an outcome suggests an essentially consequentialist viewpoint. However, part of the challenge with consequentialist approaches is that although one can operationalize “harms” (though these are still quite debatable), it has for a variety of reasons been more difficult to do the same with the “benefits” of non-medical and/or recreational drug consumption.

Duty or rights-based approaches, or deontological ethics, maintain that decisions should be made either exclusively or primarily in consideration of one’s duties and the rights of others. Deontology suggests that we should not attempt to predict consequences but rather adhere to a set of pre-defined universal principles of ethical practice that do not change merely as a result of shifting circumstances or political borders. While we may posit harm reduction principles as worthy of guiding means (i.e. the tools we use to effect change), harm reduction is also explicitly concerned with ends (i.e. the consequences of actions) (see Hunt and others recent discussion of ‘weak’ and ‘strong’ rights versions of harm reduction – Hunt, 2004; Hunt, 2005; Reinerman, 2004).

Agent-based approaches to ethics: These approaches are concerned with the character of the person performing or proposing the action, and what we might expect

from them, rather than on the action itself. For example, virtue ethics is another means-centered approach that emphasizes the processes of practical reasoning through experience and reflection rather than application of rules (Foot, 1978; MacIntyre, 1981). While it acknowledges that entirely reasonable people may come to rather different ethical conclusions about the same issue, it focuses less on duties and actions, and more on the development of individual character. It offers no viable strategy for reconciling or accommodating differences among members, groups, or institutions, which is essential to harm reduction.

Situation-based approaches to ethics: Along with the acknowledgment of multiple cultural, religious and philosophical traditions of moral inquiry (Turner, 2004), there have been increasing claims for an eclectic approach to responding to ethical questions which can potentially draw from a range of ethical theories or frameworks. However, in an increasingly globalised world where markets, ideas, knowledge and technologies are continually integrating and evolving (Scholte, 2000), it is likely that there will be nothing inevitable, consistent or permanent about the ethical judgements we make about actual practices even if we do agree at the level of principles.

Roberts and Reich (2002) suggest the reality of ethical pluralism “returns us to public discussion...as a critical process...[and that]...the task is to create a shared vocabulary that facilitates a serious exchange about the needs, perspectives, and goals of each participant...[where]...developing a capacity to participate in these exchanges, for public health professionals, can foster both the explicitness and transparency of public discourse” (p. 1058). However, in settings such as harm reduction where there is a lack of ethics dialogue, and uncertainty about the contribution that ethics might make, how do we build a ‘shared vocabulary’? All dialogue requires a starting point and a subject, but where and what is this in the harm reduction field where divergent values and beliefs have not been made explicit?

There are a number of accounts of how this ethics dialogue may occur, including ‘deductive’ approaches which start from general principles to derive the particular (e.g. principlism, utilitarianism, deontology as highlighted already), and ‘inductive’ approaches which start from particular cases or social practices. Within the inductive approaches runs a consistent theme of valuing discussion around potential ethical practices rather than the prescription of universal normative rules (MacIntyre, 1981).

One example of the inductive ‘situation-based’ approach to ethics has been called pluralistic casuistry (Brody, 1998). Brody argues that, in contrast to ethical theories that attempt to reduce morality to sets of values or principles, pluralistic casuistry reflects the reality of how we engage in moral reasoning, whereby multiple moral values may co-exist and may be modified through reflection and discussion. Casuistry or case-based ethics is a method of practical ethical reasoning emphasising the value of our moral intuitions about

actual practice rather than normative theories or principles (McKeown & Weed, 2002).

Another situation or ‘context aware’ approach to ethics in which diverse perspectives and dialogue is featured is communitarian ethics which focuses on the common good and public interests, “emphasizes social connectedness, and sees individuals as members of a community embedded in the community norms and history, and not as the atomised individuals of classical liberalism” (Sindall, 2002). In communitarian ethics, morality is seen as contextual and divergent ethical values of different communities are respected (Bell, 2001; Callahan, 2003).

Again, amongst the many different interests and communities in harm reduction, there may be reason to doubt the extent to which communitarian ethics can reconcile these equitably (Loff, 2006). Indeed, these are important questions to be addressed in any pluralistic approach to ethical analysis. Prior to this, however, there must be a commitment to articulating and responding to the ethical challenges that arise in the first place.

A pragmatic way forward

Guillemin and Gillam have recently observed that “Normative ethical theories and the principles derived from them offer a language and a set of conceptual tools that are useful in identifying what makes something an ethical matter, as well as a means by which we can talk about key ethical elements” (Guillemin & Gillam, 2006: pp. 5–6). Each of the approaches we have overviewed partially capture some aspects of ethical reasoning, however no single framework commands universal agreement (Kuhse & Singer, 1999; Somerville, 2000).

The uncertainty inherent in making ethical decisions does not excuse us from this important task. We have outlined the ways in which harm reduction is morally detached at the level of ideology, and we hope to have made clearer some of the consequences of this. In the end however, the applied everyday reality of ethical dilemmas in harm reduction necessitates some reaction. Indeed, even the “postmodern public health practitioner must still grapple with the problems of making moral decisions” (Roberts & Reich, 2002: p. 1058). This requires a pragmatic response (Rorty, 1989).

There are three significant barriers at present to achieving ‘ethics engagement’ in the harm reduction field: (1) uncertainty about the utility of ‘ethics’ as a *formative tool* for research, practice and policy; (2) the lack of *applied* ethics resources to help frame and guide ethical decision-making; and (3) the absence of institutional structures committed to promoting and developing ethics as a complementary resource for harm reduction research, practice and policy.

In our view, the initial task of promoting greater ethical engagement in harm reduction is about ‘building ethics in’ to the field by first creating a platform of structures, basic resources, agenda making and debate upon which ethics focused research and development may occur. In this sense,

the promotion of ethics engagement in harm reduction is both a challenge in advocacy (i.e. political) and workforce development (education).

Applied ethics resources

In the wider sphere of public health a similar lack of ethics engagement has been identified, and attributed to poor ethics literacy amongst public health professionals, and the lack of an agreed framework for analysing ethical dilemmas in public health (Callahan & Jennings, 2002; Roberts & Reich, 2002). In response to these concerns, debate and scholarship in public health ethics has for some time now examined important topics such as: conceptual models for public health ethics; multi-disciplinary codes of ethics; the individual rights and public health nexus; and globalisation and public health ethics (Beauchamp & Steinbock, 1999; Callahan & Jennings, 2002; Levin & Fleischman, 2002; Thomas, Sage, Dillenberg, & Guillory, 2002).

Empirical studies on ethical challenges and responses have been urged by public health experts to inform capacity building in ethics curriculum development (Thompson, Robertson, & Upshur, 2003). The creation of new public health codes of ethics in some countries (e.g. United States, see Thomas et al., 2002) has also played a role in facilitating public health ethics curriculum development. This has occurred through the articulation of core public health values as a basis for dialogue and debate, and to inform research, policy and practice (Jennings, Kahn, Mastroianni, & Parker, 2003). Dialogue on the core values of public health has been an important step towards the development of a suitable framework for ethical decision-making in public health.

Recommendations have been previously made for the development of a range of ethics resources at both the macro level (e.g. systems, policy, structures) and micro level (e.g. education and training, professional development and other resources) to facilitate ethics engagement in public health (Callahan & Jennings, 2002; Fry, Pearson, & Scully, 2004). Some of these may be adapted as also relevant for promoting ethics engagement in harm reduction, for example: (1) the development of special conferences and symposia on the theme of harm reduction ethics; (2) the editors of leading harm reduction journals should give high priority to accepting and soliciting in harm reduction ethics pieces for publication and debate; (3) case study materials should be developed around key harm reduction ethics dilemmas and appropriate responses; (4) organisations that support work in the areas of harm reduction policy, practice and research should be encouraged to provide time and resources necessary for periodic in-service ethics sessions; (5) harm reduction leaders should actively support and lobby for resources to facilitate research and development in the area of harm reduction ethics; and (6) harm reduction representative bodies should move to developing a code of ethics to signal a commitment to harm reduction ethics, and move towards making core values explicit.

Early progress and existing resources in harm reduction

Encouragingly, some of the above-suggested areas of development are already starting to occur in harm reduction. To this end, the initial task of the new IHRA sub-committee on harm reduction ethics (*Harm Reduction Ethics Committee*) is to raise the profile of ethics in all facets of harm reduction. The activities we have planned (e.g. IHRA member ethics needs assessment on harm reduction ethics issues; activities at the IHRA conference in Warsaw and beyond; and the forthcoming special harm reduction ethics issue of the *International Journal of Drug Policy*) will require attention, support and participation from all sectors of the harm reduction field.

This work can hopefully build upon the progress occurring in public health generally, where there has been a growing realisation that ethical considerations have a positive role to play. For example, Dorfman, Wallack, and Woodruff (2005) have argued that in framing public health issues in controversial policy contexts, we must understand the values and beliefs underpinning the public health changes we seek, and the potential benefits of articulating shared values. Roberts and Reich also suggest, “health professionals need enhanced skills in applied philosophy to improve the coherence, transparency, and quality of public deliberations over ethical issues inherent in health policy” (Roberts & Reich, 2002: p. 1055).

Some of the tangible benefits that can accrue from this ‘ethics engagement’ have been illustrated recently in the harm reduction arena. For example, Solai and co-workers (Solai et al., 2006) recently reported on an evaluation of how ethics dialogue and decision-making in their Geneva drug consumption room helped staff to better respond to a range of ethical challenges (e.g. intervention with novice injectors, limits of client autonomy and consent, and withholding access to services). Their approach involved structured open discussion via eight inter-related steps including: highlighting the practical ethical problem; identifying the client’s individual context, the duty of care responsibilities of staff, the values staff consider essential to responding to the problem and any conflicting values; identifying alternative solutions to the ethical conflicts identified, choosing the consensus option best suited to the programme objectives, and providing justification for the choice (Solai et al., 2006). They reported that this approach promoted better ethical decision making and practice, greater staff role satisfaction, less stress and staff turnover, greater client contact, improved transparency, and greater political and public support for drug consumption rooms (Solai et al., 2006).

In an accompanying editorial, Fry recommended that this process for promoting reflection and dialogue on applied ethics dilemmas could possibly be employed as a quality assurance and staff development resource in other drug consumption rooms, and other harm reduction settings such as Needle and Syringe Programmes (NSPs), and could also be extended to include client involvement in ethics dialogue and problem solving (Fry, 2006). We await further reports from similar initiatives.

Higgs and co-workers have also recently reported on how their approach to engagement, reciprocity and advocacy, which they align with a communitarian ethics framework, helped them to initiate and maintain relationships with research participants in a neighbourhood-based study of social and molecular epidemiology of the hepatitis C virus (Higgs, Moore, & Aitken, 2006). There is also some interesting work happening in the United Kingdom Drugs and Homeless Initiative, where Phillips, Russell, and Brennan (2006) have been studying the relationship between worker and organisational values and their contributions to client outcomes.

In addition to these encouraging examples, others are listed at the end of this paper as suitable resources for practical application in guiding ethical decision making in a number of harm reduction settings. As valuable as such ethics engagement and reflection may be, more critical yet is the need to disseminate these dialogues to the broadest possible audience.

Applied ethics engagement in harm reduction

The current IJDP issue describes how harm reduction has come of age and identifies a host of challenges that harm reduction must address into the future. Applied ethics engagement, we argue, is first among these important challenges. It is time for harm reduction to notice and make use of applied ethics as a resource to facilitate the evaluation of existing and development of new policy, service delivery, research and advocacy.

Of course, the outcomes we argue for will not happen spontaneously. As noted earlier, the challenge of facilitating ethics engagement in harm reduction will require efforts in both advocacy and workforce development in order to help make harm reduction values and beliefs explicit. We have highlighted a number of examples of the levels at which ethics engagement in harm reduction can occur, and have recommended some of what we consider as the necessary resources for facilitating this.

Crucially, ethics engagement as we have defined it in this paper should be thought of as constitutive of action, not merely regulative or restrictive. It is not intended to generate an authority or a “right answer machine.” The key features of ethics engagement are that it is based in practice, reflection, and demands social interaction and recognition of the realities and concerns of differing community perspectives.

Similar themes have been expressed in Biggs and Blocker’s (1987) original notion of being ‘ethics engaged’, adapted recently by White and Popovits (2001) who define ‘ethical sensitivity’ as:

“... the ability to step outside oneself and perceive the complexities of a situation through the needs and experiences of the client, the agency, allied institutions and the public. It is the ability to project the potential consequences of one’s own action or inaction on these various parties.

It is the ability to recognize when one is in ethical terrain. It is the ability to identify and analyze the precise ethical issues involved in a particular situation and to isolate and articulate conflicting duties. It is the ability to weigh the advantages and disadvantages of various actions and to formulate ethically appropriate resolutions to complex situations” (p. 7).

The tools and locales of harm reduction are changing. The new harm reduction will be increasingly challenged by empiricism (e.g. new evidence and methods to study new groups in different settings), clinical interventions (e.g. new substitution pharmacotherapies, vaccines and behavioural interventions), and legal innovations (e.g. diversion, compulsory treatment, drug testing in schools and workplaces). We can expect that as harm reduction continues to expand into increasingly diverse cultural settings, in concert with these frontiers of innovation, important and often unforeseeable ethical questions will arise that demand an engaged and reflexive response.

Over the last 20 years, despite growing evidence demonstrating the benefits of harm reduction approaches, there is still a reluctance to adopt proven strategies in some of the jurisdictions that need these most. Evidence alone is not enough. The potential role and importance of ethics engagement as a core harm reduction resource to facilitate policy, service delivery, research and advocacy deserves attention.

No ethical theory or framework is able to solve all problems in any given area (Sherwin, 1999), so we should not hold harm reduction ethics to the same unachievable standards. We have suggested that an important first step is to make the diversity of harm reduction values and beliefs explicit through dialogue and debate. This seems an appropriately pragmatic and democratic place to start.

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Appendix A. Recommended applied ethics resources

The following selected resources are accessible and applied in their focus. We recommend these as suitable for guiding practical ethical decision making in harm reduction. While many focus on research, there is enough here

to also be of relevance for policy, service delivery and advocacy.

- Australian Injecting and Illicit Drug Users League (2003). *A national statement on ethical issues for research involving injecting/illicit drug users*. Canberra: AIVL. www.aivl.org.au/files/EthicalIssuesforResearchInvolvingUsers.pdf (Accessed 6 May 2005).
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