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ABSTRACT

Harm reduction is a controversial model for treating drug users with little formal research on its operation and effectiveness. In order to advance the field, the authors conducted participatory research with 120 clients of harm reduction using nominal group technique to develop culturally relevant outcomes to measure progress. Second, the authors conducted focus group interviews with a different group of clients to help validate the outcomes. Third, the outcomes were used in an evaluation of the largest harm reduction program in New York City with a representative sample of 260 who completed a baseline, post and six follow-up assignments. The participatory research resulted in outcomes of ten life areas important to drug users. The evaluation results showed that the program participants make positive improvements across all outcomes with the most substantial progress made in how clients dealt with drug use problems. Along with their participation in the program, progress in some outcomes was also associated with clients' type of drug use (i.e., stable vs. chaotic) where more stable drug use was associated with the kinds or numbers of services received or the length of time in the program. This was attributed to the service delivery model of harm reduction in which clients are less inclined to associate their successes with a single worker in the program or a single service or intervention received but more with their association with the program as a whole. (Contains 13 references and 3 tables.) (Author/GCP)

Does Harm Reduction Programming Make a Difference in the Lives of Highly Marginalized, At-Risk Drug Users?

by

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Does harm reduction programming make a difference in the lives of highly marginalized, at-risk drug users?

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Abstract: Harm reduction is a controversial model for treating drug users with little formal research on its operation and effectiveness. In order to advance the field, we first conducted participatory research with 120 clients of harm reduction using nominal group technique to develop culturally relevant outcomes to measure progress. Second, we conducted focus group interviews with a different group of clients to help validate the outcomes. Third, we used the outcomes in an evaluation of the largest harm reduction program in New York City with a representative sample of 260 who completed a baseline, post and six follow-up assessments. The participatory research resulted in outcomes of ten life areas important to drug users. The evaluation results showed that the program participants make positive improvements across all outcomes with the most substantial progress made in how clients dealt with drug use problems. Along with their participation in the program, progress in some outcomes was also associated with clients' type of drug use (i.e., stable vs. chaotic) where more stable drug use was associated with better ways of making an income and types of housing. Surprisingly, progress was not associated with the kinds or numbers of services received or the length of time in the program. This was attributed to the service delivery model of harm reduction in which clients are less inclined to associate their success with a single worker in the program or a single service or intervention received but more with their association with the program as a whole.

Introduction

Harm reduction programs operate with the assumption that some people who engage in high-risk behaviors are unwilling or unable to abstain. Using a "low-threshold approach," they do not require that clients abstain from drug use in order to gain access to services, nor expect adherence to one service to be eligible for another. Rather than having abstinence goals set for them, clients in such programs take part in a goal-setting process, an approach that has been shown to correlate consistently with retention and success (Ojehagen & Berglund, 1989; Sanchez-Craig & Lei, 1986; Sobell et al., 1992). Providers help clients make connections among their complex attitudes, behaviors, and the change they are trying to pursue as a result of an interactive process—not a dogmatic format. Behavior change is regarded as incremental and based on the premise that people are more likely to initiate and maintain behavior changes if they have the power both to shape behavioral goals and enact them.

Research on harm-reduction programs has been limited largely to demonstrating their success with reducing the transmission of HIV/AIDS among drug users as a result of access to sterile syringes (Kaplan & Heimer, 1992; Lurie et al., 1993; Heimer et al., 1994; Watters et al., 1994; Hagan et al., 1994; Des Jarlais et al., 1996; Vlahov et al., 1997; Vlahov & Junge, 1998). While this is an important accomplishment, little is known about the other low-threshold services that they provide and their overall impact in assisting drug users in making changes in life conditions, circumstances, and quality of life. This is partially due to a policy and funding environment that directs most support to traditional drug treatment and leaves harm reduction initiatives at a disadvantage. As a result, considerable research has been conducted to develop outcomes of drug treatment and assess its impact. Almost no research has tried to establish appropriate measures of harm reduction and evaluate its worth.

To advance the field of harm reduction, the investigators designed a two-phase participatory research project. First they conducted qualitative research with drug users in a large urban harm reduction program to develop culturally

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appropriate outcome measures (see Ruefli & Rogers, 2002). Second, they used these measures to evaluate the effectiveness of the program.

Program Description

The evaluation assessed the largest harm reduction program in New York City which was founded in 1990 by former IDUs and activists as an underground syringe exchange program. It has served over 51,000 marginalized drug users predominantly in the South Bronx and East Harlem who are HIV sero-positive or at risk of infection including injection drug users, crack smokers, problem drinkers, those living at 100% or more poverty level, foreign born, homeless or unstable living arrangements, sex trade workers, and those who lack a regular source of medical care.

The major operating principles of the program include: (1) always be mobile and deliver services to users on the streets and in settings where they live and use drugs; (2) always provide services based on meeting users where they are; and (3) always remain participant-driven and centered on what users want and need. The major goal of the program is to connect marginalized drug users to needed services that will stabilize their lives and improve their well-being.

The services that are offered in the program include the following:

- Intensive street outreach to locate, engage, and retain IDUs and their significant others who are HIV infected and/or are at high risk of infection because of injection drug use/and or risky sexual behavior;
- Street-side services through two mobile vans, one in East Harlem and the other in the Bronx;
- Health education, including safer injection education and orientation to HIV and drug treatment services;
- Harm reduction counseling, including recovery readiness, relapse reduction, and long term recovery;
- Assertiveness training for negotiating safer sex, reducing exploitation during commercial sex transactions, and reducing the harm of abusive relationships;
- One-for-one exchange of sterile syringes for used syringes;
- Support groups including a users' group, men's group, women's group, and gay and lesbian group;
- Acupuncture (ear and full body) and Reiki;
- Transitional case management including facilitation of access to HIV counseling and testing, primary care, intensive case management, drug treatment, housing, mental health services, nutritional services;
- Access to early intervention to locate, identify, engage, and then connect marginalized people who are HIV+ or at high risk of HIV to the AIDS service delivery system and to a range of HIV-related services (e.g., HIV testing, primary medical care, case management, drug treatment, legal services, housing). More specifically NYHRE services include outreach, referral and treatment planning, treatment readiness assessments, health systems education (what services are available, how to access them), transportation and escort to services, advocacy, and self-advocacy training;
- Assistance in accessing entitlement benefits (Medicaid; SSI; Welfare; Birth Certificates) and access to an attorney

- On-site access to the Bronx-Lebanon Hospital medical van for HIV primary care, HIV testing, STD screening, ob-gyn examinations, minor surgery, health screenings, and influenza vaccines, and;

- A 1-800 HOTLINE called GETTING CONNECTED to access hard-to-reach clients.

Methods

The methods used for the participatory research are described below based on the two- phase approach of outcome development and program evaluation.

Phase I Outcome Development

Qualitative research was conducted with clients in the program to initially develop outcomes of harm reduction. The study was advertised in the six program sites and a convenience sample stratified by neighborhood, duration in the program, and types of services received was recruited of approximately 200 clients. The demographics of the sample closely represented the larger program and included 26% African American, 50% Latino, and 24% white; 72% male and 28% female; 17% $\leq$ 29 years of age; 26% between 30-39 years, and 45% $\geq$ 40 years of age.

First, clients participated in groups that allowed them to identify areas of life functioning that people like themselves (i.e., drug users) deemed important and meaningful to work on in the harm reduction program– income, housing, food (nutrition), family relations, self-improvement; connectedness to services/benefits/programs, dealing with negative feelings (mental health), health problems (physical health), and legal and drug use problems. With these ten life areas, ten groups of approximately twelve clients were conducted using nominal group technique (NGT) (Delbecq, 1976) which resulted in ten scaled outcomes that included measures of better to worse ways of making an income, being housed, etc. (see Ruefli & Rogers, 2002 for detail on the process and data analysis conducted).

Next, ten focus groups were conducted with clients to allow more of the target population to reflect on the validity of the measures. In most cases, a completely different group of clients who had participated in the NGT process for a certain outcome participated in the focus group related to that same outcome. This qualitative research resulted in hierarchical outcomes of harm reduction programming to measure incremental change in pertinent life areas from better to worse (Table 1). These measures were considered culturally appropriate to the way drug users see the world and live their lives and capable of showing how clients improve over time.

Table 1: Outcomes of Harm Reduction Programming to Measure Incremental Change from Better to Worse

Making Money

1. Entitlements (welfare, disability)
2. Job (employment, peddling, odd jobs, volunteer)
3. Family money, gifts
4. Borrowing

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5. Hustling, police informant
6. Stealing (boosting, embezzle)
7. Drug trade (selling, holding, transporting)
8. Pan handling, collecting cans
9. More serious criminal acts (robbery, loan shark, hit man)
10. Sex work
11. Selling blood, body organs

Places to Live

1. House you rent or own
2. Friend's home
3. Apt/room you rent or own
4. Drug program
5. Family member's home
6. Housing with social program
7. Institutionalized housing (shelter, hospital, hotel)
8. Living on street/ subway/bus station

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9. Jail
10. Sleeping in cars/tent/ abandoned building
11. Sleeping in tunnels/roof/ parks/stairways

Ways/Places to Get Something Good to Eat

1. Cook food yourself
2. Food from friends/family
3. Food from market
4. Free food
5. Buy food (foodstamps/ money)
6. Go out to restaurant

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7. Beg for food
8. Steal food
9. Food from facilities (jail, hospital)
10. Provide your own food (hunt, fish)
11. Food from garbage

Types of Preferred Services/ Programs to Connect With

1. Housing
2. AIDS related
3. Mental health
4. Drug treatment
5. Entitlements
6. Harm reduction

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7. Mainstream institutions (churches, library, legal)
8. Get connected services (transport, escort)
9. Support services (AA, NA, women's group, friends)
10. Prevention services (parenting, domestic violence)
11. Stress reduction
12. Work-related (WEP)

Ways to Handle Legal Problems

1. Pay for a legal professional
2. Go see a legal professional
3. Speak with a legal professional
4. Address the problem yourself (do research, write to judge)
5. Speak to non-legal person (counselor, case manager)
6. Respect the law (serve time in cb, make court appearances)
7. Learn from legal mistakes

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8. Disrespect the law, authorities
9. Face consequences (give up parental rights, go to appeal)
10. Avoid legal responsibility (jump bail, don't pay fines)
11. Get help from friends

Better ↑ ↓ Worse

Types of Family Relations

1. Love for family
2. Special family gatherings 3. Positive communication (open, honest, patient)
4. Interactive activities (picnics, play games)
5. Argue
6. Support, respect
7. Spend quality time together
8. Passive activities (TV, movies, music)

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9. Lack of respect
10. Negative attitudes (jealous, judgmental)
11. Conflicting lifestyles between members
12. Abusive relations (physical, sexual)
13. Difficult financial relations
14. .Abandonment of family
15. Deceitful relations (lying, stealing, gossip)

Ways of Improving Yourself

1. Developing more self respect
2. Relating better to others
3. Getting/ staying clean
4. Becoming more spiritual
5. Taking part in self-help
6. groups
6. Working/ developing work skills
7. Reducing stress (meditation, yoga)

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8. Helping others (get a job, babysit for children)
9. Caring for self (go to dentist, taking medications, diet)
10. Being more responsible (live on a budget, accomplish goals)
11. Behaving myself (staying out of trouble, stop lying)
12. Taking up hobbies (artwork, fishing, hunting)

Ways to Handle Negative Feelings

1. Get support (support groups, friends)
2. Spiritual help (pray, church)
3. Professional help (case manager, counselor, doctor)
4. Work a job or volunteer
5. Diversions (ball game, beach, singing)
6. Stress reduction (meditation, smoking)

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7. Physical activities (sports, cooking)
8. Self abuse (anorexia, suicide)
9. Abuse of others
10. Social relationships (visit person in jail, get married)
11. Withdrawal, isolate
12. Illegal activities (drugs, gamble)

Ways to Handle Health Problems

1. Home remedies (cleansing, praying)
2. Stress reduction (positive affirmations, meditation)
3. Drug treatment/ therapy
4. Clean living (reduce drug use, take meds, stop smoking)
5. See doctor
6. Health screening (check for diabetes, STDs, etc.)

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7. Nutritional diet
8. Educate yourself about health
9. Exercise
10. Alternative therapies (psychic, herbs, fasting)
11. Negative emotions (denial, anger, depression, suicide)
12. Use illegal drugs

Ways to Handle Problems with Drug Use

1. Admit the problem
2. Pray
3. Get social support
4. Go into treatment
5. Quit using
6. Get help from therapist
7. Stay distracted
8. Avoid drug culture

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9. Follow treatment plan
10. Get family support
11. Get spiritual guidance (NA,AA, minister)
12. Jail
13. Reflect on pain associated with drug use
14. Be deceitful (lie, manipulate)
15. Take part in illegal activity
16. Isolate
17. Use drugs, binge

Better ↑ ↓ Worse

Phase II Evaluation

The main intent of the evaluation study was to assess whether drug users in harm reduction make significant progress in various life areas based on measures that were culturally appropriate and meaningful to them. Using the drug user-generated outcomes from Phase I, data collection instruments were developed to collect data at several points in time to measure client progress using a pre, post, follow-up design. The first assessment with clients in the study, administered as face-to-face interviews, measured how clients' placed themselves on the scaled outcomes at baseline (when they entered the program, a retrospective measure) and "now" (i.e., post) Clients completing this assessment were then asked to call an 1-800 telephone number, one they used to regularly connect with the program, every three weeks to take part in phone interviews with a trained interviewer who used an adapted version of the developed instrument to assess their progress with the outcomes.

Study recruitment methods for Phase II were similar to those used in Phase I which resulted in a stratified convenience sample of 261 program clients stratified by neighborhood, duration in the program, and types of services received. As might be expected with the unstable nature of the target population, study drop-out took place across the follow-up assessments which reduced the size of the matched sample that could be used for the evaluation. As the matched sample decreased over the follow-up assessments, the decision was made to use data from six of the seventeen follow-up assessments resulting in a sample of 96 for the evaluation. While the follow-up sample was slightly older, female and more of Black/African American descent than the baseline/post sample, overall the demographics of the assessment samples represented the larger client base in the harm reduction program (Table 2).

To explore the extent of progress of clients in the harm reduction program data were analyzed using paired t-tests between baseline, post and follow-up scores. To explore the influence of other factors on client progress, multiple regression was performed.

Table 2: Demographic Characteristics of Clients in the Program and in the Baseline/Post and Follow-up Assessments

Characteristic	Baseline/Post (N=261)	Follow-up (N=96)	Program Client Base (N=51,282)
Age:			
≤29 years	11%	6%	13%
30-39 years	33%	27%	32%
≥40 years	56%	67%	55%
Sex:			
Male	62%	58%	67%
Female	37%	40%	29%
Transgender	1%	1%	1%
Unknown			3%
Race/Ethnicity:			
Latino	49%	41%	52%
Black or African American	33%	39%	28%
White	14%	17%	14%

Other	4%	3%	5%

Evaluation Results

The evaluation explored two related questions. First, it determined whether clients in harm reduction programming made overall progress from the time they entered the program to their last follow-up assessment (i.e., from baseline to their sixth follow-up assessment). Second, because there tended to be more time between when participants entered the program to the post assessment (i.e., approximately 60% had been in the program a year or longer) than from the post to the last follow-up assessment (approximately 6 months), the evaluation explored whether more client progress was made from baseline to post assessment than from post to the last follow-up assessment.

Results based on these inquiries are shown in Table 3. Findings show that there was significant client progress across most outcomes from entrance in the harm reduction program to the last follow-up assessment (i.e., baseline to follow-up) which is demonstrated in means decreasing across the measurement points. The exception to this finding was with the outcome of connectedness to valued programs/benefits. While there was significant progress from baseline to post assessment, there was not significant progress from baseline to follow-up.

Table 3: Change Across Program Outcomes from Baseline to Post and Follow-up

Life Areas	Means*			Level of Significance		
	Baseline	Post	Follow-up	Baseline vs. Follow-up	Baseline vs. Post	Post vs. Follow-up
Housing	4.10	3.28	3.17	$\leq$.001	$\leq$.001	NS
Income	5.61	4.05	3.36	$\leq$.001	$\leq$.001	NS
Family Relations	2.97	2.78	1.93	$\leq$.001	NS	$\leq$.001
Program services/benefits	5.97	5.08	5.94	NS	$\leq$.001	NS
Food (nutrition)	4.04	3.82	3.57	$\leq$.001	NS	NS
Health care	6.72	5.74	4.92	$\leq$.001	$\leq$.001	$\leq$.01
Handling negative feelings	6.35	5.86	2.77	$\leq$.001	NS	$\leq$.001
Dealing with drug use problems	9.45	7.24	5.95	$\leq$.001	$\leq$.001	$\leq$.01
Dealing with legal problems	5.11	4.50	3.71	$\leq$.05	NS	NS

*Progress across means are demonstrated in the lowering of mean scores due to the fact that the outcome scales were quantified from the "best" measures receiving the lowest scores and the "worst" receiving the highest.

Findings also show that there was not always significantly more progress from entrance in the program to the post assessment than from post to follow-up assessment across all outcomes. This expected result was shown for the outcomes of housing, income, connectedness to programs/benefits and dealing with drug problems. For the outcomes of family relations and handling negative feelings findings show that there was not significant change from baseline to post but there was from post to follow-up. For the outcomes food (nutrition) and dealing with legal problems there was not significant change from baseline to post or from post to follow-up,

although there was from baseline to follow-up. Finally, for the outcome of health care, there was significant change both from baseline to post and from post to follow-up.

To further explore the positive relationship between client progress in various life areas and participation in the harm reduction program, a number of relevant factors were addressed to determine their impact on this relationship. Using multiple regression, the factors of 'amount of time in the program', 'program dosage received' (i.e., scope and frequency of the multiple services offered), 'type of service received' and 'type of drug use' (i.e., stable vs. chaotic) were entered into the model for analysis. Surprisingly, none of these factors had any consistent significant relationship with progress made in program outcomes. Stable drug use was marginally related to progress in the outcome of housing ($p \leq .07$) and significantly related to progress in the outcome of income ($p \leq .05$).

Discussion

While the findings from the evaluation were overall positive in showing a relationship in drug users participation in harm reduction programming and improvement in various life areas, there were a number of limitations of the study that need to be discussed. First, the evaluation did not employ a comparison design to compare the progress of those who do and do not receive harm reduction programming so that results could be more confidently attributed to the program. Second, the reliability of the retrospective baseline measure is open to question. Participants were asked to provide information on the outcomes based on when they first entered the program. This meant that there was considerable variation in the recall required to obtain valid data across a individuals that entered the program from as early as one month prior to the baseline to as long as six years.

Third, the reliability of the follow-up data was questionable for some outcomes. The instrument used to gather follow-up data was designed to allow for a shorter session with clients via a phone interview than the amount of time taken for the baseline face-to-face interview. Interviewers used open-ended questions and fit client responses into the available categories of the outcome scales. While this worked well for most of the outcomes, certain ones, such as "self-improvement" did not provide adequate data to allow appropriate measures at follow-up. For the outcome of "family relations", the data collected at follow-up resulted in a revision of the scaled outcome from one with a ten item scale measuring better to worse types of family relations to a six item scale from close family relations to no relations.

The study, surprisingly, found that clients' progress in the harm reduction program was not associated with the kinds of services they receive, their length of time in the program, or the number of services they receive over time. In order to understand and explain these results, it is important to understand the harm reduction approach, the way the program is structured, the way clients are integrated into the organization and its service delivery model.

To understand the harm reduction program's service delivery model it is helpful to look at the way in which most human service organizations that work with drug users are structured and the way in which clients are integrated into the model. Clients who meet eligibility requirements are usually assigned to one worker, usually a case manager. That worker provides most, if not all,

services the client receives at the agency: intake and assessment, orientation to the agency, the development of a treatment plan, case management, behavioral contracting, referrals, follow-ups, support. Generally the relationship between the client and worker is an asymmetrical power relationship in which the worker has power and the client does not. While the client may have some input on their treatment plan, the worker generally assigns the client a number of tasks and responsibilities to perform, dictates and enforces the rules of the agency and disciplines and terminates the client if he/she does not adhere to these rules. In the service relationship, the client has little or no choice in what services received, how long the relationship lasts and when the relationship begins and ends.

By contrast, there are not eligibility requirements in the harm reduction program. Anyone who wants services can receive them. Rather than having a single entry point, clients can join the program at any part of the organization including the formal offices, the street-side service delivery sites, through any of the multiple programs offered and even remotely through the 1-800 get connected phone service. In addition, anyone of the 35 staff members can enroll clients into the program. Once enrolled, clients are not assigned to a single worker. Clients can receive services from any staff member, from as many staff members as they choose and from any preferred program. Case managers are available if clients choose to have one but it is the clients who decide which services they receive and how often they will access them. Relationships between clients and workers are symmetrical power relationships in which both are empowered. The worker assists clients in completing those tasks the clients choose to complete and the clients decide when the relationship begins and ends. While the program operates with the rule that violence is not tolerated and that clients can not buy or sell drugs on agency property, if they are asked to leave the premises for breaking these rules they are still eligible to receive services at the street-side service delivery sites.

Both service delivery models have consequences in the way workers and clients relate, the way clients feel about themselves, and the way they relate to the overall program. In the more traditional service model, the asymmetrical power relationship encourages clients to view their success as dependent on a specific worker they are assigned to and the actions taken by that worker, not their own actions. In addition, the nature of the client-worker relationship encourages subjective transference and counter-transference (i.e., client confuses the present with the past and transfers emotions and desires that are associated with important people from the past onto the worker). As a result the relationship can be turned upside down and the focus shifted from the client to the worker who the client has elevated to a level of someone important in their past. The client develops negative feelings toward the worker when they cannot solve all their problems and can often blame the worker for their problems. Clients often become overly personal in their relationship with the worker or get to the point that they complain about the worker.

By contrast, in the harm reduction model, transference becomes diluted because of the nature of the relationship between clients and workers in which clients do not become tied to a single worker and do not associate their progress with him/her. Rather, the client interacts with a number of workers who assist the client in getting their needs met. Relationships between workers and clients tend to be short and transitory and, consequently, there is no time for the client-worker relationship to develop to the point where the client engages in transference.

Without that transference, the client and workers focus on what it is the client needs instead of on an evolving relationship with a single worker. When the client has success, she doesn't say "it's the worker who helped me." Instead, the client says "it's the program that helped me." Thus, the changes in life circumstances documented by the outcome study are less likely to be associated with a single worker, a single intervention, or a single program. Instead, the changes that clients make are more likely to be changes that result from the client's association with the organization as a whole.

It is not a surprising finding of the study that the clients' type of drug use' (i.e., stable vs. chaotic) was more strongly related to their progress in the outcomes of housing and income than the other program outcomes. Making progress in these two outcomes, more than the others, generally requires either abstinence or controlled, low-level drug use to qualify for subsidized housing or to maintain an income-producing job. Clients' progress in the other program outcomes, despite that fact that their drug use may not always be stable, reflects on the impact that harm reduction programming can have on them. Having a supportive organization that believes in them, whether they are out of control with their drug use or not, helps drug users to start believing in themselves and provides a much needed social and psychological safety net to continue forward in several areas of their lives.

Conclusions

Traditional drug treatment has not demonstrated high levels of client success, yet it has been able to garner considerable political support and resources. While drug treatment is an important option that should be made available for those drug users who choose it, less resources have been made available to support drug users who do not want to enter formal treatment programs. Harm reduction programs, providing important life sustaining services to active drug users, have historically been considered a more controversial approach to working with drug users and little empirical research has been made available to judge its merits. The present study, though preliminary in nature, has shown that harm reduction programming can positively impact active drug users in making incremental and life-sustaining changes across several areas of their lives. These results, along with those that have shown the positive effects of syringe exchange interventions in reducing the transmission of HIV and other blood-borne viruses, demonstrate that harm reduction programs are a viable and scientifically sound approach to working with highly marginalized drug users.

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