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Letter from the Editor

It’s been eight years since our last issue of Harm Reduction Communication was released, and twice that long since the first issue in 1995. Whether or not you’ve read Communication before, I encourage you to check out the archives (issuu.com/harmreduction).

As we re-launch Communication, we’re excited to use this issue as both a celebration of our 2010 National Harm Reduction Conference held in Austin, Texas and as an invitation to join us for the next conference in Portland, Oregon from November 15-18, 2012!

Like Communication, our biannual conference aims to amplify voices that have traditionally been marginalized or left out. The conference is a space for all who care about harm reduction and the impact of drugs and drug use to come together and share their experiences, meet new people, remember those we’ve lost, and build hope for moving forward. It’s also like a homecoming for many folks – a reunion with friends and allies from around the country.

For this issue, we asked a handful of presenters to write about some of the hot topics from Austin, providing a sample of the diverse issues you can expect to see addressed in Portland. Greg Scott’s article on injection hygiene in the real world opens the news-letter with a challenge – how do we provide services, information, and even compassion in a way that acknowledges the actual lives of the people we’re working with? In an article about secondary syringe access, Rachel Anderson provides a gentle critique of the ways in which institutionalization of services threatens to leave big picture goals behind. Isaac Jackson’s prose poem about user organizing is a beautiful portrait of daily life on the front lines, finding hope where we can.

The National Harm Reduction Conference challenges us to be truly honest with ourselves and with each other about the parts of this work that are difficult, rewarding, painful, and inspirational. At the plenary session on stigma in Austin, several drug user activists spoke very candidly about their identities, pointing to elements of their experience from which they draw strength and even pride. These sentiments were met with some resistance — in particular, from two mothers who have watched their own children struggle with drug use. One spoke of a child struggling to survive through a period of chaotic drug use, while another mother shared her pain of losing a child to drug overdose. The session was charged with a lot of the very personal emotions that can come from collective pain, loss, and love. Denise Cullen was one of the mothers who spoke out. In this issue of Communication, she tells her story, and writes about her journey to harm reduction. Louie Jones was one of the activists who spoke on the stigma panel. We share a dialogue Louie had with fellow user organizer Erik Haberlen, exploring the role that internalized stigma plays in shaping identity.

Times are tough everywhere, and only getting tougher. Articles from Rachel McLean and J.D. Rosario offer some guidance in these tricky economic times. Rachel provides a straightforward overview of what health reform means for harm reduction, while J.D. outlines tips for those thinking about using BDSM work as a means of lessening the impact of recession.

We’re also thrilled to have Nabarun Dasgupta sharing practical tips and strategies on prescription drug use, Alice Bell writing about loss and naloxone prescription in Pittsburgh, Michael Everett looking at harm reduction through the lens of oppression, and Kevin Irwin building on ideas from the standing-room-only conference session on recovery.

It is truly an honor to be a part of re-launching Harm Reduction Communication. I’ve always had a special place in my heart for this newsletter, having learned so much from reading it over the years. Sincere thanks to all of the contributors in this issue for your enthusiasm, time and honesty, as well as to everyone who came before – we couldn’t have done it without you.

EMILY WINKLESTEIN, EDITOR
Getting Off Right ... and Left ... and Sideways
Drug Injections in the Real World, the Persistence of Hepatitis C, and the Failure of “Total Hygiene” Interventions
GREG SCOTT

Alex returns to fixing up his shot. He now has the needle stuck in one of his wrist veins. It dangles and lurches side to side as he stands up and walks across the room. Blood streams from the open wound, and with each step he takes the needle sways pendulously. As he reaches his closet I notice that the blood has run all the way up his forearm (his hand is elevated) and is beginning to form a trail on the floor. Once inside the closet, he rummages through a box of injection supplies with his free hand. Antonio stands up and walks over to the closet. As he reaches Alex he mutters, "Let me help you with that," and tries to stabilize the syringe that's been flopping to and fro in Alex's wrist. Alex allows Antonio to hold the syringe steady while he continues looking for something. "Ah, here it is," Alex exclaims, holding up a new cadet blue tourniquet, "one of these ones from the hospital ... they work better for me." Antonio, whose own fingers and hands are now covered in Alex's blood, releases the syringe, and he and Alex both shuffle back to their respective spots on the floor next to me.
Deeply patterned human behavior generally changes in the same manner in which it evolved: incrementally.

no longer) peer outreach educators working for a large, well-established harm reduction program whose outreach services I was funded to evaluate. They were responsible for providing sterile syringe access to injectors "in the field" (i.e., in their own homes and workplaces, as opposed to a stationary program site). Part of their work also involved teaching "safer injection" practices to the program’s clients. For weeks I observed them in action as outreach workers – meeting up with other drug injectors to exchange new and sterile syringes for used ones; handing out cotton filters, cookers, water ampules, cotton strips for absorbing post-injection blood; teaching overdose response techniques; and performing mock injections to demonstrate proper injection technique.

Both Alex and Tony knew the safer injection protocol backwards and forwards, yet their own injections broke almost every rule in the book.

The actuality of drug injection and the gap between knowledge and behavior became the two-sided coin on which I came to focus the subsequent decade’s worth of field research. To date I have collected field data on more than 1,500 heroin, cocaine (crack and powder), opioid pills, and/or methamphetamine injections in situ – in the participants’ natural habitats (living rooms, bedrooms, motel rooms, workplaces, vehicles, etc.) – across the U.S. (the majority in Chicago).

My data consist of 2,000 pages of typed field notes, 500 videorecordings, and nearly 4,000 photographs. I also have collected "self-report" data: persons who inject drugs’ (PWIDs’) own accounts regarding how/when/where/why they inject their drugs, what they know about safer injection practice, and why they so rarely practice "self-care" by putting into practice what they know about maximizing the "hygiene" of their injections.

In this article I share some of what I’ve learned over the years of doing field research on drug injection practices, much of which surprised me as much as (perhaps more than) it may surprise you. In the real world outside of syringe access programs (SAPs) and the safer injection protocols (SIPs) they implement, drug injections tend to be "messy," non-linear, open-ended enterprises that follow a logic very different from the logic models behind our best interventions. The adage "the devil’s in the details" comes to mind. It’s in the details of drug injection practices where we might find solutions to the problems of persistently high hepatitis B and C (HBV and HCV) rates and the high incidence and higher prevalence of skin and soft tissue infections (SSTIs). Moreover, the details tell the story of how and why safer injection interventions typically fail to yield discernible positive change and, in many cases, "backfire" and make the situation even worse.

Setting the Stage for a Study of Drug Injection Hygiene

“How do people actually inject their drugs?” Answering this question has been our chief objective. Our principal research question is “With respect to the drug injection process, which factors account for variation in the risk of hepatitis contamination?” By design, we weren’t interested in obtaining a representative sample – i.e., a small, randomly selected group of PWIDs with the same characteristics as the larger universe of injectors. Because one of our central areas of human behavior theory concerns the gap between what people know and what
they actually do, we intentionally recruited only those injectors who had received training on safer injection technique in the past three months.5

The Data: In Situ Injections
Over the years we have accrued several hundred videorecorded injections drawn from the 64-square block area of Chicago’s west side where I have conducted ethnographic immersion research for the past 12 years. My deep fund of trust-laden relationships with drug users and strong ties with local street drug suppliers enabled our recruitment of a non-random though arguably representative sample of “injection hygiene savvy” PWIDs.

Of the 400 drug injection video-recordings, we consider roughly 100 of them to be “pristine.” However, because we receive no external funding for this study, we can mobilize only so much research support. Doing the best we can with the resources we have, our net yield for the current analysis is 40 drug injections (or “injection episodes” as we call them). These 40 are “representative” of the larger sample of 400; that is, the excluded cases don’t differ in any significant or patterned ways from the ones we’re analyzing.

Preliminary Findings:
How Do Trained Injectors Actually Inject?
Our analysis plan revolves around answering the question “How do injections actually unfold over time?” One of our key hypotheses is that the risk of acquiring or transmitting HCV is unevenly distributed across the injection episode: Some aspects of the drug injection process are systematically riskier (more blood, more contaminant-filled, etc.) than others. Similarly, some injection activities involve more “contamination” of the injector and/or the habitat than do other activities.

After nine months of coding and analyzing 345 minutes and nine seconds of footage (i.e., 6,206,649 unique image frames) across 40 distinct injection episodes, we’re starting to see some distinct patterns emerge. Our coding scheme allowed us to chronicle every activity for every 1/30 of a second. We organized coding into seven “activity domains” (see list in the table below) and noted every “inside-out” and “outside-in” contamination. A few of our key preliminary findings merit discussion.

Finding #1: Sequence of Injector’s Activities
Our first major insight is this: Drug injections follow a serpentine route and hardly ever assume the linear pathway implicit or explicit in the dominant “total hygiene” safer injection training protocols. This is not to say, however, that their sequencing is random. Indeed, it’s quite patterned. Most injectors begin the injection episode with the preparation of the drug.

Shorter/quicker injections are the safest injections.
The participants who rapidly injected their drugs exhibited far less risk and far less contamination than did those who took their time about it.

Illustration of how five typical injections unfold over time (Y-axis), with “activity” phases (A-G) in color and contaminations indicated with a dot. Click the links to watch short, coded injection sequences that demonstrate the concepts from the article:

vzaar.com/videos/811232
vzaar.com/videos/812607
We see that everyone jumped straight to preparing the drug and loading the syringe, and no one spent much time finding a vein before puncturing the skin.

One of the core diagnostic criteria of “addiction” is that the drug – in this case heroin – displaces all other life concerns as the fulcrum around which daily life revolves. Given the heroin-dependent person’s fixation on procuring the drug, it makes sense that once the drug is in hand, the next step would be its preparation.

The serpentine nature of drug injections carries with it adverse health consequences. Our data show that the more serpentine an injection episode is – the more back-and-forth movement between/among “activity domains” we observe – the greater the risk of viral and bacterial contamination. In an ideal world, the injection process would unfold in a linear fashion. But the fact is, it doesn’t. And we know of no program/intervention that has succeeded in transforming the winding injection episode into a linear one.

Finding #2: Time is the Enemy
Contrary to popular belief in the “harm reduction community,” time is the enemy when it comes to drug injection and the risk of HCV acquisition and transmission. A good deal of research literature has dealt with the issue of social control agents or withdrawal symptoms creating pressurized temporal, physical, and/or psychophysiological spaces – situations wherein PWIDs must hurry their injections, fix up in suboptimal locations, and so forth. We find no support for these ad hoc theories and folk beliefs.

In our study we find that longer injection episodes involve a significantly higher number of activities and more activity/stage changes. And the number of activity/stage changes is positively correlated with the number of contaminations. Why? Because longer injection episodes typically involve a higher number of punctures, and it’s the puncturing of the skin that creates the health hazard.

Shorter/quickier injections are the safest injections. The participants who rapidly injected their drugs exhibited far less risk and far less contamination than did those who took their time about it. And we found no support for the “dope sickness hypothesis.” Those who were dope sick tended to inject quickly but carefully. This, too, makes sense when you really stop to think about it. With more time, people engage in a greater number of distinct activities, such as readying their injection surface, preparing the drug, locating a vein, inserting the syringe, getting a register, etc., and thereby enjoy a higher number of opportunities to make mistakes.

Finding #3: Differential Salience of Stages
As I mentioned above, most injectors begin with the drug preparation stage/activity. They skip over surface preparation and the gathering of injection materials. And even those who spend more time injecting don’t have all the time in the world. The fact is, every injector is operating in a limited time window. So most injectors will complete only those steps absolutely necessary for “getting high” (even though most are only “getting normal” or “getting the sick off”).

Not all steps are of equal salience when it comes to the risk of acquiring or transmitting HCV. Shortening the drug preparation phase, for instance, is far less consequential than is shortening the “finding a vein” stage. Indeed, most injectors cut corners in the “finding a vein” department. While

“Leaky motherfuckin’ veins. You actually taught me somethin’, Doc. See, that’s what I’m talkin’ about. We need useful information. Enough of the scare tactics. I mean, you’re still tellin’ me about bad health and shit, but this is different because it’s, like, dope fiend useful.”

Jennifer, who didn’t take time to locate a viable vein before injecting, punctures herself repeatedly with the same needle, “probing” or “fishing” for a vein. Photo: Greg Scott.
Finding #4: Contamination Risk
In our study we have adopted a simple but high-threshold conception of contamination risk: Blood released by the injector and the direct contact between the injector’s open wound and material carrying (or potentially carrying) someone else’s blood. We assume all blood to be HCV positive for the sake of risk analysis, which is consistent with the “Universal Precautions” that govern the handling of biohazardous materials by medical professionals, infectious disease specialists, and so forth.

In this study we find a great deal more Outside-In (O/I) contamination risk than Inside-Out (I/O). Although injectors do release a good deal of blood into their injection scenes, and while this blood certainly could come into contact with other injectors’ bloodstreams, PWIDs tend to be more vulnerable to acquisition than active as agents of transmission. Every injector interacts with her environment—her immediate ecology and the injection and non-injection related objects in it— a great deal during a typical injection episode.

More than ¾ of the variation in contamination risk we observed in these injections was attributable to the number of activities in which the injector engaged. Again, the greater the number of activity changes in an injection episode, the higher the contamination risk, even when controlling for how long the total injection episode lasts. Unfortunately, the greatest proportion of contamination risk points occur NOT in the non-essential domains (cleaning the surface, gathering injection supplies all together before beginning the injection, etc.) but rather in the activities that injectors must do: preparing the drug for injection, cooking the drug, getting the drug into the syringe, and puncturing the skin with the needle.

On average, we observed one marked HCV contamination risk point (either I/O or O/I) every 33 seconds in these injection episodes. That’s a lot of potential viral infection. To summarize our findings in this area, drug injections are messy business, rife with viral contamination points, but some aspects of the injection process are more risky than are others. Interventions would do well to incorporate this insight.

Implications for Program Development: Misguided Linearity, the Folly of Totality, and the Gloom & Doom of RISK
Our ongoing study continues to offer up material from which we develop insight and ideas concerning how to intervene, and how NOT to intervene, in people’s injection practices. In this section I share some of the lessons we’ve learned from analyzing the field data on actual injections, the evaluative data I gathered in the course of studying a large SAP’s impact on clients’ injection practices, and studies of “micro interventions” designed to improve injection hygiene.

Inappropriate Linearity
Every safer injection program protocol we have identified and reviewed unfurls in a linear fashion: “Follow these 25 steps and you will have performed a safer injection” is an exaggerated rendering of the normative message. Even the safer injection protocol that my colleagues and I developed was linear, with the imparting of knowledge transpiring incrementally through a sequence of steps/stages that we extrapolated from our firsthand observation and knowledge of injection. Of course, there’s nothing intrinsically wrong with linearity. But when it comes to intervention on a real world cluster of activities, it’s problematic for at least two reasons: 1) “Real-life” injections are non-linear phenomena, and 2) injectors simply don’t conceptualize their injection episodes as being comprised of three, five, seven, or any other number of abstract stages, steps, phases, or segments.

The Folly of Totality
Most SAPs need to revisit and revise, if not completely overhaul, their approaches to injection hygiene intervention. Even if equipped with the best intervention in the world, those of us who work in harm reduction are painfully aware of just how tangential the issue of injection hygiene is or can become. After all, many of us are fighting tooth and nail to retain enough funding for the provision of sterile syringes, let alone sufficient staff for dedicated interventions designed to change clients’ drug injection practices. But if we step back for a moment, we might be able to appreciate a different view, a new vista on the issue.

Getting PWIDs to use new syringes is comparatively easy; it’s generally just a matter of adopting a new and usually better technology (new vs. old syringe). Out of frustration over the realization that poor injection technique is the driving force behind intransigent HCV and SSTI rates, and perhaps from the recognition that changing PWIDs’ injection practices (which are deeply engrained) must be nearly insurmountable, many of us believe (mistakenly I would argue) that safer injection interventions should be built on a relatively grand scale. But what we have observed in our work is that “small is beautiful.”

The “total hygiene” approach of most protocols is entirely unrealistic given the behavior target in question and given the tremendous variance in PWIDs’ life conditions. Also, in light of the serpentine, dynamic “back and forth” nature of the injection process, it’s no surprise that the “stickiest” messages we’ve observed were those delivered in a highly tangible way, as freestanding and memorable “tips” as opposed to messages that were part and parcel of a long, convoluted “total hygiene” approach. Deeply patterned human behavior generally changes in the same manner in which it evolved: incrementally.
The Gloom and Doom of RISK

One night last summer I was preparing to teach a safer injection session at the west side Chicago CRA outreach site where I've been volunteering for the past 11 years. A veteran participant, “Johnny,” noticed me preparing injection supplies for the teaching session and asked what I was doing. I told him that I was preparing to teach a session on the risks of drug injection and how to change injection technique to reduce that risk. His reply hit me like a skid of paving stones:

Aw man, not another “and here’s another way you can get sick and die” infomercial. You know we hear this shit all the time, right? Don't you think we already know that just doing this is bad for us? That’s the main reason that I shoot dope in the first place. The thrill. Don’t be a Dr. Killjoy, man. There’s enough of them kind of doctors already in our faces. Why don’t you try somethin’ else for a change – tell me how I can get more good, not how I’m gonna feel more bad.

Johnny’s absolutely right: The vast majority of safer injection interventions invoke the “gloom and doom” of disease/infection risk as the principal motivating factor. At a fundamental level, most SI programs carry a threat: “If you don’t follow these practices, you will suffer.” This sort of message arguably dissipates and rapidly loses steam amidst the cacophonous barrage of negative messages that PWIDs receive (and often internalize) every day from friends, loved ones, social control authorities, etc. Perhaps it’s time for an inversion of the risk-reward quotient with regard to formulating the basis for intervention.

How did I respond to Johnny’s challenge? Well, I stood there nodding dumbly for at least a full minute. Then an image came to mind: “leaky veins.”

“Well, let me put it this way,” I began. “One of the things I teach is that you should insert the needle at a 15 degree angle, which is really shallow compared to how most people do it.” Here I showed him the picture above.

“Now, most people go in way too steep, like they’re stabbing themselves,” I continued. “Yeah, and . . . ?” he replied. “Well, if you do that, then the needle goes through the top side of the vein, you get a flash of blood in the syringe but before you know it, you lose the flash and have to pull back out a little bit, and then you get it again.” Johnny enthused, “Yeah, that happens to me all the fucking time, like almost EVERY time I shoot!” I carried on: “Okay, so check this out . . . the veins like a hose, right?” He nods. “So when you go in too fast and too steep and you make TWO holes in the vein, one on the top and one on the bottom, what do you think happens when you do finally shoot the dope into your system?”

Johnny looked at me, then back at the picture, and then exclaimed: “The shit leaks out the other side!” he bellowed. “Exactly. You got yourself a leaky vein. A little bit of your shit leaks out the other side, which means you’re only gettin’ $7 or $8 out of that $10 bag you just bought, so the rush won’t be as strong and the high won’t last as long. Not to mention the fact that having two holes is worse for you health-wise than having one hole.” At this point an awkward staring contest ensued. After what seemed like a 10-minute stare-off, Johnny broke out a grin: “Leaky motherfuckin’ veins. You actually taught me somethin’, Doc. See, that’s what I’m talkin’ about. We need useful information. Enough of the scare tactics. I mean, you’re still tellin’ me about bad health and shit, but this is different because it’s, like, dope fiend useful.”

Over the next few weeks of field work, I noticed the “leaky veins” idea taking on a life of its own. What started as an improvised repackaging of an old message became a social marketing campaign. And it was rooted in the quest to maximize pleasure, not minimize risk. It's time for SAPs to consider alternate, pleasure-based “frames” for their safer injection protocols. For injection drug users, principal concerns – which can serve as excellent intervention message frames – include maximizing the rush and the total quantity of drug entering the body, increasing the length of time that their primary veins remain accessible, and reducing the visibility of stigma-precipitating track marks.
Conclusion
Over the past decade of attending harm reduction meetings I have perceived growing complacency with persistently high rates of HCV infection and SSTIs, as though we’ve come to view their uncontainable existence as fait accompli. But I strongly disagree. As harm reductionists, we have failed to be adequately innovative in how we learn about real world injections (even those of us who are former injectors) and about how PWIDs’ seemingly “irrational” behavior is, in fact, perfectly rational. We’ve also dropped the ball when it comes to developing interventions. We need to get out in the field and observe drug injections in real time and in real places and work with current injectors to develop sensible, practical, and pleasure-based intervention messages. There’s no time like the present.

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Notes
1. Throughout this article I use pseudonyms in place of injectors’ real names to protect their identities.
2. Ethnographic field research is often characterized as “hanging out with a purpose” or “deep hanging out” (see Clifford Geertz’s 1998 book Deep Hanging Out for an in-depth reflection on ethnography as a research strategy).
3. In this article I use the term SAP to refer to all manner of sterile syringe provision programs, whether they’re exchanges (1 for 1, 2 for 1, or whatever the ratio), distributions, or something else.
4. Note that we have focused our analysis on HCV, not HBV, HIV, SSTIs, or venous health.
5. The participants we recruited all had undergone SI training based on one or more of the following “gold standard” SI protocols: “Getting Off Right,” “Take Charge, Take Care,” Chicago Recovery Alliance’s (CRA) “Better Vein Care” illustrated guide, and/or some adaptation of one or both of these interventions.
6. Full coding protocol available upon request.
7. An “inside-out” contamination risk point occurs when the injector appears to introduce potentially virus-infected matter (most often blood) into a shared injection environment; an “outside-in” contamination occurs when potentially virus-contaminated matter (usually blood) makes direct or indirect contact with the injection wound.
8. I realize that it’s not always this simple, for there are a good number of injectors who prefer used needles with slightly worn points because they find comfort or security in the skin’s resistance to a blunt point. Indeed, I have seen many PWIDs take a new syringe and blunt its tip intentionally so as to get better “traction” when doing the injection.
10. For an excellent discussion of this, see Maggie Harris’ article on the Injecting Advice website: injectingadvice.com/articles/guestwrite/241-magdalena1

Click the links to watch videos of short, coded injection sequences that demonstrate the concepts from the article:
vzaar.com/videos/811232
vzaar.com/videos/812607
She’s applied for every strait-laced office gig she can find – regardless of hours, pay or whether her university degree makes her absurdly over-qualified. She went from being a manager to fighting for personal assistant positions. But last month, after innumerable unanswered cover letters, overdue bills and a delay in her unemployment checks, she entered a new world.¹

The trickle down effects of a failing economy always impact more than Wall Street and American-made car sales. These days, middle-class advantages, like a solid college education and professional work experience, don’t offer the same level of protection that they did once. Faced with fewer compelling jobs, some people may find the sex industry an attractive option. Strip clubs, X-rated webcam companies and escort managers across the country have reported an increase in job applications since the beginning of the financial fall. In the midst of a deep financial recession, 2007 to present, there was a blur of media attention about women who began to work as freelance dominatrices, or pro-dommes (circa 2009), as a way of coping with decreased hours, pay or layoff. There still exists a stigma against these professions, however being a dominatrix may be a more palatable option for people looking to enter the sex industry.

Pro-dommes are responsible for the use of psychological dominance, the physical body, and pain or related practices in a safe, legal, and consensual manner in order for the participants to experience erotic arousal and/or personal growth. Many people engaged in the sex industry consider kink and sensual massage to be the most difficult sectors of the field in which to work. Nevertheless, it holds a number of benefits that have made it an increasing popular choice for people attempting to supplement their steadily decreasing income. Working a shift in a dungeon means that even with the fee taken by the house, sometimes 60-40 on a session, a dungeon shift is significantly more lucrative than your average hourly side or day job.

BDSM has become a draw for those entering the sex industry as it has moved more into the mainstream in recent years; just turn on your radio to hear Rihanna sing, “I may be bad / but I’m perfectly good at it … Sticks and stones / may break my bones / but chains and whips / excite me.” Hollywood has explored sex work to the extreme that HBO must turn to extensive male sex work to give it some edge in the series “Hung,” about a man who becomes an escort. Also, this form of sex work, BDSM, is not regarded as “prostitution”; it is a legally regulated industry which eliminates the risk of arrest. Dungeons and other play spaces are free to run openly and are often the sites of sex worker organizing and/or unionizing. Lastly, this form of sex work does not necessarily involve intercourse thereby reducing the risks of sexually transmitted diseases and unwanted pregnancy. As Tracy Quan noted in 2009, these perceptions make this form of sex work appealing to “everyday women who are just looking to pick up a little extra money.”

What is not always clear is the increased risk and skill necessary to professionally dominate or submit in a safe, sane and consensual manner. Over the last two years, harm reduction agencies who serve sex workers have been tasked with responding to the needs of this emergent community. Advanced safer sex and sexual risk reduction counseling have become necessary skills. Anyone who desires to enter this community is encouraged to learn as much as possible about technique and safety prior to accepting clients. Some general guidelines include:
I’ve worked in the field of overdose prevention professionally for about 10 years now. I conduct overdose prevention trainings in the County Jail and at the needle exchange here in Pittsburgh, where we also have a naloxone prescription program. I’ve heard a lot of stories over the years of overdoses, stories of people who survived and of those who didn’t.

A year and a half ago I got a call from my best friend saying that her son, whom I’d known since he was a baby, had overdosed on heroin and was in the hospital in a coma. Four days later he died. Since then, I’ve had two other friends, people I knew personally, not through my job, whose kids died of overdose. These deaths, along with another from a few years ago, make a total of four. As sad as it makes me to hear the stories at work, it hits you differently when it’s people who you really know, who have been part of your life, so participating in the panel on Overdose and Stigma at the Harm Reduction Conference in Austin last year was especially sad for me.

Mulling over the inevitable question that arises when someone young dies, “Why?” I keep thinking about the fear and shame of being known by others to use drugs — well, certain types of drugs.

When Alex died, 21 years old, from too much OxyContin, he called his friend in the middle of the night and said, “I’m not feeling so good,” and his friend told him to go to the hospital. If he’d been feeling that way after taking legal medication, he’d have called 911. But he was on probation and he didn’t want to disappoint his parents and his friends, so he said, “No, I’ll be okay, I’ll just sleep it off.” And they found him dead the next day.

When Alisa (not her real name) died at age 30, a mother of two, her friends left her alone. They were afraid to be found there with her shooting dope.

When Ray (not his real name) died at 22, his father called 911, but somehow didn’t tell the paramedics that it might be a heroin overdose, so they didn’t give him naloxone. He was ashamed to tell people that his son was a heroin user.

When Brody (also a pseudonym) overdosed on heroin, his friends drove him around for half the night before getting help. Apparently, they were afraid to get him “in trouble” with his parents. Again, the fear of people knowing what they were doing resulted in death.

If every time a doctor prescribed painkillers, they also offered a prescription for naloxone, you wouldn’t have to identify, or be identified as a “drug abuser” to get naloxone.
After a year and a half of struggling with blaming herself for the death of her 22-year old son, my friend, Kate, finally came up with the following:

*Just from a personal perspective here, I can say that if the stigma of abuse had not existed, Nick might still be here today. He was so ashamed of newly beginning to use heroin and he had so little information about the drug. If he had admitted to us that he was using heroin, we would most certainly have tried to help him... but it really was the stigma of this drug that killed him, the fact that he was too ashamed to tell us, and that he had planned to be entirely alone to use it, as his friends had advised against it. It was the shame and lack of knowledge that led to his death as much as the overdose itself.*

Of course by the time I learned any of this, it was too late.

Parents who keep going over the mantra: “What could I / should I / would I have done” to keep kids alive fear the stab of judgment from others. Not only do they struggle with their own feelings of guilt and responsibility, but they often feel others believe it is somehow their fault. Even within the confidential confines of a bereavement group, no one wants to admit it was an overdose that killed their child. So even in the place where you go to get support in dealing with the most awful experience of losing your child, you still feel isolated and stigmatized.

Opiates are painkillers. People take them to kill pain, to feel “better.” Sometimes this can cause other problems, maybe worse problems, but as long as our society continues to see this as criminal behavior, people will continue to be covert and fearful of calling for appropriate medical attention when problems develop, even life-threatening problems.

This is why I’m convinced of the importance of developing a model where the best practice for pain medication routines includes also prescribing naloxone whenever opioids are prescribed.

Project Lazarus pioneered this model, in Wilkes County, North Carolina, in response to high rates of opioid overdose death from prescription opioids. They established a program whereby doctors would give patients information on overdose risks, symptoms, and effective response, and also a prescription for naloxone with information on how to use it. The idea is that this will happen almost any time someone gets a prescription for opioids. In Pittsburgh we have been using a sort of “seed and snowball” approach that could be adopted pretty much anywhere. We started out talking to individual physicians in a variety of health care settings who seemed willing to adopt naloxone prescribing as a practice for their patients who may be at risk. We’ve gotten feedback from them about obstacles to their doing this on a routine basis, and we are working to develop the types of training materials and model programs that would allow this practice to be easily instituted in a variety of settings – from a family practice to a free clinic. We are also working with a community-based pharmacy that is willing to provide overdose prevention education and training on naloxone administration, in addition to dispensing naloxone prescribed by physicians.

Yes, this is an important strategy for increasing access to naloxone; if it’s in everyone’s medicine cabinet, it will make it a lot easier to get to when it is needed. But also, and perhaps as important, this model for increasing
widespread prescription of naloxone helps to tackle the role of stigma in the high rate of overdose deaths. At the syringe exchange where we do overdose trainings and naloxone prescribing, when people tell us about overdoses they have experienced or witnessed, more often than not (in about two out of three cases actually) they say that no one called 911. The most common reasons given for not making that call is that they were afraid of police involvement. People often say that if an ambulance came, “the neighbors would know.” They don’t want it to become public knowledge that they are “drug abusers,” because the perception is that “drug abusers” are the people who overdose.

The reality, of course, is that anyone who takes opioids, legal or illegal, prescribed or not, is at potential risk for an overdose. If every time a doctor prescribed painkillers, they also offered a prescription for naloxone, you wouldn’t have to identify or be identified as a “drug abuser” to get naloxone. These days, it is not uncommon for almost everyone, at some point in their lives, to take opioids in one form or another; perhaps you had an injury, or surgery, or maybe you had a tooth worked on. If naloxone is prescribed to anyone receiving any form of opiates for any reason, then the risk of overdose will start to be seen as something that concerns everyone. Maybe then, people won’t feel that they have to live in fear and hide and die.

Author’s note: Some of the names have been changed to protect the families of individuals from the ill effects of stigma associated with having a loved one die of drug overdose.

Alice Bell is the Overdose Prevention Project Coordinator for Prevention Point Pittsburgh [pppgh.org] and a Licensed Clinical Social Worker.

Have you ever saved someone’s life using Naloxone? Has your life ever been saved with Naloxone?

In collaboration with the Eurasian Harm Reduction Network and with the support of harm reduction organizations all over the United States and globally, the Harm Reduction Coalition is declaring that WE ARE THE EVIDENCE — naloxone works.

We are backing up this declaration with a series of short stories documenting instances where naloxone (otherwise known by the prescription name Narcan) has been successfully used to reverse an overdose.

We want to hear and document your stories on video to prove to the world that naloxone works!

Eventually these incredible stories will be collected into a larger work that will be presented, along with other advocacy materials, at a meeting with relevant bodies of the United Nations. To learn more and join the campaign visit: facebook.com/naloxoneworks
Looking back …

I remember attending the Harm Reduction Coalition (HRC) conference for the first time in 2006, when it was held in Oakland, California. The experience was unlike that of any other conference I had ever attended. I remember being both shocked at how few young people of color were present and yet amazed at the diversity amongst conference goers. While I didn’t witness diversity in terms of race or among youth and adolescents, there was broad representation of active and non-active drug users, HIV prevention specialists, addiction specialists, friends and family of people impacted by drug use, and even members of faith-based communities.

At the time, I was newly employed by a youth organization that had always worked to incorporate harm reduction strategies into their work with young people (which seemed radical then). The Executive Director when I was there believed in exposing staff to harm reduction, as it seemed like a promising tool for addressing issues staff were facing at the drop-in center. To this end, the Director made it a priority to send 17 of her staff members as well as some participants all the way from Philadelphia to Oakland to experience an event that occurs once every two years. The workshops and the people were both fascinating. However, the general agreement amongst staff from my organization was that there were barriers keeping harm reduction and the harm reduction community from being accessible to young people and some persons of color. By the time we returned home, we learned that while there are diverse communities across the country (and beyond) practicing harm reduction, it would be necessary to develop different strategies in order to expose harm reduction principles to those who have traditionally been unable to access them.

Beyond that 2006 experience, I continued to attend harm reduction conferences. I also struggled with this idea that I needed to find opportunities to make harm reduction accessible to people who looked like me and had grown up with my experiences. Much like the young people I was working with, I grew up in a household with a Mother who struggled with her own addiction issues. I remember that the only option provided to my Mother was abstinence. For over 20 years, my mother suffered in silence – never feeling quite good enough for her family or the people in our community. I also lived the shame of her addiction; I felt unsupported in my personal decision to meet my mother where she was, while managing my own desires around the person I wanted her to be. We were confined to the limitations of a Narcotics Anonymous culture where cliché’s did not account for individual experiences; I struggled with what I perceived as the Christian-rooted, codependent nature of the program, which was operationalized in both covert and explicit ways.

I also struggled with this idea that I needed to find opportunities to make harm reduction accessible to people who looked like me and had grown up with my experiences.

... and moving forward

The 8th National Harm Reduction Conference was held in Austin, Texas during the same year that I came to work for the Harm Reduction Coalition as a Capacity Building Advisor. I’m fortunate that in this role I get to work strategically and concertedly to promote harm reduction as a viable option, particularly for those within the helping profession. The bulk of my work and advocacy experience has been around HIV and I appreciate that capacity building has helped to sustain my interactions with HIV/AIDS organizations. However, HIV-specific capacity building housed at a harm reduction organization has not only allowed me to expand my understanding of harm reduction from a drug use perspective, but also from an organizational perspective. This has meant offering organizations ways to identify potential harms incurred by an agency’s participants or staff – in addition to public perception of the agency – as a result of its mission and policies.

The “harm reduction for agencies” concept comes from some of the work I have done with organizations that serve Black men who have sex with men (BMSM). It was through my capacity building work that I started to hear employees question certain dynamics, institutions and policies within their organizations, and more broadly, within the field. For example, I heard people exploring things like the impact of all white leadership in institutions that serve BMSM as well as issues that come up when BMSM participants are hired to do outreach in the communities where they live, date and/or frequent. Another taboo topic raised in these conversations — which came out as a common issue at some agencies — is intimate relationships between staff members or between staff and participants. These issues are all potentially harm-initiating factors that could threaten the sustainability of organizations and prevent...
core values from being fully experienced in a positive, empowering way. I recognize that some groups struggle with harm reduction — such as people of color and young people; however perhaps it is because the institution of harm reduction has been inaccessible to them. By inaccessible I mean that despite the fact that people use forms of harm reduction within their everyday lives, the concept of harm reduction has been stigmatized and misrepresented as tool for promoting drug use and the legalization of drugs. The people of color in my community — teachers, young people, politicians, and parents — are often times already stigmatized as drug users because of what they look like or where they live and have, therefore, worked hard to be disassociated with any perceived promotion of drug use. In addition, I think that harm reduction has meant different things to different people; in turn, messaging consistency has become complicated and resulted in rejection from populations who could benefit from it.

Exploring new strategies
I spent the last six years thinking about what my contribution to harm reduction could be, and it was at the 2011 conference where I was able to actualize that opportunity. I worked with a colleague at HRC to develop and present a workshop entitled, “Different People Common Ground: The intersections of Human Relations and HIV Prevention”. The workshop deconstructed value assumptions and invited conference attendees to examine service provision through the lens of oppression. This workshop challenged participants to process change through the ecological model, examining the implications of the social environment while also being empowered by the impact an individual can make on society.

The ecological model is rooted in domestic violence prevention. It draws on systems theory to dissect social systems to more clearly identify what promotes and sustains problems on the individual, interpersonal/relationship, community and societal levels. For example — let’s assume an agency has recently hired a participant to provide outreach services. Let’s also assume that the employee was subsequently reprimanded a few times for engaging in “inappropriate” behavior with other participants during outreach hours. The ecological model may be a useful tool for this organization to gain a broad yet specific perspective of the issue (see figure left).

From the individual perspective — thinking about what is going on internally — the employee might indicate that knowing everyone in the neighborhood makes it difficult for her to engage professionally. The employee might feel that it is not a “big deal” because these people are her friends and her relationship with these people is actually the reason that other participants are more likely to engage in service.

From the relationship perspective, it’s possible that the employee is feeling pressure to engage in familiar behaviors, and to be the “same person” amongst her friends that she was before she was hired by the agency. This tension can complicate things.

The community area of influence asks us to question the culture or climate within an organization that might promote or perpetuate certain behaviors or interpersonal dynamics. Continuing the example above, the community perspective may look for contradictions or inconsistencies in policy that could have had an impact on the situation. Perhaps the agency tolerates informal relationships to a degree — such as a program manager and program staff person who are best friends or even a staff member and a participant who are roommates. The newly hired outreach worker may be confused by these different boundaries, recognizing that, to some degree, there is a relationship beyond a professional one. Agency tolerance of the other relationships (for whatever reasons) may lead the outreach worker to feel that she can also navigate the professional and familiar roles with agency participants.
Lastly we have the societal level, which speaks to the structural forces that create policies and procedures, and that further impact the way an agency exist. For example, policies around employee and participant fraternization are intended to protect the agency from liability. However, most of these policies do not take into account the likelihood that community members who are hired because of their association with a target population may carry a greater burden as a result of such policies than staff that are not. This could result in heightened frustration among outreach workers primarily because a great deal of their support might come from the community and participants of the organization.

The information within this framework reveals where harm exists beyond a traditional perspective that simply seeks to govern participants. Rather, the analysis also encourages management to revisit ideas around who and how to hire, as well as how to create a working environment that does not ask participants to compromise themselves or their relationships for minimum wage. The ecological model also helps participants in understanding the complexity of potential harms from various perspectives. This means that organizations can be more intentional about the work they do and the people they do it with and for.

The workshop in Austin attracted a broad range of participants from Centers for Disease Control Program Officers to outreach workers and other frontline staff to volunteers, all seeking to make a greater impact within their agency. The workshop focused on leadership development, managing up, internal capacity building and succession planning. Some of the hopes coming out of the workshop were that people will be able to see harm reduction in a different context – a context that promotes harm reduction values and usability beyond its most common association which is injection drug use. It’s important that the general messages around harm reduction and its principles promote values such as empowerment and individualism, while establishing options with people to reduce harm. Lastly, it is equally important that we develop collective values about packaging harm reduction as a philosophy and ensure that these values reflect the complex needs of all people. After all, what good is useful strategy if it is inaccessible to the people who stand to gain the most from it?

Michael T. Everett is the Team Leader for the Harm Reduction Coalition’s Capacity Building Assistance Program. For the past 12 years, Michael has been working in non-profits with various populations most impacted by HIV/AIDS and other social health issues. Michael holds a Masters degree in Human Services and is currently working on a Doctoral degree in Education.

9th National Harm Reduction Conference
November 15–18, 2012
Portland Marriott Downtown Waterfront Hotel

Join us in Portland in 2012 for the 9th National Harm Reduction Conference.

See the inside back cover of this issue for details or visit harmreduction.org

FROM PUBLIC HEALTH TO SOCIAL JUSTICE
Here are tips and tools that can help reduce the potential harms of taking prescription drugs. These are practical steps that apply to people taking pharmaceuticals, even if you're getting them from your doctor with a prescription. If you work with people who use prescription drugs, feel free to copy these or use them however you'd like.

General Advice to People who Use Prescription Drugs

The single most important thing to know is what pill you are taking. There are thousands of different pills out there. This may be obvious, but: How do you identify what pill you are taking? Here are five questions, in order of importance, that offer the most efficient way to identify your pill:

1. What color is it?
2. What are the letters, numbers or logo on it?
3. What is the shape (round, oblong, capsule, etc.)?
4. How big is it? (Use your thumbnail as a reference.)
5. Is there any “scoring” on the pill (a line down the middle, a seam where different colors come together, etc.)?

You may be used to getting a tablet that looks a certain way because you've been getting it from one source or one pharmacy. However, there can be dozens of generics of the very same drug, each of which may look different. Don't get duped – know what you're getting and know what you're using!

You may want to draw or write down a few distinguishing things about the pill that you use most often and put it in your wallet. Or, send yourself a text message that mentions the letters and numbers of the pills that you like to use (if you're afraid of incriminating yourself, use codes that you'll remember or hide it in the body of another text).

Why are the numbers important?
Here's an example of why it's important to pay attention to the numbers imprinted on pills: two of the most common forms of hydrocodone (generic Vicodin) have the markings “M357” and “M367”. Surprisingly, the lower number “M357” has 10 mg of hydrocodone, while the higher number “M367” has only 5 mg – but otherwise, they look the same and are the same size! So if you're taking a few pills at a time, that small mistake can make you feel too high or even push you towards an overdose.

Here are some resources that can be used to identify pills:

- Online sites for pill identification: dailymed.nlm.nih.gov
  drugs.com/imprints.php
- The most common searches for pill identification on these sites are for hydrocodone (generic Vicodin) and other prescription opioids. If you are a harm reduction program, follow the link below and print out color copies of the brochure of the most common prescription drugs used on the street. While not totally comprehensive, they are a great resource to help clients identify drugs or to just get the conversation started.
- The poster has color-coded sections to help you learn what the different kinds of prescriptions drugs are and which ones are similar to others.
### Understanding Pharmaceutical Drugs

This table lists the pharmaceutical drugs discussed in this article, plus others that may be of interest. New drugs are launched and others stop being manufactured, so this list will change over time.

<table>
<thead>
<tr>
<th>Category</th>
<th>Uses</th>
<th>Immediate-release</th>
<th>Extended-release / long acting</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Opioids</strong></td>
<td>Treatment for pain, cough and opioid addiction</td>
<td><strong>Pharmacy Names</strong> (generic / Brand Name)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Widely prescribed</td>
<td>oxycodone / Percocet, Oxeta</td>
<td>oxycodone / OxyContin</td>
</tr>
<tr>
<td></td>
<td>• Offers a warm body rush, pain relief</td>
<td>Roxicodone / Tylox</td>
<td>oxymorphone / Opana ER</td>
</tr>
<tr>
<td></td>
<td>• Have contributed to an increase in overdose deaths</td>
<td>hydrocodone / Vicodin, Lortab, Lorcan, Norco</td>
<td>methadone</td>
</tr>
<tr>
<td></td>
<td>• Withdrawal can be really unpleasant with symptoms such as chills, sweats, nausea, insomnia, diarrhea</td>
<td>hydromorphone / Dilaudid, Exalgo</td>
<td>morphine / MS Contin, Kadian, Awinza, Embeda</td>
</tr>
<tr>
<td></td>
<td></td>
<td>buprenorphine / Suboxone, Subutex</td>
<td>fentanyl (patch) / Durgesic, Mylan, Sandoz</td>
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<tr>
<td></td>
<td></td>
<td>tramadol / Ultram, Ultracet</td>
<td>buprenorphine (patch) / BuTrans</td>
</tr>
<tr>
<td></td>
<td></td>
<td>oxycodone / OxyContin</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>oxymorphone / Opana ER</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>methadone</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>morphine / MS Contin, Kadian, Awinza, Embeda</td>
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<td></td>
<td></td>
<td>fentanyl (patch) / Durgesic, Mylan, Sandoz</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>buprenorphine (patch) / BuTrans</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Benzodiazepines</strong> (&quot;downers&quot;, &quot;benzos&quot;)</td>
<td>alprazolam / Xanax</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>• Widely prescribed</td>
<td>clonazepam / Klonopin</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Gives a sleepy, fuzzy feeling</td>
<td>diazepam / Valium</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Withdrawal can cause seizures and should be done gradually and with care.</td>
<td>lorazepam / Ativan</td>
<td></td>
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<td></td>
<td></td>
<td>temazepam / Restoril</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>zolpidem / Ambien</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Stimulants</strong> (&quot;uppers&quot;)</td>
<td>amphetamine / Adderall</td>
<td>lsidexamfetamine / Vyvanse</td>
</tr>
<tr>
<td></td>
<td>• Most commonly prescribed to teens and college students</td>
<td>methylphenidate / Ritalin</td>
<td>methylphenidate / Concerta</td>
</tr>
<tr>
<td></td>
<td>• Often used to enhance studying and academic performance</td>
<td></td>
<td>amphetamine / Adderall XR</td>
</tr>
<tr>
<td></td>
<td>• Can promote intense focus and prolonged energy</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Sedatives</strong></td>
<td>carisoprodol / Soma</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>• Less popular recently, but some still prefer them</td>
<td>methaqualone / Quaaludes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Mostly replaced by benzodiazepines in medical use</td>
<td>meprobamate / Miltown</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Gives a sleepy, stunned feeling</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Other pharmaceuticals</strong></td>
<td>steroids, Serostim</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>Enhance body building performance, treat male sexual dysfunction</td>
<td>Viagra, Cialis, Levitra</td>
<td></td>
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</tbody>
</table>
Harm Reduction Communication

• Police departments can order the poster and brochure for free from the naddi.org website. naddi.associationdatabase.com/aws/NADDI/pt/sp/abusedrx
• You can look pills up in the pictures at the beginning of a large reference book called the Physician's Desk Reference (PDR), which should be available in all public libraries. It is published every year, is really thick and usually red or dark blue. You may be able to find old copies at yard sales.
• Pharmacies often have pill identification books for sale.
• You can call poison (control) centers. Many states provide a free pill identification service over the phone that is quite accurate (and they don't ask too many extraneous questions, although they may be judgmental): 1-800-222-1222.
• You can do pill identifications and see black market/street prices for prescription drugs at StreetRx.com

Know how much drug (“active ingredient”) is in a pill.
It's not enough to only know the name of the drug. Use the tools above to be sure you also know how many milligrams of the active drug are in each pill. For example, a Percocet can have between 2.5 mg and 10 mg of opioid; that leaves potential for there to be four times more drug between pills that can both be called “Percocet.” How high do you want to get and how much can your body manage?

Know the difference between “immediate-release” and “extended-release” formulations.
Extended-release (also known as modified-release or controlled-release) pills contain much more drug than immediate-release (also short acting, rapid onset) pills. The difference is, when taken in pill form by mouth, extended-release pills are designed to release the drug into your body over a longer period of time, but immediate-release pills put the full dose into your body all at once. If you haven’t been taking Rx opioids or heroin regularly, snorting a 40 mg, 60 mg, or 80 mg OxyContin can be enough to kill you. If you’re not opioid tolerant, chewing a Duragesic/Sandox/Mylan fentanyl patch can overdose you. Some extended-release formulations, such as Opana ER and Kadian, will stay in your system for 24 hours if you swallow them whole, so think about how long you actually want to be high.

Some painkillers also contain dangerous amounts of Tylenol.
Ever notice how big Vicodin and Percocet tablets are? The bulk of the tablet is made up of Tylenol, also called acetaminophen or abbreviated “APAP” on the bottle. Some brand name opioid painkillers that include Tylenol are: Vicodin, Percocet, Tylox, Loracet, Lortab, Norco, Darvocet, and Ultracet. Taking Tylenol every day for weeks can damage your liver, which means that so can taking Vicodin or Percocet every day. This can be especially serious if you have hepatitis C, are drinking alcohol a lot, or have liver problems. Avoid taking more than 4 g or 4000 mg of Tylenol per day. If you are still in pain after taking several Vicodin a day for more than 10 days, you should seriously consider seeing a doctor to prescribe you something without Tylenol. If you can’t see a doctor and are treating your own pain, try to find painkillers that don’t have “acetaminophen” or “APAP” written on the label.

Take laxatives — prescription opioids can constipate you.
If you are taking prescription opioids (or heroin) every day, you may get constipated. Drinking more water and eating high fiber foods can help relieve constipation (popcorn is a tasty choice, as are leafy green vegetables like collard greens). Ask a pharmacist for gentle laxatives, like those containing senna, that you can buy over the counter.

Taking Tylenol every day for weeks can damage your liver, which means that so can taking Vicodin or Percocet every day.
Drink water, chew gum, and/or brush your teeth to avoid dry mouth.

Taking prescription stimulants like Adderall or Ritalin during binges or long study sessions can give you a really dry mouth or make you grind your teeth. A dry mouth and grinding can really damage your teeth, just like when using other stimulants (cocaine, meth). There are some simple things you can do to keep producing saliva while taking prescription stimulants, such as drinking water, chewing gum, or brushing your teeth. The saliva will help protect your teeth from getting cavities and other dental damage.

Cut back on painkillers if you have a bad cold, asthma, or if you snore a lot.

Overdose deaths are more likely to happen if you take a lot of opioid painkillers and have a chest infection (bronchitis, pneumonia), chronic obstructive pulmonary disease (COPD), or emphysema. If you are coughing up phlegm, it may be harder for you to recover from the slow breathing (respiratory depression) that comes with taking too much prescription opioid. Loud snoring or sleep apnea (waking up gasping for air) can put you at risk for a more severe overdose if you take too much painkiller. Unusual snoring after taking painkillers can be a sign of an overdose.

Important! You can get busted for carrying prescription drugs without a prescription.

There is a misconception that it is legal to carry pharmaceutical drugs without a prescription. Unless you can prove that pharmaceutical medication has been prescribed to you, you can be arrested for having the drugs in your possession. Police and prosecutors are paying more attention to prescription drugs these days, and are less likely to believe that the pills someone is carrying on them when they get busted are just Tylenol.

Use around other people, especially when trying a new medication.

If you are using prescription opioids for the first time, make sure there is someone around who can help you if you overdose. This is also true if you are trying more than you normally use, are trying a new drug, or haven't used in a while. If you overdose, you won’t be able to tell someone what’s happening, so it is important to teach those around you what to look for ahead of time. Make a plan with them about what you want them to do if you overdose (what to say to EMS, what to do with any leftover drugs, etc.). If you switch from regularly taking one painkiller to another, especially if it’s methadone or an extended-release opioid, be very careful during the first week to make sure you don’t nod out too quickly or experience trouble breathing after you take it – these are signs that your tolerance isn’t high enough and that you’re at higher risk of overdose.

Mixing painkillers with alcohol can be dangerous.

Mixing extended-release formulations and methadone with alcohol can lead to fatal levels of the opioid being released all at once. This is sometimes called “dose dumping” and it increases the likelihood of overdose. This isn’t a high worth chasing. Don’t wash down prescription painkillers with alcohol.

Advice on Specific Formulations

There is no such thing as a “morphine patch.”

Be careful if someone tries to give or sell you a “morphine patch.” There are only two opioid pain patches available in the United States, neither of which has morphine in it. One is called BuTrans and it contains buprenorphine, which means that it will put you into withdrawal if you are opioid dependent (including on heroin, methadone and oxycodone)! The other one is called Duragesic/Mylan/Sandoz and it contains fentanyl. Fentanyl is a lot stronger than oxycodone or morphine. If you chew, smoke or inject a patch, you could end up with approximately 50 times more opioid in your system than if you were taking oxycodone orally – so be very careful of overdose risk.

If you put a patch on your skin, you
can take it off if you decide you don’t want more opioids in your system, but talk to your doctor first if you are seeing one. Keep in mind that you will still have opioids in your body and it could take an hour or longer for you to stop feeling the opioid effect, so be careful with taking more. If you try to chew, smoke or inject the patch, you won’t be able to go back once you’ve taken it, will have less control over the dose and could be at increased risk of overdose.

**Be extra careful with fentanyl.**
Fentanyl is available in several forms. It comes as a:

- patch (Duragesic, Sandoz, Mylan)
- “lollipop” (Actiq)
- tablet that dissolves against the cheek or under the tongue (Fentora, Abstral), or
- film that is placed under the tongue (Onsolis).

Fentanyl is very strong and your likelihood for overdose is high unless you have been taking other strong opioids regularly.

It’s hard to compare how potent one opioid is to another, but fentanyl, hydromorphone, and methadone are the three most potent opioids you’ll find being used. Overdose risk is higher with these, especially the first few times you use them.

**Wait before taking more methadone.**
If you are taking methadone for pain or withdrawal, remember that it can take more than an hour to take effect. That means it may not be safe to take more even if what you have already taken is not working. This is especially true if you don’t take methadone regularly.

If you are still in pain after taking your normal dose of methadone, try taking aspirin, ibuprofen (Advil, Motrin) or acetaminophen (Tylenol). It’s best to either wait until your next regularly scheduled dose before taking more methadone or call your doctor or a poison center for advice. Being in pain or withdrawal sucks, but taking more and overdosing is worse.

Methadone stays in your body for nearly a day, and builds up in your system when you take it for a few days in a row. When this happens, you may not feel much of a buzz, but it’s still there. Be careful if you decide to take heroin, prescription opioids, anti-depressants, sleeping pills or alcohol with methadone because these things put you at increased risk of overdose. If you are dosing yourself, wait as long as possible since you last took methadone, preferably more than a day before taking additional opiates or depressant drugs.

**The new OxyContin OP is difficult to crush.**
There has been considerable attention to the new OxyContin OP formulation. The old OC formulation stopped being shipped in August 2010 and most of the OxyContin sold by the end of 2010 was the new OP formulation. This makes OxyContin OP the newest entry in what is likely to be a trend of new drugs that are “abuse deterrent” or “tamper resistant.”

The new OP formulation has been changed in two ways with the specific goal of making it less desirable to inject and snort than the old formulation:

1. The new formulation is harder to crush.
2. If OxyContin OP is crushed, it takes on water really quickly and becomes a gummy mess that is hard to suck into a syringe.

While there are complicated recipes online that talk about how to defeat the new formulation and get it prepared for injection, the process is complicated and/or will take too long for most people to do without a degree in chemistry. Also, street chemistry recipes try to get the drug out of the “abuse deterrent” formulations, but they can involve harsh chemicals. As a result, it has been suggested that people who had been using OxyContin are turning to heroin, Roxicodone, or Opana instead.

Roxicodone (oxycodone) and Opana (oxymorphone) are prescription opioids that are popular right now.

Oxymorphone (brand name: Opana) comes in two formulations in the United States. One is an immediate-release product (Opana) that comes in 5 mg and 10 mg. The second form is Opana ER and it’s an extended-release version that comes in 5 mg, 7.5 mg, 10 mg, 15 mg, 20 mg, 30 mg, and 40 mg.

Oxymorphone has been used in medicine since the late 1950s, but Opana only came to pharmacies a few years ago. It’s about twice as potent as OxyContin, oxycodone, hydrocodone, Percocet, Tylox, Percodan, Vicodin, and methadone, and about three times as potent as morphine. So a 20 mg Opana ER is roughly equivalent to a 40 mg OxyContin. The high should feel similar to other opiates. Opana has recently been reformulated to make it very difficult to crush, like OxyContin OP.

Overdose risk with oxymorphone is similar to OxyContin and other opioids, but since oxymorphone is twice as potent as many other opioids that folk’s are used to, there may be increased overdose risk based on an incorrect belief that there is a one-to-one conversion.

Roxicodone is an immediate-release form of oxycodone that comes in 15 mg and 30 mg tablets. Since Roxicodone and OxyContin both contain oxycodone, if you are swallowing them whole, the milligram strengths will be about the same. If you are crushing them and snorting or shooting them, the Roxicodone will have a little less oxycodone than the same milligram strength OxyContin.

Naloxone should work to reverse oxymorphone and oxycodone overdoses.
Fair warning: taking lots of Vicodin may be associated with hearing loss. There have been reports from poison centers and hospital emergency departments that suggest that some people have experienced sudden, permanent hearing loss after shooting or snorting Vicodin (hydrocodone). There has been little research done in this area and evidence for this comes from just a few individual reports. We don’t know how or why this problem might occur, nor can we suggest specific ways to avoid it.

Injection and Snorting Advice

Don’t snort, swallow or shoot a pill that was already crushed when you got it.

Some people will crush their medicines to snort or inject them. Even if it’s a friend or someone you buy from regularly, ask to see the tablet before it is crushed, before it goes into the cooker or before it is made into a line. If you don’t recognize the pill, look it up before taking it. Labels on prescription bottles aren’t always reliable because someone could have changed the pills (or the bottle) before showing them to you. This is especially important if someone else usually prepares your drugs for you.

Dissolve as much of the pill as possible in water or saline before injecting.

There is talc (same as baby/body powder) in most prescription drugs. If you are crushing it for injecting, dissolve the pill/powder in as much water as possible, and use a little bit of heat if you need to get the pill to dissolve. The fewer solid particles you see, the less likely your risk of clogging the syringe or your veins, or getting an abscess, and the more likely you are to not waste your drugs.

Use a clean filter for every pill.

Pharmaceutical drugs usually have lots of talc, cellulose and other fillers in them that can get caught in lungs and vein valves, causing serious damage. The fillers can also damage your heart and raise the blood pressure in your lungs; some people have even died related to complications from shooting pills for an extended period of time. Using a clean, cotton filter can reduce the risk of pharmaceutical fillers and impurities getting into your body. Some harm reduction programs have special filters that fit on the ends of syringes to get rid of most of the talc.

There is no way to lick or rub off the time-release if you’re shooting the tablet.

You cannot “get rid of the time release” by putting a pill in your mouth and licking or rubbing off the outer coating. The colored part of the pill is just a colored film, and it doesn’t affect how quickly the drug is released. Putting the pill in your mouth covers it with bacteria and fungi that naturally live in your mouth; if you crush a pill that’s been in your mouth and inject it, you may be putting yourself at risk for nasty bacterial/fungal infections in your blood. Don’t inject someone’s lunch.

Use a saline nasal spray to clear your sinuses after snorting.

Some of the talc and Tylenol in prescription drugs ends up in your sinuses after you snort them. This can increase your risk for sinus infections and bloody noses. Consider keeping a simple saline nasal spray around if you’re going to be snorting pills, especially bigger ones like Vicodin and methadone. You can get these sprays for cheap and without a prescription from the pharmacy or grocery store. If you’re having trouble snorting the entire tablet, it’s not a good idea to also snort something else (e.g., Klonopin, mints) that will make your nose run. Consider swallowing the tablet whole instead.

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Reframing Satellite Syringe Exchange
It’s About Power

RACHEL ANDERSON

A little background
At the Harm Reduction Coalition (HRC) conference in Austin, 2010, I presented a paper on the Satellite Syringe Exchange Training and Support Program (TSP) of SANE (Safer Alternatives thru Networking and Education)—the oldest syringe access program in Sacramento, California. During the Q&A session, I was reminded of how things have changed since the early 1990s when SANE was vilified regularly at national syringe exchange program (SEP) meetings for “allowing” that sort of activity to occur in our SEP. Now, satellite syringe exchange (SSE) seems to be one of the “hot” topics in harm reduction circles. In the last few years there has been an increasing number of presentations on SSE at harm reduction conferences, students are writing papers on the topic, government health departments have begun addressing the topic, the State of California Office of AIDS funded a five-year pilot program to evaluate SSE as an SEP operational strategy (the program was cancelled in 2009 when Arnie cancelled State-supported HIV prevention activity, including testing), and in 2011, HRC published an excellent report on SSE and New York SEPs. For SANE, SSE has been a strategic and intentional part of the SEP from its inception in 1993. SSEs have always delivered a significant portion of SANE materials and education, representing 35% of contacts in 1993, 61% in 1994 and over 90% every year since 1999.

Who’s got the power?
Satellite Syringe Exchange (SSE) is one of the commonly acknowledged names assigned to the practice wherein injection drug users (IDU) obtain syringes from authorized syringe access programs (e.g., syringe exchange programs, pharmacies) and re-distribute them among their friends, family, social networks and communities.

SSE is a broad term encompassing a range of both formal and informal arrangements. Another term for this practice is secondary exchange, a term rejected by some as unsupportive of participants and an understatement of the actual exchange process. Jim Britton, my partner in starting SANE, always said, "If there must be a hierarchical delineation between drug users doing exchange and providers doing exchange, the drug users are the primary exchangers and we (agency staff) are the secondary exchangers; as the participants do most of the work and our job is to ensure they have adequate supplies and accurate information, including referral information, to distribute."

In the early years, we used the term “designated exchanger” for those designated by their social networks to be the contact person for the network with the SEP. However, this passive term doesn’t acknowledge the “designated exchanger’s” role in the process. Another term used to describe SSE is peer-delivered syringe exchange (PDSE). One problem with this term is it is an inaccurate description of some of the SSEs; for example, some SANE SSEs are not IDUs and some do not use drugs in any manner. These non-peer SSEs are friends and family of IDUs or concerned members of the local community. Thus, the PDSE label is not accurate all the time and, as Jim said, “accuracy is a prime tenet of harm reduction.” Additionally, the PDSE term requires those IDUs who want to do the work to “out” themselves as injectors. Being identified as an IDU often elicits stigma and negative judgments, and always carries enormous risk of arrest as well as potential loss of housing, family, friends, children, job, etc. Also, the “IDU” label stays with one for life.

So we came to call those IDUs who provided services to others satellite exchangers, considering that to be more participant-oriented language and, as such, movement toward supporting the human rights of individuals. Therefore, in this article those who provide syringe access services...
themselves have already developed.

When Jim and I started SANE, we were trying to figure out how just the two of us were going to get enough sterile syringes to local IDUs to slow the spread of HIV in our community. At that time, local research showed the prevalence of HIV among IDUs in Sacramento County was 9-11% (9% among heroin users, 11% among speed users) and we knew once the virus has infected 10% of a population, it begins to spread at an increasingly rapid pace. Besides having only two “staff”, geography was a potential obstacle to getting sterile syringes to local IDUs. In densely populated urban areas, a significant portion of local IDUs can be concentrated in specific neighborhoods; whereas in suburban and rural areas, IDUs can be spread throughout a large geographic area (over 2,000 square miles in SANE’s region). Additionally, in many areas of the US there are geographic barriers (such as mountain ranges) and infrastructure barriers (such as lack of adequate public transportation) to service access. Thus, many IDUs, including those in the Sacramento region, face significant barriers to accessing fixed-site SEPs. The Sacramento County Health Officer and other local stakeholders credit SANE’s SEP as a significant factor in reducing and sustaining the HIV rate among local IDU to less than 2%.

Jim and I knew of and appreciated the Australian Injecting and Illicit Drug Users’ League’s approach to providing services; it is based on respect and a recognition that people who use drugs can and do educate and learn from each other in their everyday interactions. We decided to look at how drugs were distributed in our area. It was the early 1990s and pagers were all the rage, so we felt confident that local IDUs could (and would) utilize the inherent, organic social structure of the IDU community to get syringes to those who needed them.

We approached a few folks that we knew had a great deal of contact with IDUs every day and proposed the SEP to them. The idea of an organized SEP generated a lot of excitement. Some IDUs already were purchasing syringes from pharmacies and distributing them to others on a regular basis. Folks liked the fact we were willing to organize the activity and would work to sustain a program. After we organized the SEP, we provided individuals doing SSE work with extra training (especially on how to deliver education messages), adequate injection supplies and literature, and large disposal containers (sharps). Some SSEs agreed to document their activities and many independently opted to arrange “backup” – someone to step in and assume the SSE duties if the original SSE wasn’t able to continue (due to illness, arrest, etc.).

The training for SSE work and other SEP operational characteristics has been adjusted and altered over the years in response to feedback from SSEs and other SANE participants, epidemiological evidence, and changes in the local context (e.g., political situation, funding availability, etc.). Many participants report SSE creates a sense of membership and belonging, while at the same time promoting safer injection practices and other risk reduction strategies.

More than a decade after SANE started, we were part of a California research study of SEPs. The research demonstrated there could be some increased risk involved in SSE work and offered a recommendation to provide training and resources to SSEs as a way of mitigating the risks. Taking into consideration the study data and recommendations, staff along with some SSEs decided training and resources, as well as additional support and networking opportunities, would be helpful. In 2005, we formalized the SSE Training and Support Program (TSP) to meet this need.

The TSP consists of monthly meetings, half of which are training sessions (topics selected by group members); the other half are networking and support activities that are more social in nature and include sharing a meal. According to feedback from SSEs, the TSP has decreased feelings of isolation, improved access to accurate harm reduction information and resources, enhanced personal risk reduction strategies, and created a thriving support network. Some TSP activities have been curtailed due to funding cuts to the SEP (e.g., conference attendance), but the support network is strong and significantly contributes to SANE’s ability to survive the current fiscal crises.

Control issues
These days, SSE is one of the “newest” ideas to be discussed as an SEP operational method. That said, many people — public health service providers, academic researchers, even some harm reduction and drug policy reform activists — see SSE as controversial. Yet this is not usually the case when...
it comes to IDUs themselves. Why? Supposedly, the problems or concerns involve issues of efficacy, but how then is efficacy being defined and by whom?

In discussions or reports about SSE, it is not unusual to hear or read comments like, “For many reasons, there are some IDUs who are unwilling or unable to go to an SEP directly. We must increase the number and frequency of direct IDU contact with the SEP.” In other words, how do we get more IDUs to come to the SEP more often? The most frequent explanation I hear for the need to increase frequency of IDU contact with the SEP is the importance of IDU exposure to other prevention, medical, and social services and opportunities. There seems to be an assumption all IDUs need and want these other services, and that it is insufficient for IDUs to only receive injection supplies, especially on a regular basis.

I think a more appropriate (and likely more accurate) summary of the controversy over SSE utilization or expansion is that many SEPs are unwilling or unable to make their services available to large numbers of IDUs through SSE – the difference being SEPs carry the burden of ensuring syringes and education get to IDUs (as opposed to IDUs getting to the SEP). Framing the situation in this way requires a change of perspective regarding power. It requires: 1) acknowledging SEPs (or other harm reduction service providers) have power in IDUs’ lives; 2) openly discussing by whom and how power is exercised; and 3) examining how these power dynamics manifest in SEP policies and processes. Openly acknowledging and discussing these control issues can and does make some providers uncomfortable, perhaps even threatened. Yet I believe these are important discussions to have – not just about SSE, but about all of the processes, policies, and operational decisions we make in trying to provide harm reduction-based services.

Power or control issues manifest in the lives of IDUs through syringe distribution policies – the number of syringes an IDU can receive in any single contact with an SEP (assuming distribution or exchange policies are determined only by the SEP). In need-based distribution, the number of syringes an IDU receives is determined by the IDU. In other distribution/exchange policies (e.g. one-for-one, one-for-one-plus, etc.), the amount of syringes an IDU receives is determined by the SEP.

Further, given the pursuit and persecution of drug users in the U.S., I have always found it difficult to understand the unwillingness or inability of some harm reductionists to grasp the inherent risk IDUs face when traveling to and from service locations. In addition, the “forced proximity” or frequency of contact compels participants to become dependent on programs. Given the fluctuations in political and fiscal support for SEPs in many locales, creating that kind of dependency on programs is risky at best, and potentially disingenuous.

For providers, it sometimes can be easy to say, “We treat IDUs with dignity and respect.” However, it is not always so easy to do consistently in day-to-day practice. It can be challenging to respect an individual’s right and ability to make their own choices, set their own goals, and take their own actions – especially when those goals or decisions are perceived to be unhealthy or possibly risky to the individual or to the program. It can be easy to accept the stance that programs must set boundaries and take control – we have funders to answer to, bureaucrats to please, neighbors and community members to respond to and, in many cases, politicians to mollify (or at least, not anger or irritate). However, I think it’s possible for us to meet these organizational responsibilities and still convey authentic respect for IDU rights and abilities, all while keeping the goal of stopping the spread of disease among our top priorities.

Power shifts
In the US during the 1980s, when we first began the struggle for legal or authorized, low-threshold access to sterile syringes, we placed emphasis on making an adequate number...
of syringes available to IDUs in order to stem the spread of HIV and other infectious diseases. In other words, the volume of available syringes had to be sufficient to meet the “one-shot-one-syringe” needs of a significant portion of the IDU community (aka “coverage”) in order to be effective. As of May 2011, we are still struggling to achieve adequate coverage, even in major urban areas of the US with large SEPs (e.g., New York City, San Francisco, and Chicago).

Most IDUs in the US do not have consistent, easy access to a sufficient quantity of sterile syringes to achieve the “one-shot-one-syringe” goal. However, instead of investigating and advocating for additional methods to achieve this goal, some (SEP advocates/providers/researchers) have been somewhat distracted — focusing instead on adding ancillary services and debating the efficacy of various syringe distribution methods (wherein increasing the number of syringes available to the IDU community is rarely the primary definition of “effective”). For example, I have heard many debates among harm reductionists about whether or not SSEs can deliver accurate risk reduction education messages, whether SSEs will distribute risk reduction materials (including sterile syringes) fairly and consistently, and whether SSE workers can maintain the responsibility and the ethics of the position over time.

Again, the ubiquitous “they” will say effective means achieving sustained behavior change among IDUs, so we must make sure that a) SSE workers are always passing on specific public health messages (read: messages that aim to achieve explicit, sustained behavior change), and b) IDUs are not conducting SSE for profit-driven, power-accumulation, or other personal motives. We must make certain SSE workers are not “abusing” the “privilege” being “given” to them by the SEP/public health authorities. I say, Nope — that’s not the problem. That line of thinking holds IDUs to a different standard than other workers and implies IDUs cannot be trained like other staff. First, do we make sure SEP employees are not taking the job for profit-driven, power-accumulation, or other personal motives? Is accepting a wage or a position with power abusing the privilege of having the position? In other words, questioning SSE worker motives comes from the stereotype that all IDUs are self-absorbed and their every action is motivated by the desire to obtain drugs. Shouldn’t it be sufficient if SSE workers are distributing syringes to IDUs consistently (with accurate education, when it’s wanted)?

Second, if equal resources are devoted to training SSEs to be educators as are devoted to training staff (possibly in a different format with a different frame of reference), SSEs can be as competent as other workers in passing on accurate public health messages, consistently, fairly, and ethically.

I’m not arguing against adding ancillary services as these services are vital to many participants and significantly contribute to improving overall health and wellness of program participants. Nor am I saying that examining the efficacy of various distribution strategies isn’t valuable; we need that evidence to design useful programs and address organizational concerns. However, I am saying it is important to acknowledge different perspectives and address them openly. For example, when examining SSEs’ abilities to do the work, it is valuable to take SSE design into consideration and not use just traditional “job descriptions” as the norm. Some of the networks in SANE have several members who function as their SEP contact rather than having just one representative. In other words, the SSE role rotates among network members, falling to whomever it is convenient for on a particular day, has gas in the car on the meeting day, or is well enough to conduct the training, etc. This type of arrangement may not fit into an agency’s usual employment format; however, if it works for the IDU network in establishing and maintaining a consistent syringe supply, that should be an important part of the efficacy measure. Other frame of reference shifts include separating distribution

The truth is, SSE work is occurring, whether or not SEPs choose to acknowledge (or support) it. SSE work occurs in many communities that do not even have SEPs and, in actuality, the SEPs of today were borne out of SSE.
will improve the efficacy of both SSE and SEP work. Acknowledging SSE and incorporating the work of SEPs into SSE work is practicing true harm reduction – meeting folks where they are at, respecting the rights and abilities of drug users to make decisions and take action, and creating and sustaining an environment in which folks can use drugs safely, without justification or explanation to anyone.

Political, bureaucratic or ideological pressures can sometimes make it easy to gloss over the fact that the goal of more IDU contact with the SEP often equates to more control for the SEP and more chances for the SEP to get IDUs to adopt the SEP agenda. The unfortunate truth is that the more IDUs that SEPs can get into medical care or drug treatment programs, the more political support and money programs will get and, in turn, there will be less opposition to SEPs in general. These are not "bad" or inappropriate goals per se. However, when these goals are not made explicit, then the related power and control issues aren’t out in the open and therefore rarely get discussed, let alone negotiated and/or accounted for.

So as harm reduction service providers (researchers, policy makers, and activists), how do we hold each other accountable to the “uncomfortable” issues? How do we call organizations or individuals out on issues without being threatening or disrespectful? How do we operationalize the tenets of harm reduction while still satisfying the bureaucratic, political, and funding, etc., needs?

I believe the creativity of harm reduction “solutions” is formidable and amazing. SEPs are one example of this creativity. Overdose prevention and response programs are another example of harm reduction “solutions” that not only have saved thousands of lives, but have contributed to renewed self-confidence and sense of community for many IDUs. Let’s use harm reduction’s creativity to address the problems of reporting requirements, evaluations, and paperwork in all its manifestations. Let’s also use that creativity to acknowledge and address the power differences and various frames of reference of those involved in harm reduction programs – whether it be participants and providers, women and men, younger and older, management and line staff. I do believe in harm reduction practitioners’ creativity and our ability to implement inspiration. I do believe we can and will challenge the many ways we get trapped by oppressive or stigmatizing barriers. And I do believe we can and will help this movement grow so we can finally rid ourselves of the current draconian drug policy and welcome an approach that enhances quality of life for drug users and their communities.

Rachel Anderson is a long-time advocate for the human rights of drug users. She has worked as a drug treatment counselor, an epidemiologist at the University of California, Davis, and Executive Director of Safer Alternatives thru Networking and Education (SANE) [cleanneedles.org] since 1993. She also has provided technical and political assistance to emergent syringe exchange programs in several Eastern European countries and currently is working on a multi-year project to improve services for women at Ukrainian syringe exchange programs.

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Many sessions at the 8th National Harm Reduction Conference were well attended, but one in particular was bursting at the seams. With people in every chair and sitting on the floor, the standing room only crowd spilled into the hall. The topic was “Recovery and Harm Reduction.” I had the honor and privilege of moderating the session. The panel was comprised of seasoned veterans in the movement, each bringing over 15 years of experience working in, managing and directing harm reduction programs. Each shared her/his own unique insights on the often uneasy and challenging experience of being in recovery and working in harm reduction. Here, we try to capture the general recurring themes of the panel contributions and group discussion, followed by some suggested topics that deserve candid dialogue and cooperative action.

First, of course, there is hardly an agreed-upon definition of “recovery,” and this may be even more the case in harm reduction circles. Each individual who considers her/himself to be “in recovery” is engaged in a unique personal process that changes over time. For one person this may mean long-term abstinence from any types of psychoactive substances, while for another, some types of substances or frequencies of drug use are acceptable. Some consider engagement in replacement therapy as being in recovery and some do not. Some may have experienced multiple relapses and some have not. Some may not consider themselves in recovery from drug dependence alone, but mental health and/or other issues. But for most, recovery includes some degree of abstinence from psychoactive substances. A recently convened SAMHSA Working Group, including people in recovery from mental health and addiction problems, generated a useful, common Working Definition of Recovery:

“Recovery is a process of change whereby individuals work to improve their own health and wellness and to live a meaningful life in a community of their choice while striving to achieve their full potential.”

The relevance of recovery and the role of abstinence for people working in and around harm reduction organizations and programs are as old as the movement itself. It is the essence and the very strength of many harm reduction programs that they are staffed with those who have a wide range of drug using experiences. For many, the devastation and loss associated with drug use, as well as the hope and strength in their own recovery, serve as motivation to help others and to be active in the movement. However, by immersing themselves in and around active drug use, many people also complicate and challenge their recovery. Their collective experiences are a vital source of wisdom, insight and strength. Working in harm reduction while in recovery poses a number of challenges for which there can be no single set of best practices, policies or right answers. Many must wear several different hats – as friends, peers, fellow activists, co-workers and supervisors. For those in recovery, meeting self-care needs in a harm reduction context can lead to confusion, discomfort and unintended consequences, but not necessarily due to any disjuncture in principles.

The secrecy, distrust, and silence borne of the pernicious stigma of addiction is still salient, even within the harm reduction community.
Environment
Indeed, there are plenty of friends and allies in harm reduction who have never had an unhealthy relationship with drugs and never will. Likewise there are many for whom the benefits of their drug use continue to outweigh any harms. And of course, there is a significant cadre of people for whom some or all drug use is simply no longer a viable healthy practice. For those who identify as being “in recovery” the resources available in and around the harm reduction movement can be as challenging and unhelpful as they are supportive and nurturing. Indeed in harm reduction one can find an environment that is just as supportive of one’s use as their abstinence. Many report having been witness to the escalation of drug use by people in the movement to the point that harm to self became evident, and yet for whatever reasons, intervention did not occur. The inertia created in which folks either don’t feel that they have a place to reach out, or that intervention is less likely to happen, deserves much more attention.

People in harm reduction understand that one’s setting, or environment, is critical in shaping the patterns and consequences of their drug use. The same is true for those in recovery. Harm reductionists, including those in recovery, are typically vigilant about the benefits of creating spaces for people that does not condemn, deprecate or punish their drug use. In doing so we often seek to prevent any real or perceived appearance that a given program is coercing people into drug treatment. This vigilance can unintentionally create an environment that can be stifling for the discussion and support of recovery, and one in which the people working in harm reduction programs may be even less likely to get assistance when they wish to have it. Likewise, efforts to create these spaces can create a false dichotomy between “active users” and “people in recovery.” Abstinence has always been part of harm reduction just as drug use can be part of recovery. Whether actively using or not, we aim to support the goals towards better health and wellbeing for all people.

Recovery Identity
Often people in harm reduction come to be known as “in recovery,” or “former drug users.” Frequently, clients, staff and colleagues may subconsciously make assumptions or invest meaning in these identities that may not be shared or accurate. This can also have the unintended consequences of closing the space for folks who are in recovery, especially if they have begun to use again.

Most harm reductionists are comfortable having very frank conversations with people in the community about all aspects of their drug use. And yet, when relapse occurs among people within the harm reduction movement, the dialogue often becomes coded, abstract, protective and whispered. The secrecy, distrust, and silence borne of the pernicious stigma of addiction is still salient, even within the harm reduction community.

It is a cruel and sometimes fatal irony that among the very collectives of people who are dedicated to open and honest discussions about drug use, drug users and addiction, we can also unintentionally create vacuums or spaces of silence. Even programs that are vigilant about having open and honest conversations about drug use among staff may have folks lingering in silence.

Coming to consensus was not an objective of the “Recovery Session” at the Austin conference. There was a unanimous sentiment, however, that the issue of recovery is in need of far more attention and dialogue. The lack of dialogue about recovery in harm reduction leads to missed opportunities and preventable losses. We cannot benefit from the experiences and wisdom of those who have left the movement, either because they did not find it to be a healthy environment or because they were taken from us. As we go forward, many questions remain:

Going Forward
• How can we create spaces for healthy dialogue about recovery and harm reduction?
• How can we better learn about the role of recovery in harm reduction from the experiences of those who have long been in the movement?
• What is the price one pays for disclosure of relapse, and what can be learned from those who have relapsed to reduce those costs?
• How can we better support recovery in synergy with harm reduction principles?
• Who and what resources are available to folks in the harm reduction movement who seek assistance with their recovery, and how might these be expanded?
• What are the specific features of harm reduction programs or organizations that enable or constrain people’s capacity to meet their own recovery goals?
• What practices do programs do well (or not so well) in acknowledging and supporting the recovery of all levels of staff and others?
• How can we identify and learn from missed opportunities to make treatment or other recovery supportive services more available and accessible?

Harm reductionists fight hard against dogmatic drug policy and practices,
and to validate the experience of drug users. Often, treatment, abstinence and recovery are an important part of that experience. There is a need to create and cultivate an environment that supports dialogue that is as open and candid about recovery as it is about drug use. Just as we fight against the labeling and assumptions about people who use drugs, we must take care not to make assumptions about folks who identify as being in recovery. One’s sobriety may be important to them, but it is no more a defining characteristic of their being than one’s drug use. Supporting sobriety is not a condemnation of drug user rights or liberties, nor is it at odds with harm reduction principles.

The SAMHSA Working Group also produced a set of “Guiding Principles of Recovery,” suggesting that recovery is best when: person-driven; holistic; supported by peers; supported through relationships; culturally-based and influenced; supported by addressing trauma; occurs via many pathways; involves individual, family, and community strengths and responsibility; is based on respect, and emerges from hope. The harmony with harm reduction principles is unmistakable.

Harm reductionists have all been witness to profound losses of friends, colleagues, family, and loved ones. Many folks in recovery have been to the brink and survived — some several times. There are far too many recent examples of long time harm reductionists who have been lost as their use was shrouded in secrecy. Each loss is devastating and we cannot bear to lose any more. Among friends, in programs and organizations, in gatherings small and large, a more open, candid and deliberate dialogue about recovery and harm reduction is vital to the health of the movement. If the recent conference session attendance and spirited dialogue is any indication, many are ready, willing and able.

Kevin Irwin is Director of Prevention and Harm Reduction Programs at AIDS Project Hartford [aidsprojecthartford.org]. Kevin wrote this article in consultation with panelists from the “Recovery Session” at the 8th National Harm Reduction Conference: Heather Edney, Mary Howe, Mark Jenkins, Mark Kinzly, and Jay Rucker.

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A Day in the Life of a Drug User Activist
A Prose/Poem
ISAAC JACKSON

An early August morning in 2010... I'm running late as usual. Six fucking AM ... where in the hell am I going again? SACRAMENTO!!!!!!! The radio is blathering on about the “don’t ask, don’t tell” debate. In jest, I put on the song “I love a man in uniform” and take another hit on the speed pipe. Shooting up will take too long and I need to take a bath, anyway. A few more puffs ... fade out Gang of Four ... fade in LSD (Lucy in the Sky with Diamonds) ...

As the golden reddish sunlight hits my windows, which are covered in cream-covered vinyl (shower curtains gone soft from summer sun), a strange light pushes out any traces of the preceding night’s neon light. I step into the water ... jump cut ... waiting for the bus and the phone rings ... Alexandra wants to know where I am ... “on the way ... hey is the bus there already ... can you guys pick me up at the corner of Van Ness and O'Farrell ... if you guys are ready to leave?” ... turns out it doesn’t matter ... the bus is not on time either ... GREAT ... jump cut ... bus hurtling across the San Francisco Bay Bridge in bright sunlight fade in...

We're on the way to our first demonstration in the capitol of the fuckin' golden state of California ... on a rented tour bus ... I feel the coffee and donuts coming on like microdot acid as we cross the bay in glorious motion ... I see the ancestor spirits of Alcatraz: prisoners, Indians, angels. I see the merry pranksters ahead on the road to knowhere.

By the time we get to Oakland I'm down. But what a rush. All aboard: fellow drug user activists from OASIS join us near the north Berkeley BART. I'm still hungry for junk food. We go on a short expedition to the nearest grocery store. Obviously strangers, crack heads from the night before follow us into the store, curious about who are these red-eyed conquistadors ... chips, soda and a strong wind and we're off ... we share tobacco and stagger back to bus.

Bus ride is wonderful ... meeting our counterparts for the first time ... the OASIS CREW IS COOL ... THEY ARE WORKING ON HEP C ISSUES in Oakland. We have placards and signs we made in an earlier drug users' union meeting ... their placards are better than ours BECAUSE YOU CAN READ THEM FROM A DISTANCE!! Ours only work if you have the vibes and stand close to us ... we are not experienced ... jump cut ...

Sacramento is so clean... the sand in the park across the street from where the state legislator meets is sooo clean ... my cat would love it here (I think).

MOMS AGAINST THE DRUG WAR organized this demo and we were invited to help out. I wasn’t sure how a bunch of drug users from the SF Bay area would be welcomed here. But all is cool. They like us and make us feel at home. On the other side of the park Yahoo! has a table pushing sugar (cookies) and liquids. I stop by and grab a handful. There must be a junk food god or goddesses ... then the demo starts.

Tearful sad testimonies from mothers whose sons and daughters have died for no reason at all except that the drug war is insipid and mean. I am asked to say a few words. Unsure how to respond, I tell the assembled crowd that the drug users’ union is here so that no one should ever have to die alone. People agree. The air is heavy and then the air is light: dry, transparent and rising with the sun. Time to go into the State office building to lobby legislators. I beg off since being up all night is catching up with me and I just sit on the official concrete gray government steps / moving every minutes to stay in the shade. Eventually it’s high noon. No more sun-shade. I move to the litter box park. A couple of state troopers ride by on horseback. Just don't shit in front of me, Mr. Horse or I'm going to get dope sick from your whiff of authority. They read my placard and say something to each other and keep going. No shit. Good.

Silently, park rangers come and pick up all the litter left by the demo and soon it is like it never happened. But the world knows that it did. The sun sets. We go home. Tomorrow another junky will die and a mom will cry and I’ll get high and the sun will rise and bleed reddish light through my window. But what is different is that a group of us registered a complaint to the state of California / a group of us said that when we wail over unnecessary deaths, we no longer wail alone / we the mothers of the drug users and the drug users wail together / and the politicians may pretend no one ever asked them to stop / or that we caused each other to cry / we now know that isn't true/and we did say: Stop The Drug War that day in Sacramento 2010 / and we did vow that no one ever dies alone or in vain/not to us, anyway...

Isaac Jackson is a blogger and Senior Peer Organizer for the San Francisco Drug Users’ Union [sfdrugusersunion.org and on twitter @drugusersunion]
What Health Reform Means for Drug Users and Harm Reduction Organizations

RACHEL MCLEAN

More than a year after the passage of the Patient Protection and Affordable Care Act (ACA), also known as health reform, many drug users and harm reductionists still don’t know what’s in the bill, let alone how it can benefit their friends, families, clients, and communities. This is not surprising; health reform is complicated. But there’s no need to understand it all. What matters for harm reductionists is that health reform has the potential to dramatically improve access to preventive services, mental health care, drug treatment, and primary care for drug users. However, this will not happen on its own. To make health reform work for us, we have to work for it.

In this article, I will talk about a few key pieces of health reform most relevant to harm reduction organizations and present some ideas for moving us closer to a society where drug users receive the compassionate, quality health care they deserve.

Major Provisions of Health Reform

Coverage expansion
A major goal of health reform is to increase the number of people in the U.S. who are insured by expanding coverage in three different ways.

Think of the coverage expansion for people who are currently uninsured as a Neapolitan ice cream sandwich. On the bottom is the vanilla; the middle tier is the strawberry; the top layer is chocolate.

The Vanilla: In 2014, all U.S. citizens with an income less than 133 percent of the federal poverty level ($14,483 in 2011) will automatically be eligible for Medicaid. Except for our friends and family members who are undocumented or incarcerated (more on that later), a lot of people we know and serve will suddenly have health insurance regardless of their disability status. ("Legal" immigrants will continue to be ineligible for Medicaid for the first five years that they are in the U.S.)

The Strawberry: At the same time, all U.S. citizens with an income between 133 percent and 400 percent of the federal poverty level ($14,484 – $43,560 in 2011) will get subsidies and tax breaks to help them buy coverage through health insurance “exchanges” (i.e., centralized marketplaces for buying health plans).

The Chocolate: U.S. citizens with incomes greater than 400 percent of the federal poverty level will be able to buy their own insurance or be covered by their employer but will not necessarily receive any new subsidies or tax breaks for this purpose.

Coverage for people already insured through their employer will basically stay the same.

Prohibitions on discrimination for pre-existing conditions
Already under health reform, children can no longer be denied insurance due to “pre-existing conditions” (e.g., substance abuse, mental illness, HIV, hepatitis C); in 2014, the same thing will be true for adults. Health plans will also be forbidden from kicking people off of their insurance plan once they get sick (a practice known as rescission). In the meantime, the federal government and some states have made available health plans for people who have been denied insurance for having a “pre-existing condition.” Unfortunately, the monthly premiums for these pre-existing condition insurance plans (PCIPs) are still unaffordable to many (e.g., $460/mo.) so enrollment in the plans has been low.

Investment in prevention
Health reform makes a significant investment in public health and disease prevention. Under health reform, all new health plans (including expanded Medicaid, Medicare, and health plans participating in the health exchanges) will be required to offer a basic package of “essential benefits.” In its definition of which benefits are essential, the federal Health and Human Services agency (HHS) includes behavioral health services (mental health and drug treatment). HHS has also said that health plans must offer all preventive services that are recommended by the U.S. Preventive Services Task Force (USPSTF), without a patient co-pay. The good news is that the USPSTF recommends hepatitis A and B vaccination for at-risk adults, following CDC guidelines, which means these vaccinations will be free for drug users and other people newly insured under health reform. The challenge is that USPSTF does not currently recommend other preventive services that are important for drug users, including hepatitis B and hepatitis C testing.

Investment in primary care
Health reform also invests in training primary care doctors in public health and infectious disease and commits $11 billion dollars over the next ten years to supporting federally qualified health centers (FQHCs) and other community clinics to increase their capacity to deliver primary care for newly insured low-income individuals. Within FQHCs, health reform sets up incentives for creating what they are calling “patient-centered medical homes,” which, if you read the HHS...
guidelines, reads a lot like a harm reduction based model for structuring and delivering health care. The basic idea behind this project is to provide a single place for coordinating the care for people with two or more chronic health conditions, including mental illness, substance abuse, asthma, diabetes, hypertension, and HIV. (Hepatitis C is not currently considered a qualifying condition but it could be if harm reductionists make it one!)

Limitations
Before we go on, let’s pause and talk about what health reform does not do for our communities, particularly for our friends and family members who are undocumented and/or incarcerated. Health reform does not expand coverage for undocumented immigrants. In fact, the ACA bars undocumented immigrants from Medicaid and from purchasing insurance through the health exchanges. (It is not clear to what extent the government intends to dedicate resources to establishing applicants’ immigration status.) However, FQHCs and other community clinics that currently serve persons who are undocumented will continue to be a vital safety net for these individuals and it will be our shared responsibility to ensure that people who are undocumented get the care they need.

In general, health reform will also not cover people in prisons and jails during their period of incarceration. (Some states allow people on Medicaid to put their enrollment on hold while in jail, rather than terminating their coverage. Similarly, some prisons allow people to begin the Medicaid enrollment and eligibility process in preparation for their return to the community from prison or jail.) For this reason, it will still be vital to work to improve the quality of preventive services and care in jails and prisons and to connect community clinics and public health departments with prison and jail health providers.

Making Health Reform Work for Harm Reduction
No matter what, health reform, if implemented as written, will benefit low-income people, drug users, and people with HIV and hepatitis C all over the United States. The challenge is that even if drug users have health insurance, doctors are not necessarily suddenly going to be nonjudgmental when dealing with injection drug use or crack use or hepatitis C. For this reason, it is up to the harm reduction community to help primary care clinicians and other health professionals working in FQHCs and other health care settings become friendlier to drug users and other members of our communities.

My question is: What are we going to do make health reform work for drug users and other communities we serve? Here are a few ideas. Please share your ideas, too.

Train health professionals to provide drug user-friendly care
One idea is to synthesize into a set of clinical guidelines what we already know about delivering tailored, harm reduction-based preventive services, mental health care, drug treatment, and health care to drug users. A draft could be developed based on existing guidelines for infectious disease testing, prevention, and treatment, syringe exchange, drug treatment, overdose prevention, soft tissue infections, etc. and fill in remaining gaps. Once developed, the draft could be reviewed, changed, and ultimately endorsed by key local and national organizations, including drug users’ unions, front line workers, health professionals, researchers, and others with expertise in serving drug users.

Even with clinical guidelines, research shows that written information on its own does little to change provider behavior. Instead, approaches that have been shown to work for providers include reminders (such as “pop-ups” in electronic medical records) and one-on-one visits and mentorship from another clinician. Any new clinical guidelines would need to be followed up by hands-on training for doctors and other health professionals in providing culturally competent care. I am not sure who should do this, but the time to start thinking about this is now.

Get paid for your expertise
Harm reduction organizations may want to explore making their services and expertise billable under Medicaid, Medicare, and private health plans. For example, if a local clinic wanted to treat hepatitis C but lacked experience providing social support to current and former drug users, could a harm reduction organization provide their expertise in providing peer support groups and patient navigation and get paid for it? Maybe harm reduction organizations could get paid to help doctors figure out how to write nalox-

The challenge is that even if drug users have health insurance, doctors are not necessarily suddenly going to be nonjudgmental when dealing with injection drug use or crack use or hepatitis C.

and health care to drug users. A draft could be developed based on existing guidelines for infectious disease testing, prevention, and treatment, syringe exchange, drug treatment, overdose prevention, soft tissue infections, etc. and fill in remaining gaps. Once developed, the draft could be reviewed, changed, and ultimately endorsed by key local and national organizations, including drug users’ unions, front line workers, health professionals, researchers, and others

Demand that policies implementing health reform serve the needs of drug users
Another thing harm reductionists can do is to keep close tabs on all the health reform-related guidelines and regulations coming out of the federal, state, and local governments and make sure that they serve the
interests of drug users and other communities. While reading draft regulations may sound as fun as filing your taxes blindfolded, getting a good policy on the books (and then getting it implemented) can be a powerful way of making a big, “upstream” difference. Policy work is not for everyone, but many harm reductionists are already adept at arguing with local boards of supervisors about the need for drug treatment and syringe exchange. Participating in the implementation of health reform is an extension of that work and is just as important. 

**Do something!**

Health reform has incredible potential to increase access to preventive services and health care for drug users and for many low-income people in the U.S. who have been uninsured for too long. But for health reform to work for us, we have to work for it. Whether by developing and reviewing clinical guidelines on how to deliver comprehensive care to drug users, training health care providers on how to implement those guidelines, contracting with clinics and health plans to provide direct services, commenting on draft regulations, or coming up with fabulous new ideas for how to make the most of health reform, there are important roles for everybody. The important thing is to get involved.

For more information about health reform and how to get involved in its implementation, see the websites of Trust for America’s Health [tfah.org]; the Kaiser Family Foundation [kff.org]; and Families USA [familiesusa.org].

**But for health reform to work for us, we have to work for it.**

Rachel McLean, MPH, has been working in harm reduction for 15 years and founded the Drug Overdose Prevention and Education Project. You can read her article, “Tales of a Housepunk Nothing, or I Was a Twenty-Something Outreach Worker” in the Spring 2002 issue of Harm Reduction Communication [issuu.com/harmreduction/docs/spring2002].

**Notes**

1. In 2011, the federal poverty level for an individual is $10,890; 133% of the federal poverty level is $14,483.
2. Health reform also invests in prevention through the development of a National Prevention Strategy, “to shift the nation from a focus on sickness and disease to one based on wellness and prevention;” the creation of a Prevention and Wellness Fund, to support public health infrastructure; and the creation of Community Transformation Grants, to address structural and community-level determinants of health.

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Harm Reduction Coalition has an exciting new line of t-shirts and sweatshirts that are perfect for wearing on outreach, at the syringe exchange, or pretty much anywhere. Oh – and we’ve got sexy “I love drug users.” undies too! They’re all great conversation starters and a fun way to challenge drug-related stigma.

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The early days

I learned about harm reduction in the early '90s as a way to address the spread of HIV and Hepatitis C. I was fortunate to learn from Edith Springer, an incredible teacher and passionate woman. I was excited to learn something new, something that could reduce the spread of this deadly disease, and yet was surprised that it was not being commonly discussed in the medical field. To me this was huge! To be able to provide services that would not only help people from becoming infected, but also get them to eventually come back for information, services, and resources was such a great idea.

At that time my focus was as a social worker, working the frontlines of the AIDS epidemic; my interest in learning harm reduction principles and techniques was solely directed at stopping the spread of the horrific, terminal illness caused by HIV infection. Although HIV and sexual risk was my focus at that time, and I was learning about harm reduction within that context, I could see the benefit in the area of substance use as well (preventing overdose was not part of what was presented at the time; these were "Social Work and AIDS Conferences").

In later years, when our population changed from gay men to predominately IV drug users, the information was invaluable. But in our county, we had no needle exchange program and little to no talk of harm reduction. Orange County, California is a very conservative community. I found myself among the big proponents of "Just Say No" ideology — people who believed that if we provided sex education, condoms, or birth control, we were "condoning" or even encouraging sexual activity among young people. We are light years behind Los Angeles or San Francisco (same state), to say the least, regarding social issues. It was clearly going to be an uphill battle.

We help them from where they are, hoping always for steps, no matter how small, that lead to an improved life for our clients and those around them.

My son, Jeff, was alive then. He was 10 years old when my career led me to help those marginalized, to put it mildly – folks who were considered "those people." People who chose their fate, and therefore deserved their suffering. Respected public leaders, especially evangelical leaders, were continually blaming HIV-infected people for bringing their fate upon themselves. These were very tough times for the gay community, and those in the medical and social service professions trying to help them. As I look back, I can see how the same situation is playing out with drug users. After all, drug users, drug addicts, CHOOSE to take drugs, don't they? Just like homosexuals CHOSE to have sex with same-sex partners, which led to their infection with HIV. Since those early days, although there are still struggles, there has been a lot of progress made.
a mom without her child. You see, my boy is one of “those people.” He was severely addicted. He suffered and fought very hard to change that fact, and he lost. On August 5, 2008 he died of an accidental overdose.

Part of my work now is focused on helping others who are struggling with their drug use to stay alive and healthy long enough for the time to become right for them to make changes in their use. I work now in the hopes that people can achieve recovery without the serious illnesses that can come from their drug use, such as HIV, hepatitis C, and lesser but still life threatening conditions such as endocarditis.

Probably as a result of my work in HIV, my son knew not to share needles. Once, when he was on a run, refusing to come home, I left him clean needles outside his old bedroom. Every time I did this, I also included a card or note begging him to come home, to get help. Although the note was always unopened, he found a way to get there, to get the needles. One thing I am grateful for is that when Jeff died he was both HIV and hepatitis C negative.

I believe that harm reduction is still underutilized. Why? Because many still believe that it “encourages” drug use. Some of my friends said similar things to me when I provided the needles for Jeff. His drug counselor, however, told me that if it were his son, he would do the same thing.

**Full circle**

There is a very safe, inexpensive drug that should be made available to all users of opioids, whether for “legitimate” medical reasons, or for those physiologically addicted. When used during an overdose, this drug, naloxone is available by prescription only. To me, it is insanity that a form of ‘treatment’ that can save lives is withheld — actually made illegal in order to send some moral message. This is criminal. Aside from the general absurdity of this line of thinking, the reality is that no opiate-dependent drug user would intentionally use or over-use naloxone because it would, in effect, put them into an immediate state of withdrawal — a very painful condition.

I have talked with hundreds of people who have been the one to find their friend, their loved one, experiencing an overdose. They tried all the usual ‘remedies’ — cold water, ice, slapping them. However, all these actions do is waste precious time. If they had access to naloxone and knew how to use it, their loved one could have been saved. Making naloxone widely available — especially to people who use drugs — is simply the humane thing to do!

It is also abhorrent that people are being released from jails and prisons without an in-depth “exit interview” and transitional services. The rate of overdose is at epidemic proportions and many of these overdoses occur after a period of abstinence, often as a result of incarceration or drug treatment. Yes, overdose is mentioned — sometimes, but not nearly enough. People must be made aware of their sky-high risk for overdose in these situations, even after only a short period of abstinence, and they must be given the tools to keep them safe — knowledge and naloxone.

Call me cynical, but in some cases I believe that policies denying access to naloxone and other vital resources are an extension of a “those people” type of mindset among those who interfere with the simple humanity that is harm reduction: Just one more junkie off the street, right?

It is through these understandings that I realize the ways in which I have come full circle. The same ignorance that caused the infection of
Innumerable people with HIV and other diseases is now causing the spread of those same diseases, in addition to actually killing people at epidemic proportions through drug overdose. The people who are getting sick and dying are our sons and daughters, friends, sisters, brothers, even mothers and fathers.

I hear it every day. I get an average of three phone calls or emails EVERY DAY about another loss to overdose. These are people with value, with loved ones, with gifts to contribute. Why can’t we keep them alive, reduce the devastating negative social and emotional consequences of drug use until the time comes when they find their way, or we care enough to invest in better treatments, and finally a cure? I truly thought that this would happen in Jeff’s lifetime. It didn’t. Maybe it will happen in the life of someone you know and love.

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Inside Out/Outside In
The Vicious Cycle of Stigma
LOUIE JONES AND ERIK HABERLEN

In June 2011, I was supposed to sit down with New York City-based drug user activists and organizers Louie Jones of Users United and Eric Haberlen of VOCAL-NY to talk about their perceptions on drug-related stigma … but unfortunately I got the flu. So instead, I sent them some questions to think about and just let them kick it on their own. Here’s a short excerpt from their conversation.

— Emily Winkelstein

Q: The word “stigma” is being thrown around quite a bit lately, and I think that it often gets confused with discrimination when it can be a lot deeper than that. Can you talk a little about what drug-related stigma means to you and what you think it is important for people to understand about it?

LJ: Yeah, I’m glad that we can make this distinction because there are so many [kinds of stigma] – HIV/AIDS-related stigma, race, class – but we’re talking about something that stigmatizes, criminalizes, vilifies, demonizes drug users and it’s targeted at drug users, there’s no mistake about it. No matter what color, what class, what race. You know that, and you feel it, even if you can’t articulate it — you know it has something to do with the fact that you use drugs. It shows up in places where drug users go for their healthcare, or their housing, or other opportunities or rights, that people take as privilege or take for granted. We know that because we reveal, we disclose, trying to be honest — I don’t want to lie no more, you know? But, it’s gotten to the place where once it’s out that I’m on methadone even — something that’s legal, something that I do by choice, that’s medically approved, medically supervised and research driven — it has its stigma.

EH: You said it’s uncomfortable to disclose and the reason a lot of people don’t want to disclose is because of the stigma. It’s probably fair to say that most drug users, whether or not they’re aware of what stigma is and what it does …

LJ: … they know how it feels.

EH: Yeah, they know that people are going to treat them a certain way and have certain attitudes about them because of the drugs they use, not because of who they are … that’s what stigma is; it’s a social process, where people get marginalized.

LJ: Right … and it’s almost being supported. It’s almost like [drug users] are the problem.

EH: And that’s what stigma is, it’s the popular belief, that the average citizen will agree with it and not see anything wrong with it.
LJ: [Stigma] shows up as: if you are on drugs — supervised, not supervised, anything to do with drugs — there's already thinking about who you are, what you're about, it's sort of justified — signed off by society, that they're protecting us from those users.

EH: Yeah, and it's really unfair and unjust that due to stigma, an individual is defined by the substance they use. Not by what they do, who they are, their actions, their thoughts, how they treat other people — they're defined by the drug...[Stigma] is a preconceived notion about who you are and what you're gonna do.

LJ: Exactly! That's a good definition. Drug-related stigma is about drugs and how it labels people, and gives a dynamic with stigma where people don't feel comfortable disclosing that they're a drug user so they don't feel comfortable getting the help that they require ... or they don't feel comfortable talking to people and figuring out what it is to moderate their use... which can lead to overdose, death, will abuse that too — you're an addict. That's what it will come to.

EH: One thing before we move on, I think it's important to recognize that drug users aren't innocent either, I mean, we stigmatize each other. Drug users stigmatize each other. Someone who uses heroin may say, "Oh no, I don't fuck with crack, I don't mess with 'crackheads'".

LJ: Yeah..."I don't take it through the pipe, I don't smoke through the pipe, I just roll it up in a blunt..."

EH: It's like when an abused child grows up to beat his kids...where someone who's oppressed looks for someone that's down the food chain that they can oppress.

LJ: It's true.

EH: A lot of it is human nature.

LJ: It's the internalization. You're looking down on me? I've got someone I can look down on too now.

EH: Yeah, and that brings us to the role of internalized stigma. I think ... that a sign of internalized stigma is ... you know, any heroin user that says they shoot once a month but they shoot once a week — that would relieve the pain that you have or stabilize you psychologically — mental health issues are compromised as well. Especially with medications that they say or feel, because of your background...they will deny you because there will be an assumption or preconceived idea that you people preconceived notions as to who you are without knowing who you are ... And, the stigma does, for some users, get internalized as well.

EH: Yeah, and it's a lot broader because all drug use is stigmatized to certain degrees, and it's generally internalized by everybody...

LJ: It gets deadly, I mean, stigma kills. Stigma labels and emotionally it has an effect as well...people hiding from their family members — it shouldn't be the case.

EH: Let's elaborate on that. A huge thing that we say is that stigma kills, but I think it would be good if we could elaborate on that and give examples so people can make a clear connection between stigma and the actual cost of human life...in reality. There's poor decisions ... it can lead to people not feeling comfortable, because of stigma, going to get clean syringes which can lead to transmission of diseases ... and again, potentially death.


EH: Or you might be denied certain services that you require.

LJ: And denied certain medications that you have not abused, and have no intention to abuse, and have a right to — that would relieve the pain that you have or stabilize you psychologically — mental health issues are compromised as well. Especially with medications that they say or feel, because of your background...they will deny you because there will be an assumption or preconceived idea that you

And that's the most harmful thing — even more than the drug itself — it's the emotional feeling that people have about themselves, how they view themselves, how they believe people view them.
eight bags a day — and you know, we've all done it...

LJ: [Laughing] Right... it's funny because it's so true.

EH: But it's an indicator of internalized stigma. The internalized stigma makes people feel like, "Man, I'm a real piece of shit. I'm a scumbag because I'm doing heroin."

LJ: And that's the most harmful thing — even more than the drug itself — it's the emotional feeling that people have about themselves, how they view themselves, how they believe people view them. I think it's the worst harm ever — more than any drug that a person could choose to do, it's the emotional, internal feelings that they have towards themselves, as a human being, as a person.

EH: And you and I both know that, I don't want to say the majority, but a lot of the drug users we know are street pharmacists, they have issues that they're self-medicating. A lot of times it's things like depression, and the reason they even started taking the drugs, continue to take the drugs, is because it helps with the depression. But unfortunately, the internalized stigma compounds it and makes it worse, which actually makes the need for the drug worse. It's a vicious cycle where the stigma makes the drug use worse, which might lead them to behaviors that are stereotypical.

LJ: It's like a self-fulfilling prophecy ... what people are saying, it's like a role that you begin to play out yourself.

EH: And that's because of internalized stigma ... you say, well, everyone expects me to do it — so, ya know — fuck it, I'm gonna do it'. People internalize it ... it's like lowered expectations.

LJ: The beautiful thing about harm reduction is that it helps you look at your drug use and to look at yourself as an individual. Not just fall in line, because "we're all the same". No — we're not all the same. We're saying [drug users are] individuals — that there are all sorts of reasons as to why people would choose to use, and not everyone that uses is someone who can't be productive and responsible. They may never be acceptable by societal standards — I may not want to be accepted by societal standards — but I can be responsible, I can be active, I can be productive.

EH: I'm sure we all know people who have held long-term habits, you know “addictions”... people who have used for years and maintained a job, paid their bills, hung out with their kids, put in quality time with their family.

LJ: That's right ... good mothers, good fathers.

EH: I'm sure every single person knows someone, but we may not know that they're doing it.

LJ: Right, and good citizens in society ... these people are driven as the silent majority, really. It could be a white middle-class woman in the suburbs, who needs to have her Xanax ... you know what I'm saying? On the real.

It's not so much the person and the drug that they're taking; it's also what else is going on in their lives. Harm reduction is about a holistic way of looking at a person. When it comes to drugs — who really has the blinders on? Is it the drug user or is it society? If people started looking at people as people who deserve love and compassion and reasoning, then you're not looking at what they're using ... that is symptomatic of something else.

EH: If we had a society that treated people as people and looked at every person as an individual, capitalism and society as we know it would grind to a halt; it depends on people being oppressed and marginalized.

What do you do personally for internalized stigma? How do you combat it, work with it, work around it, deal with it and live with it?

LJ: That's a damn good question ... it really is. I'm still working with it ... it's very hard. And I don't have any clear answers ... except for what I'm just learning, even though I've been around harm reduction for quite some time. From when we were giving out syringes ... and once we realized that there were neighborhoods that we weren't gonna get any kind of syringe exchange program, that was still a novelty at the time. Harm reduction was still "us versus them" ... the abstinence-based groups and those of us ... and people thought that harm reduction meant drugs, drugs and more drugs. We, ourselves had to grow and evolve too, to understand for ourselves what it meant to out ourselves as users.

EH: What did that involve?

LJ: It involved me saying what I needed to say as a person as they were whispering, HIV ... or I've got HIV. What I had to do personally was break my own silence about the shame that I felt and the blame that I felt, when it wasn't about any of that shit. It was about me not knowing, it was about ignorance, it was about a lack of honest information and education around how one gets HIV ... and/or understanding what were the drugs I was using...what were the choices I could make in regards to the drugs. Something like manage my drug use? Either you did drugs, or you didn't do drugs. That meant then that you either were acting out the stigma role to the fullest, or you were the good NA person or treatment product, “we produce for you today, Mr. Acceptable to Society!” with the haircut and the suit.

What I personally had to do for myself, as early as I was exposed
to what Edith Springer was talking about and HRC and others that were courageous, saying look at the bio-psycho-social phenomenon. It's like the chicken and the egg. Is it the housing or is it my mental health stuff... even without any drugs? Or is it the need for medication and decompensating and not knowing that? Or is it the neighborhood I'm living in and the kind of environment I'm exposed to coming up as a child, and the people I'm surrounded by. It was very complex! Instead of just saying you're using drugs, then boom! You get punished. I realize on a personal, personal level, that I'm still reflecting and looking at the right action I need to take. That there are places where I need to stand up and speak out, and say, I am a drug user. That's the truth. That's my identification.

EH: And there's probably some places where you shouldn't stand up.

LJ: Yes, there are some places where you shouldn't. You learn. I have a lot of those experiences too (laughs).

EH: I think part of dealing with the internal stigma is realizing the difference, because there are two sides. You can internalize stigma and say I should never disclose. Then because of internal stigma you try and combat it and you go too far and you say, I should always disclose — even when it's not in your best interest.

LJ: Right, and I've been to both spectrums at some point in time. Especially because once I was able to open up and realize I could break my silence about my being HIV and an active drug user, I also had to respect the rights of anonymous drug users, who had the right to be anonymous... that you didn't belong because you didn't want to disclose — NO. Because then that puts me in the driver seat of who's got the power and also, then I'm judging...

EH: Yeah, you're stigmatizing...

EH: I know for me personally, that for me to fight the internalized stigma and come to terms with my drug use and not internalize it and oppress myself is that, at one point before I really came to a more enlightened place in life, I let my drug use define me. I took the fact that, okay, I inject heroin every day, so, I'm a drug user, I'm a junkie, this is what I do. And everything became subordinate to the heroin use, probably because I internalized that stigma and these preconceived notions that I had been given and force-fed through media, and "officer friendly" and society at large... that it's all or nothing. Either you're a junkie and a heroin user, or you're a sober person. There was no grey area. So, I internalized that stigma and everything became subordinate... it all became about doing dope, pretty much to any cost, aside from very few things that I hold dear in my life, which were just personal morals. But, I had to come to a point where I said, you know what, I'm not a junkie, and I'm
not a heroin user – I am a father, I am an artist, I’m a guitarist, I’m a student, I’m a lover, I’m a fighter, I’m a son, I’m a brother, I’m someone who reads books ... I’m a pizza maker, I’m a fighter for social justice, I’m a liberator and dot, dot, dot ... and when I want to – I get high. It’s as simple as that – its one part of a much larger picture. And, it’s probably actually a very small part.

LJ: Right ... and you learn how to prioritize. Something that speaks to me in regards to what is healthy in my drug use is balance, and what that may mean to me or to you could be totally different things. What balance more than a person of color, I’m a person of consciousness – that frees me, man! I’m a citizen of the world – that frees me!

EH: You can’t let any attribute define who you are, because it consumes the other parts.

LJ: Absolutely. So when I say, I’m a drug user, I do have to qualify that, because I’m more. That’s an identification, and with it [comes] all the struggles that we have. But then, there’s also the identity of a guy that I’m learning for the first fuckin’ time, called Louie, ya know? Who wasn’t born with a spike in my arm, that has a mother he loves I had to come to a point where I said, you know what, I’m not a junkie, and I’m not a heroin user – I am a father, I am an artist, I’m a guitarist, I’m a student, I’m a lover, I’m a fighter, I’m a son, I’m a brother, I’m someone who reads books ... I’m a pizza maker, I’m a fighter for social justice, I’m a liberator and dot, dot, dot...and when I want to – I get high.

may mean to me is that I can’t make the fuckin’ appointments that I was missing all the damn time because I had put use before my health, I had put use before my family, I had put use before anything and everything, just like you said. We got that in common, no matter what ... we may come from two different hoods, but what makes us one and connects us, is the fact that we’ve all had to come down a road to place of realization, a moment of clarity or however you want to put it. It’s beautiful the way you said it – I love that freedom that I have of choice. I love that I’m not going to be identified, or labeled by any one thing. I’m more than anything (who has passed) ... that taught me some things, like you said, to have morals, values.

The thing is that I’m not just any one thing, I’m multiple, and things that I haven’t even discovered yet. There’s unlimited possibilities. I really am a possibility – I’m not just “having potential”. I hate that shit ... sometimes it sounds very patronizing ... you know when someone says, “You have such potential...” Fuck that! That’s code word for, “You’re a fuck up!”

EH: “Potential” is a euphemism for not doing shit ... for no ambition.

LJ: What I’m saying when I say I’m a harm reductionist is that I’m a responsible user, and that users can be responsible.

EH: Another thing that has helped me battle my internalized stigma is being able to identify as a drug user – and socialize with other drug users and have it be an identity and create new identities, new archetypes that aren’t negative.

It’s been liberating for me to align myself with other users, for instance the Users Union, the users groups, support groups comprised mostly of users and even better led by users. But I think it’s important and liberating for us to get together and say, you know what, we do use drugs ... and to make new examples and create new dynamics for users interacting with each other and interacting with society at large, and people who have never used drugs or have used drugs in the past and are abstinent.

LJ: And we’re not bad people. We’re not taking the position that it’s about, or we’re about, promoting drugs. That’s the experience ... unfortunately.

EH: Yeah, we’re about promoting dignity.

Louie Jones is an organizer with the Users United Users’ Union. He organizes drug users around public health and social justice in New York City.

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Editorial Policy

Harm Reduction Communication aims to:

- Provide a forum for the exchange of practical, “hands on” harm reduction techniques and information
- Promote open discussion and reflection on theoretical and political issues of importance to harm reduction and the movement
- Inform the community through resource listings and announcements of relevant events
- Document the struggles, experiences and lessons of our movement as a tool for strategy-building
- Ensure that our history is not erased.

Harm Reduction Communication is a product of the harm reduction movement — it is not written by Harm Reduction Coalition, but by the people on the ground making harm reduction happen. In our editorial role, the Harm Reduction Coalition is committed to presenting the views and opinions of people who use drugs, former users and people in recovery, people accessing medication-assisted treatment, people living with HIV or hepatitis C, sex workers, incarcerated or formerly incarcerated persons, outreach and front-line workers, and others whose voices have traditionally been marginalized or ignored. We aim to provide an outlet for exploring harm reduction issues in an honest and critical way — with full respect for the messy, complex, vulnerable, dynamic, hopeful and inspiring nature of what we do and how we do it.

Since a large part of harm reduction is about casting a critical eye toward the thoughts, feelings, and language we have learned to have and use about drugs and people who use drugs, Harm Reduction Communication assumes that contributors choose their words as carefully as we would. Therefore, we do not change ‘addict’ to ‘user’ and so forth unless we feel that the author truly meant to use a different word, and contributors always have last say.

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Please write with your comments, feelings, and responses — we want to hear from you.

If you would like to submit an article, or photos or artwork, we would be happy to look at your material. HRC gives a voice to communities that are ignored by conventional media: people who use drugs, people of color, individuals who are living with HIV or Hepatitis C, and lesbian/gay/bisexual/transgender individuals. If you have never written something for publication, assistance is available: just ask for it. You can call the editor at 212 213 6376, or include a note with your submission.

Send submissions and correspondence to hrc@harmreduction.org or by mail to: Editor, Harm Reduction Communication, Harm Reduction Coalition, 22 West 27th Street, 5th Floor, New York, NY 10001.
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The Harm Reduction Coalition is a national advocacy and capacity-building organization that promotes the health and dignity of individuals and communities impacted by drug use. Harm Reduction Coalition advances policies and programs that help people address the adverse effects of drug use including overdose, HIV, hepatitis C, addiction, and incarceration. We recognize that the structures of social inequality impact the lives and options of affected communities differently, and work to uphold every individual’s right to health and well-being, as well as in their competence to protect themselves, their loved ones, and their communities.

Harm Reduction Coalition promotes the use of harm reduction as an alternative to traditional coercive and punitive drug policies and approaches. Harm reduction is a set of practical strategies that reduce negative consequences of drug use, incorporating a spectrum of strategies from safer use, to managed use to abstinence. Harm reduction strategies meet drug users “where they’re at,” taking a nonjudgmental stance to addressing conditions of use, along with the use itself.

Harm Reduction Coalition works to fulfill its mission through five core programs:

- Capacity building assistance and training to both organizations and individuals on issues relevant to drug user health and well-being, harm reduction service provision, and organizational and professional development.
- Policy analysis and advocacy at the local, regional, national and international levels.
- Overdose Prevention Projects that provide education and training on overdose prevention and response.
- Publications, reports, and other topical materials to communicate critical knowledge, skills and education.
- National and regional conferences, community forums, and coalitions.

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