Syringe Service Programs

Stakeholder Input Summary

April 14, 2019

Background

As part of a NASTAD-funded project to develop a set of best practices and performance standards for syringe service programs nationwide, consultants Shelley Facente and Katie Burk have worked in collaboration with NASTAD to secure stakeholder input from a wide variety of subject matter experts. This included:

1) an online town hall during which the consultants, along with representatives of NASTAD and CDC, described the project and solicited preliminary input from members of the harm reduction community who responded to a broad call for interested participants;
2) a series of 14 60-minute phone conversations with SSP leaders from various settings around the country, and
3) an in-person stakeholder meeting held in Washington, D.C. on April 8, 2019, during which 18 subject matter experts from around the U.S. gathered to provide feedback on best practices.

This report summarizes the key findings from this stakeholder input, as an aid to the development of a performance standards document as the next major step in this project. A list of stakeholders consulted for this project is available in Appendix A.

Types of programs

Stakeholders – all of whom had been asked to give input because of their experience with model SSPs in a variety of settings – described many different types of SSPs, including:

- Fixed sites, including independent storefronts (sometimes primarily as drop-in centers where syringe services were also available), health department buildings, and embedded within existing community organizations primarily providing other types of services (i.e. HIV service organizations, health clinics, or drug treatment providers).
- Van-based or tent-based services in temporary but stationary locations, where services are provided on a planned, consistent schedule for a short term in sites across a region,
- Roving van-based services, where the van would move around to multiple neighborhoods on an unplanned schedule, looking for people who might want services. One stakeholder noted this model worked: *"Why? Because we want to literally be able to go where people are at. We do this both physically, psychologically as much as we can, emotionally, and socially as much as we can. We come from a social justice perspective to harm reduction."*
- Car or backpack-based outreach services, often conducted outside of permitted sites, and
- Secondary exchange, whereby some participants would receive large quantities of syringes and other injection equipment or naloxone in order to disseminate these materials within their social networks.

Some stakeholders were from community organizations and some from health departments. Some worked within one specific site, some worked in organizations with multiple sites in their area, and some worked in state health departments that oversaw dozens of SSPs statewide. In some jurisdictions providers worked at least partially underground or without city or county approval; in others local permits needed to be secured on a site-by-site or county-by-county basis, either through the city council, municipal court, health commission, and/or health department.

SSPs' accessible hours varied greatly among the programs represented by the stakeholders. Often depending on the type of site, some providers offer services 7 days and upwards of 50 or 60 hours each week (with one offering 24/7 services), some providers offer services a 3-5 days per week during the regular 9-5 business window, and some providers offered services on a more limited schedule (a few hours a day or a few days a week) due to resource constraints. Services offered through roving vans or temporary tent services were often for only 30 minutes at a time, or a few hours one day a week, but at times when participants knew they could be found; sometimes these services (and car or backpack-based outreach services) were on the lookout for specific participants in their regular hangout locations, one-by-one.

Programs ranged from less than 1000 unduplicated participants per year to more than 10,000; some distributed 250,000 syringes per year and some distributed more than ten times that amount. Depending on local regulations and policy restrictions, some stakeholders described a preference to distribute larger quantities of syringes at a time, allowing them to provide services for a particular group of people only around once a month; others preferred (or were restricted to) more frequent interactions during which fewer syringes were provided.

Syringe distribution

All stakeholders consulted for this project made clear that they understood needs-based syringe distribution, a practice in which a program participants can receive as many syringes as they request regardless of how many syringes they return, to be a best practice. Failure to provide participants with the amount of equipment they need undermines the harm reduction framework. One explained:

> *You don't understand harm reduction, if you're saying, 'If you don't bring me any, I won't give you any.' And some syringe exchanges here are literally like that. So there's a real lack of knowledge of how harm reduction can and will affect the HIV epidemic…or really touch on the HCV epidemic. And more importantly, what are good policies for the participants, and what are good policies to push in society so we're better to drug users?*

Many providers saw unrestricted, needs-based distribution of syringes as a non-negotiable component of their SSP; however, 4 of the 14 people interviewed said they were unable to provide needs-based syringe distribution in their jurisdiction due to legal or political issues or resource constraints. These providers instead provided 1:1 exchange, or 1:1 exchange plus a "starter kit" of a limited amount of syringes. As one provider described: *"It's more important to be doing the work than it is to be perfect."* Two of the ten who generally provided needs-based services still felt compelled to cap the number of syringes that could be provided to an individual at any one time, due to limited resources. While stakeholders throughout these conversations noted ways in which they had to compromise for their program to survive, one emphatically called her colleagues to continually push back against restrictive policies that may undermine programs' successes:

> *I get that in some places the ONLY way to do syringe exchange at all is 1:1, and in those places that's definitely better than nothing. But I think as soon as there's a little window to push away from that, we all need be focused on getting away from those practices that can be so damaging…everyone has to be in that mindset that you are settling because of these constraints you can't do anything about, and the second that you're able to push, even if it's a year or two later, you have some successes, you're able to say, "Remember before, you were skeptical, but look what I'm doing…" You have to constantly strive to [follow best practices].*

Another explained:

> *We used to have a 1:1+ exchange model…We gave people 30 syringes when they came originally regardless of how many syringes they had, and then thereafter it was 1:1 with rounding up for packaging. And then a couple of years ago, we switched over to negotiated exchange. We had to do a regulation change in order to do this…We still encourage them to return their syringes to us. But what we found is that…before what would occur is people would try to come up with ways of scamming the system to get what they need. We were encouraging people to be dishonest with us about what they needed, and then they wouldn't talk with us about other barriers or issues they were having. This was a real problem… [Now] people are*

> *being much more honest with us. And not just about the syringes, but about other things. Because it's not just about that talking, but having additional communication.*

Being unable to provide needs-based syringe distribution also undercuts a program's ability to explicitly support secondary exchange, which was universally identified as a best practice by stakeholders.

A few providers also noted the importance of buying high-quality syringes; some SSPs in their regions had purchased cheaper syringes from other countries or even tuberculin syringes because they saved money and allowed for purchase of an increased quantity. However, low quality syringes can cause an increase in soft tissue infections due to the likelihood of increased injection attempts, or can simply reduce the willingness of people who inject drugs to obtain their syringes at a SSP.

Minimal services to provide

All stakeholders agreed that the minimal services that must be provided for any SSP were syringe distribution (this should be needs-based), distribution of injection equipment ("works"), safe syringe disposal, and naloxone training and distribution.

Regarding the idea of naloxone training and distribution as an essential component of SSPs, stakeholders emphasized the importance of SSPs distributing naloxone directly to people who use drugs (as opposed to police, Health Departments, etc.). One stakeholder explained that programs should aim for high levels of saturation of training and naloxone in communities of drug users so they are all aware of how to respond to an accidental overdose and have the tools to do so.

Other services provided

In addition to the minimal services, most stakeholders described complementary services offered within their SSP. These services were sometimes provided by the SSP staff, and sometimes by partnering agencies. They include:

- Education about safer injection, overdose prevention, hepatitis C, HIV, and other issues relevant to drug user health (always offered but never compulsory)
- HIV, HCV, and/or STD testing
- Basic wound care
- Drug testing strips (e.g. Fentanyl testing strips)
- Distribution of sharps containers for safe disposal
- Distribution of safer smoking or snorting kits
- HIV PrEP
- Low-threshold buprenorphine
- Low-threshold suboxone
- Medication management (pill lockers)
- Case management
- Mental health and/or addiction counseling
- Linkage to drug treatment
- Linkage to HIV and/or HCV care and treatment
- Linkage to legal counsel and/or employment services
- Housing assistance
- Identification (ID) services
- Vaccines for HAV, HBV, HPV, and sometimes influenza, pneumococcal, and Tdap vaccines as well
- Provision of condoms, dental dams, and lube

Some also described providing hygiene kits and/or food to participants, though particularly with food there were mixed feelings, as food was sometimes provided through partnerships that did not align with the mission of the SSP and attracted others to the space for food when their primary need was not harm reduction.

Balancing quantity vs. comprehensiveness of services

Multiple stakeholders argued that the goal of an SSP should be to function as a one-stop shop for their participants, offering as comprehensive a set of services as possible. One noted, *"We try to make it as easy as possible for them, to get them the services they need and not create barriers for them."* However, political or financial limitations often factor in to how programs are implemented, with many stakeholders describing a constant negotiation between service reach and comprehensiveness of services. One stakeholder explained that he thought the best practice would be to provide mobile services is standard locations two times every week, but that in order to provide the comprehensive level of services he thought was necessary, at this point he could only afford to provide services once per week at each location. Another said they had decided to stay small and more limited on purpose, so they could provide personal, less bureaucratic services that were accountable to participants and more palatable to neighbors. People running van-based services especially noticed restrictions in the breadth of services they could realistically provide. The barriers to program implementation and maintenance are significant, especially for newer programs. One stakeholder advised, *"Start small, don't try to conquer the world. Do what you can, focus on strengthening process and your procedures."*

Bathroom safety

Given the high risk of overdose on-site at an SSP, during all three types of stakeholder input at least one person emphasized the importance of bathroom safety protocols. Recommendations from stakeholders for bathroom safety policies included:

- Have a plan to address the lock on all bathrooms, ideally disabling any locking doors and having a "knock before going in" policy
- Have fresh injection equipment available in the bathroom, just in case people go there to use
- Have naloxone nearby and staff trained to administer in in the event of an opioid overdose, but also have staff trained to respond to non-opioid overdoses
- Identify whose responsibility it is to watch the bathroom during all shifts; also identify whose responsibility it is to support and back up that person, should an incident occur

Stakeholders also noted during the in-person meeting that if you make a bathroom available, it's your responsibility to keep it clean; don't expect participants will (or need to) do that and plan accordingly.

Hiring, training, and supporting staff and volunteers

One of the most common themes across all stakeholders was the critical importance of hiring staff with lived experience, both former and active substance users. This was both because it results in superior services, and because it helps participants, as one described: *"I think that's part of our job in this world, to create employment opportunities and sustain people in them so they can move beyond for the next step of their lives."* This extends specifically to people who are still actively using substances, with one provider noting the only two requirements at their SSP are that staff and volunteers not be high at the time they're conducting work, and they find someone else to offer the services to people they use substances with. That said, this can cause hiring challenges in health departments, universities, or other settings where a history of substance use or felony conviction can prevent hiring through bureaucratic channels. Still, stakeholders were universally clear that this complication was imperative to overcome, because hiring of people with lived experience was a foundational pillar of a good SSP. Training HR and managers in hiring and onboarding people with lived experience – along with advocacy for fair hiring policies – is an important part of SSP advocacy.

Hiring people with lived experience of substance use also comes with a need for substantial training and ongoing support, to set people up for success, as one stakeholder explained: *"If you want these programs and the people who run them, particularly if they're from the population served, to be leaders in this specific way, there's a lot of training and technical support, program development support that needs to happen to support them as true leaders in this work."* Some examples of training provided to participants as they transitioned to staff roles included harm reduction counselor trainings, including information about drug-related stigma, harm reduction 101, overdose prevention, boundaries and disclosure, HIV and hepatitis C, engagement and outreach strategies, wound care, first aid/CPR, and de-escalation skills. Other stakeholders mentioned SAMHSA-based counselor certifications and recovery coach training through the Recovery Coach Academy.

In addition to training during the onboarding period, stakeholders noted that ongoing support is also necessary, including regular staff meetings and supervision that meaningfully focused on real support and clinical supervision for people in a challenging role. External clinical supervision with someone who doesn't supervise or have power over staff but can truly listen and offer support and guidance, is an important way to ensure staff can cope with the vicarious and direct trauma they may experience, along with other stressful aspects of this work.

During the in-person stakeholder meeting, there was wide consensus that it was critical to involve participants in the hiring process for all staff positions. They, after all, are the people being served, and they have important insights to offer about whether the person interviewing for a job feels like a fit. Ensuring that staff reflect the community being served is also vital, including hiring people who use drugs, people of color, sex workers, and people who are trans and gender non-conforming. These individuals should not just be hired as frontline staff or outreach workers, but into positions of leadership as well.

Other hiring issues mentioned by stakeholders included attention to preferred language. One SSP found through period point-in-time surveys of participants that the number of people who spoke Spanish as their primary language was increasing over time; as a result, they prioritized bilingual staff in hiring. Depending on the types of services offered, it may also be important to include nurses, case managers, treatment/addiction counselors, and highly skilled phlebotomists on staff. If clinical care is provided by nurses, it is important to have standing orders from a medical director and nursing protocols that allow them to offer more complex wound care, vaccines, and treatment starts. Regardless of the type of staff needed, a number of stakeholders described the importance of adequate staffing – if someone overdoses onsite it takes two people to respond, and there should be at least one more person on shift at all times to be able to keep services open.

In addition to the core staff, many stakeholders mentioned the potential for useful support from students or community members wanting to volunteer. One provider related,

> *I think that one thing that some [SSPs] don't do that great of a job at is having a sufficiently broad…array of ways that community can plug into programming and do low to moderate-intensity volunteer work, that isn't handing out needles to people who use drugs. Because that's…an inappropriate volunteer activity that's not for, just sort of concerned and interested community members. But there's all kinds of other stuff that can feel meaningful that programs absolutely need that there should be sort of set up for people to plug into.*

However, many providers cautioned that their responsibility was to the participants, not community members who wanted to do a good deed. Hiring only the right people as staff and volunteers is critical to the program's success, as one described:

> *I am a stickler about it…I think we've all done the "hire the wrong person" thing, and I'm like, "Nope! Not in this environment." Especially because, if clients have been treated poorly everywhere else, it CANNOT happen here. But as a result, we don't have a lot of good applicants for harm reduction…We have some pretty awesome opportunities that if I were younger I would move here for, but it's hard to get that message out. Because everybody says they are into harm reduction until they're actually in the room, and then it's like, "'I don't know about that.'"*

Planning and program design

When it came to conversation about design of a program in a particular area, stakeholders universally responded with two themes: 1) use local data to determine actual need, and 2) involve people who use drugs in the planning and design process. One person put it simply, *"You can check in with the neighbors and you probably should, but what should determine a site is where people are when they need you, and when." Another said, "Listen to drug users. To your participants. They are participants. They are not clients, they are definitely not patients. And as participants they should be part of your decision-making process. Have them part of your board, have them part of your decision-making. Even if it's just making sure [you are] constantly asking your participants what's working and what's not."*

Stakeholders described their own data-based assessments looking at overdose data, suicide deaths, and information from participants about location of needle-sharing and actual use of drugs. If not available through health department data, a simple survey of participants (or potential participants) or focus groups can serve this purpose. One stakeholder explained,

> *The first advice I would give to new programs is that they need to have at least one, and probably ideally a series of focus groups with active drug using participants or potential participants who can offer insight into exactly what materials people want and need. I really don't think anything else will do…I don't think it's sufficient to pull together a list of local recovery coaches, or people who identify as being in recovery or having a history. I just don't think that's sufficient…Some things change really rapidly. That would be my first advice is do not even think about opening your doors before doing that… in a way that is respectful, and ideally pays people for their time and expertise.*

Ultimately, gathering data helps inform not just the location of services, but the focus of the services as well. One stakeholder who runs an SSP from their health department noted,

> *You have to look at your community and what's going on. What's the problem you need to solve? It isn't one size fits all. In one community what you really need to be working on is academic detailing for prescribers, or some way to limit the prescriptions without sudden cessation, which we're pretty convinced drives people to injection use. If you've got that problem – you might not have that much of an injection problem, you may have more of a need for support to enter drug treatment or maybe you need more testing and linkage to care services. Maybe you need telemedicine for MAT. What will best serve your county?*

However, one stakeholder cautioned that truly listening to the expertise of participants can be challenging, because it means making changes that may not match your initial vision:

> *Taking the harm reduction truly person-centered approach means risking doing the work the way you've always wanted to do it…Really follow people, and use their guidance. Do it right, not just the actions that are associated with best practice! Respecting and honoring the people in front of*

> *you and their ability and knowledge and needs is the core of everything. Really listen to the needs. That doesn't mean it's not negotiable…[listen] in conversation with the realities of the circumstances.*

Notably, people who are actively using substances shouldn't just be consulted at the time the program is set up, but also involved in ongoing discussions to improve the quality of the program as it continues. This can take many forms, from a monthly "participant advisory meeting" at a sit-down restaurant: *"They get served by a waitress…and they talk about what's going on in the community, what's going on in the agency and how we can push forward together. That's where all the rules for the space come from. New services and programs come out of that committee. They're primarily the boss of me [as the Executive Director] much like our Board of Directors is the boss of me."* Another stakeholder had tried that method for gathering input from participants but was unable to secure resources to continue those meetings, instead opting for quick methods for near-constant input, just as a poster in the SSP that says, "Are you interested in these things?" and people can put stickers on the poster to indicate if they're very interested, somewhat interested, or not interested.

Another theme common from community-based SSP organizers was that with the recent influx of opioid-related money, there are new opportunities for health departments throughout the country to access funds to provide harm reduction services. However, in those communities there are typically harm reductionists who have been providing services underground or through community-based organizations for many years. Rather than reinventing the wheel, health department staff could first look for opportunities to partner with these established harm reduction efforts, then build new services to complement or fill gaps if that's really needed in the community. Taking it one step further, one stakeholder asserted that in all conversations about services for people who use substances, *"If a harm reduction representative is not a person actively using drugs then you need another person there."*

Some stakeholders felt that it was easier to work independently, without compromise, to provide the most appropriate services to a highly criminalized and stigmatized population. However, many stakeholders thought that it was better to build agreements with law enforcement, the health department, and other key stakeholders before providing services, so that *"people know what you're doing, so that you're transparent but also respecting the anonymity of the clients and their right to privacy."*

Finally, stakeholders continuously emphasized the importance of writing down detailed policies and procedures, and training staff accordingly, before beginning services. Too often SSP providers are "building the plane as they fly," which is natural given the crisis nature of SSP service provision. Yet service provision in the absence of well-planned and documented policies and procedures leads to inconsistencies, and can be near-catastrophic if a critical staff member leaves or dies unexpectedly.

Engaging participants in service provision

In addition to involving participants in program design and planning, stakeholders universally also agreed that it was a best practice to also meaningfully involve participants in service delivery whenever possible, making special effort to involve participants of color in conversations. This took many forms, and having many options and thresholds for involvement was in itself considered a best practice. One stakeholder described asking participants if they were willing to do little chores around the drop-in, such as sweeping up, picking up cigarette butts outside, greeting others coming into the space. Another said, *"The card we give them [when they enroll as a participant] says they're a volunteer. And we ask them to pick up syringes they see in the community so that gives them a legal defense if they're caught with syringes. So from the very beginning you're made to feel a part of things here."* Service as secondary exchangers is another way that participants can be a critical part of the program, while doing things they often decide to do on their own, to support their network. In fact, one program coordinator described the unofficial secondary exchangers (people who ask for a lot of syringes every time they come to the SSP so they can redistribute them to people in their networks) as being a main source of new volunteers, because staff are trained to approach them and said, “Hey, do you want to make this more formal?” Secondary exchange programs that are institutionalized and well-paid can also be a strategic, successful method of workforce development for SSP participants.

Volunteer work can be an important point of entry for participants. One stakeholder described,

> *We try to get folks to participate in volunteering with us. A lot of times people will say “Oh, when I’m living a life of recovery, I’ll be back.” And we’re like “No, no no. You have so much to give today…start volunteering with us now.” So we’ll get people that’ll volunteer with us at the street outreach table or go on outreach. Or just help out in the space which is very nice. Five of the staff are current or former injectors, seven of the eight staff volunteered before they were hired...I’m very big on hiring volunteers because I know how they work, we know them. I know that they know how we are…So when people are like “Someday I’m going to work there,” I’m like, “Great, start volunteering today!”*

However, taking the step from helper or volunteer to full staff member or board member can be a more challenging leap for some programs. Setting participants up for success as volunteers or staff at an SSP is critical; however, there needs to be a true commitment to working out the logistics for the benefit of the program. Recognizing the value of life experience over education or degrees is one important step; drug-free workplace policies (particularly those involving drug testing) can be a significant barrier. One stakeholder said it well:

> *I’ve heard of other programs that have these sobriety requirements, like you have to be 5 years sober to work for us. That’s basically asking people to be disengaged from the community you’re supposed to help. I just want to emphasize that having drug users at the table on every level inside the organization is imperative. And that’s a lot of what health departments are missing. And they have this very sterile idea of what can be effective for this to work.*

Similarly, another said,

> *That’s my most fundamental critique of [SSPs] that are…health department run… there’s nobody who knows nothing about drug use in any of these programs. And they’re just another job responsibility…There is a lot of content that can easily be learned but that is not sufficient to run a SSP.*

Yet participants are often pigeon-holed into a second tier of the organization, where they are expected to “pay it forward” for the help they’ve received, rather than being treated equally to any other staff person or volunteer. One stakeholder emphasized,

> *I want to be very clear that peer is not a level of a position in an organization. Peer – peer educator, being a peer drug user, post-drug user, it’s a vantage point, or positioning that this person has vis-à-vis drug use, sex work, homelessness, whatever. Peer is a vantage point, not a position. I just want to make sure I take a position on the…many times peers are seen as, that’s the lowest position, a peer, and then you graduate to being an outreach worker, and then a coordinator. No, ours are peer outreach workers. Like an outreach worker with a peer perspective. Hopefully someday we’ll have a peer Executive Director.*

Another talked about fair compensation, saying, *“[Participant volunteers] prefer cash, so we’ve paid them cash, and we’ve used gift cards, and right now we’re trying to solidify how we compensate them. They deserve a voice in how they’re paid, and their preferences need to be honored, and then there’s some budget constraints as well* *about what we can and can't do."* However, policies that treat participants as unable to manage their own income from their work – unlike all other workers who are paid for their time and expertise with no strings attached – create a separate but unequal environment within the SSP.

Ultimately, in the in-person meeting stakeholders agreed that it is important for SSPs to have a clear, defined pipeline for how participants can move from volunteer to staff to leadership roles. This requires clarity about the definition of an "active participant" for each SSP; it may be necessary to consider a waiting period for active participants before they are able to enter the pipeline.

Maximizing program accessibility

In order to ensure that SSPs are not just available but truly accessible to the people who need the services, there were a few key points that were repeated by numerous stakeholders in both the one-on-one conversations and the in-person meeting:

- **Nighttime and weekend hours are necessary.** More than one person noted that many of their participants have 9-5 jobs, so working regular health department hours would render services inaccessible to many potential participants. One person explained, *"Realizing that 70% of people who are injecting drugs work is something that the general public doesn't want to acknowledge. Models that were developed to serve homeless people are fine, but our homeless have wonderful access to us where we are. We don't need to expand so much for homeless, we need to expand for working housed individuals."* Stakeholders were particularly bothered by programs run through health departments for only a few hours on a single day per week, which felt like token services and not meaningful offering of services to a community in need.
- **Have a wide variety of service options.** Some people want services close by, some want them further away where no one is familiar. Some want a fixed site with reliable hours, and some will only participate in services if the van or outreach worker comes to them. One stakeholder noted that an important consideration for programs where many participants drive to reach them is prevention of impaired driving – it may be important to have "chill rooms" where participants can relax until it's safe for them to drive.
- **Secondary exchange is often the only way to reach enough people,** especially in rural areas. Stakeholders were emphatic about how crucial secondary exchange is in order to broaden the reach of the SSP.
- **Hire participants to work the front lines.** The way to make participants comfortable is to set up services so they are talking to someone who doesn't judge them because they've been there.
- **Remove restrictive policies about being on time for appointments, not being high to receive services, etc.** One stakeholder noted, *"It's cruel not to give folks what they need when you have it right there."*
- **Consider literacy.** One program director noted that after many years they realized their data collection was hindered by participants' difficulty reading the forms. Rather than wait for participants to identify a literacy challenge (especially because many would never want to do so), the program started saying, *"Is it easier for us to read it to you? Or would you rather just do it yourself? I've done this a thousand times and I'm a lot quicker at it, so is it easier if I just ask?"* Most people say yes to the help, and then they don't have to admit why.
- **Drug treatment is one option, not the goal of an SSP.** One person articulated what many referenced in their conversations: *"The illusion of micromanaging people's drug use is not worth spending a lot of time on. Don't spend a lot of time trying to push people into drug treatment. It just interferes with the trust. The relationship is the most important thing you've got there."*

- **Think about the impact of the neighbors.** In this case, stakeholders meant law enforcement and drug courts; as more health departments offer SSPs in their county complexes, proximity to the sheriff's department or drug court facility can be a strong deterrent for SSP participants. Ultimately, if people feel scared or threatened they are not likely seek services. One stakeholder who helps run a drop-in center for people who use drugs said, *"A lot of people have bad experiences [elsewhere]. They can feel disrespected even when they aren't. And we have…for some reason we have way less incidents, way less mental health episodes when folks are throwing stuff…there's been no fights here, no threats. I think it's just because people don't feel scared or threatened when they come in."*
- **Prepare to adapt quickly.** Community members can be unpredictable, and push back can be sudden. Being ready to change strategies quickly to ensure that participants can continue to receive services when community attitudes turn cold is a necessary part of SSP planning.
- **Carve out time for vulnerable participants.** A number of stakeholders at the in-person meeting recommended having special service times reserved just for women and/or gender non-conforming participants. Everyone deserves to come seek services at a time and place where they can feel safe.

Barriers to program implementation

When asked about barriers to program implementation, almost every stakeholder responded with the same set of barriers that they or their colleagues had experienced:

- Approval requirements giving power to elected officials (e.g. city councils), meaning decisions about whether and where an SSP can operate are driven by political pressures instead of public health. When this is the case, small number of homeowner (read: voter) complaints can shut down or prevent an SSP. Restrictive policies that stakeholders experienced as a result of processes like these include 1:1 exchange, no secondary exchange allowed, and no drop-in space, all of which are actually best practices. These policies result from a misunderstanding of harm reduction, and a misunderstanding of public health – reacting to a fear of syringe litter or increased crime, which literature shows is unfounded.
- Insufficient access to medication-assisted treatment, respectful healthcare meeting the needs of people who use drugs, and safe and affordable housing are major impediments to provision of true harm reduction services in many communities
- Insufficient funding, period. Lack of funding for operations, adequate staffing, and supplies to meet demand were commonly cited as major barriers to proper program implementation.

Availability of drug treatment

Insufficient access to medication-assisted treatment was a commonly-mentioned barrier to program implementation, but it was also a general theme of SSP planning and implementation. *"[Being able to offer] real access to treatment-on-demand would be fantastic," said one stakeholder. "Low-barrier suboxone on site, even to manage withdrawal in addition to just looking at it as a detox agent. Just substitution therapy so you can be dosed with suboxone or buprenorphine when you're on the vehicle, at the site, or alternatively started up on a treatment regimen that's based out of there without any judgment or extra barriers that come with going in and seeking out inpatient treatment."*

Trying to offer SSPs in an inhospitable environment when there are no treatment options for participants who wish to stop using – or long waiting lists for treatment – is challenging. Many SSPs have tried to address these limitations by seeking grants to offer low-threshold treatment services themselves. One stakeholder from a program that just obtained that funding noted, *"It's just nice to be able to offer people treatment. And with low barrier, they're also not getting discharged for poly substance use, so they really feel like we're hanging in there with them. And if they show up at 4pm for a 2pm appointment, we still see them. It's really the way it should be."*

Relationships with policymakers, law enforcement, and community

Ultimately, the success of SSPs often depends on their relationships. Despite the public health evidence supporting the effectiveness of SSPs, these services continue to be controversial and politically challenging in many jurisdictions. SSPs who have managed to find allies and support in their communities tend to thrive, and those who are met with constant opposition find it difficult to survive. All the stakeholders consulted during this input process had direct experience with these challenges, and words of wisdom for others, including the importance of building relationships slowly and diplomatically, collecting data to show the results of the SSP, and growing programs in a cautious way that leverages those data and relationships. Especially in this era of opioid funding, many people are starting programs that do not embrace the true fundamentals of harm reduction. Gently educating about these limitations and providing trainings to proactively build good relationships not only improves knowledge and awareness about harm reduction but also builds good will.

Still, it is important to consider relationships carefully. One stakeholder noted, *"A lot of people say 'We've got MOUs with 60 people.' I'm not concerned about having 60 MOUs. I'm concerned about having 5 that are thorough, and amazing. With people that we know are going to treat our people well."* Each SSP needs to enter into relationships on their own terms, and be clear about the areas in which they're willing to compromise, and the areas where they simply will not. Many stakeholders talked about compromises they were forced to make in order to be allowed to provide services, but many also talked about times they drew the line, such as around 1:1 syringe distribution or certain types of data collection.

The goal for all SSPs is to have a community support system, working together to improve services and resist opposition. As one person said, *"It's really incredible when everybody is at the same table saying 'What do we do to make it easier?'"* Having someone in a position of power who is willing to stand up to community members with NIMBY complaints can be a huge asset. One stakeholder described her experience:

> *We needed a big brother from time to time. We needed the State, and we needed our partner organizations/ The LGBT Center came out and fought with us when we were going to lose the site. They created a space for us…we were working out of their parking lot when we couldn't set up anywhere else because of community opposition. Having the City AIDS Coordinator come out and stand next to us in a meeting in a supportive way when things were going south was really, really important…CDC having a program manager that is willing to come out and say 'This is our program! We support this!'…Sometimes it could go a long way. Finding a way to stick with programs that are experiencing the totally predictable community opposition that comes up from time to time, and being a real partner in this, is really important. It's normal to the process, and you have to have a system that treats them as normal and not as a failure.*

Yet sometimes someone in a position of power is a barrier, and it can be a near-impossible situation. Most stakeholders acknowledged that when this happens, there is little that can be done. Some advice offered included searching for advocates in high levels of leadership who can help (such as a city councilmember or the mayor). Trying to "win hearts and minds" with data or appeal to good nature is not likely to work, and likely not worth the effort. One person noted, *"It's worse to ask for permission and to have it denied than to not ask for permission at all…. sometimes it backfires a little bit but if it backfires a little bit a year down the road at least we've developed a data set and some relationships and we can say, "Look, this has been going on for an entire year and you didn't even know – this is the benefit, so it's ok, right?"*

Health departments

Some stakeholders were *from* health departments, and others were community-based but had excellent health department relationships. Many, however, did not. One health department staffperson who has been a major champion for SSPs in a conservative, generally inhospitable area said, *"The lane of the health department, besides monitoring complications like death, is to provide harm reduction services. In our due diligence we found we were authorized to do it, we had a compelling reason to do it, we were not prohibited from doing it, and no one else would do it."* Other described support they received from the health department for data analysis and reporting, legal counsel, and logistics. Ultimately, many harm reduction providers simply want health department staff to recognize their expertise and ask for them to be at the table. *"There's a million different coalitions and meetings and task forces that state and local government has to go to. And if people who are doing harm reduction services are not at the table or were never asked to be at the table, they should say that [and insist on being included],"* said one community-based stakeholder.

Health department staff who misunderstand harm reduction can be major sources of opposition, however, consuming energy of SSP providers if not actively blocking services. One stakeholder described, *"Average injection here in [this area] is 7 times a day. And [health department staff] were saying, 'Why are you giving them 10 syringes?' And it was like, 'Wait. Let's talk about what you think SSPs should be."* Another said,

> *A major role of our public health department in [this area] concentrates on things like vaccination or WIC, so they're really mama/baby focused, and people who use drugs are the worst for mama/babies, is the way a lot of people think. That's where the opposition comes from. This is opposition to operating, opposition to starting programming, and opposition to accessing any sort of outgoing funding.*

Law enforcement

Stakeholders throughout the project were clear: it is the responsibility of SSPs to minimize harm that law enforcement (including ICE and child protective services) can cause to participants. This includes identifying advocates who can support participants when problems arise, keeping logs of incidents and reporting inappropriate action by law enforcement. It also often means trying to find a law enforcement champion, and using them, since people are more likely to listen to peers than someone they see as "other".

Feelings about SSPs building relationships with law enforcement range ran the gamut, however, from those insisting that SSPs should have as little interaction as possible with the police and never partner, to those who intentionally brought them into the space, with one describing,

> *When you try to run 300 people through a place in one day, you're going to have conflict. So to protect programs from conflict and make sure there were no hassles when they were here, we had the police come and patrol it. And when the participants found out the police were there to protect their ability to get the services safely? Their whole attitude changed. He was not here to hassle them, he was not here to do investigations or anything like that, he was here to protect the peace so that people could get their services.*

Another person described their local sheriff as initially threatening to jail anyone who tried to operate an SSP, but after open conversation they realized what he wanted was transparency – open bylaws and awareness of what was really occurring at the SSP. *"I have a great relationship with him now, he's very, he's one of our biggest allies now, to be honest with you,"* he said.

Other advice stakeholders gave regarding working with law enforcement included:

- Remember to frame asks of law enforcement with a public safety lens, not a public health one. We want them to do *their* job as well as possible, not do our job.

- Always prioritize participant safety when building relationships with the police. NEVER let police view your program as a source of information (it's a slippery slope).
- Build close relationships with people who can hold police accountable (e.g. city council, mayor, the media).
- Be aware of how difficult it can be for staff to witness police/participant interactions, especially staff of color, and provide support and counseling to address this.

Legal counsel

At the in-person stakeholder meeting there was a clear recommendation that SSPs identify legal counsel – either independently or through their city health department or other structures – who can help when inevitable legal challenges arise. One stakeholder recounted,

> *We hired a lawyer who worked in the Attorney General's office, and worked in a unit that worked on human trafficking, sex crimes, those types of things. And then he was a prosecutor with the Salt Lake County DA's office. So we're leveraging his relationships throughout the state to help mediate concerns with law enforcement, add some credibility to our program, add some protection for our staff, so that if something happens we have representation immediately. So that's been helpful.*

Community members

As described in the previous section, perhaps the biggest barrier to SSP program implementation can be objections from members of the surrounding community. Syringe litter was the most commonly mentioned reason that community members complained. Stakeholders were clear that s*yringe litter can be mitigated but there need*s to be funding for safe disposal and community pickup, which health department allies can help secure. Secondary exchangers can also be utilized for this purpose, by incentivizing pickup and return of used syringes at least as much as distribution. Others described working with law enforcement and the Department of Public Works or Parks and Recreation, who are generally responsible for syringe pickup; demonstrating that an SSP is proactive about cleaning syringe litter shows a commitment to public safety, and willingness to be a good neighbor, which can often help when community concerns arise.

Generally, community concerns result from a lack of understanding about how SSPs function. One stakeholder noted,

> *One of the programs is in this super-gentrified spot, and that's the one place where there's consistent problems...we often find the most buy-in is from rural conservative districts because the people dying are the people that they personally know. And so they want our programs to help fight overdose. And help fight disease among people they personally know.*

Given this, willingness to have open conversation with neighbors and invite them into the space can typically go a long way. There were multiple stories of building friendships, then finding that the community resistance dissipated. *"My goal is to get a meeting with the residents to start to humanize the problem to be like, 'We're you're neighbors! Everyone here is your neighbor,"* said one.

Another stakeholder explained her program strategy of employing a good neighbor agreement that every party can sign off on, saying,

> *I believe very heavily in the good neighbor agreement. It's very awkward initially because you sit down with a mediator, law enforcement, some neighbors….then talk about what you're going to do and how you're going to do it. And then everybody signs off and then they allow you to just do it and implement it. I like that. Because honestly the good neighbor agreements are very nebulous but people feel heard.*

Bringing visitors to the SSP

A number of stakeholders described inviting community members – including city councilmembers – into the space to see what really occurs. *"So many people have never been to a syringe access program before, sometimes they think it's just a free-for-all,"* said one, but once they come by they realize it is orderly, important work that respects fellow neighbors and participants alike. Many stakeholders talked about inviting community members, funders, healthcare providers, and city councilmembers to visit their SSP, to see the good work that was happening. *"I think it's important to get folks to come inside to see what it is, see what it isn't…and talk about all the other services that we offer,"* one explained. However, resistance to "poverty tourism" was also noted as important. Non-participant visitors should only come one at a time, and law enforcement or similar authorities should only come to the SSP when participants are not seeking services. Respect for participants and their privacy is paramount.

One stakeholder spoke specifically to her refusal to allow any visitors when participants are present:

> *We get a TON of requests for people to visit and check out the syringe exchange, or shadow – we don't do that when clients are in the building, but we get a lot of pushback around it…on the whole, people shouldn't be viewing the syringe exchange when there are clients there…I do bring people in and talk about what we do, I just don't do it during business hours. There's just a weird voyeurism thing going on. Like, do you do this at primary care doctor's offices?*

Relationships with other SSPs

Multiple stakeholders consulted during this process described substantial challenges with other SSPs in the region that didn't follow best practices. Common complaints were extremely limited hours, failure to distribute naloxone, and restrictive services or strong pushes toward abstinence-based recovery instead of harm reduction. One stakeholder elaborated,

> *The other syringe exchanges [here] are 1:1. With the limited hours and the 1:1, you're not really doing syringe exchange; you're not getting people what they need. And politically, it's a little bit of a nightmare for us doing needs based, because they're always talking about how they're 1:1, and I don't know what the deal is with their statistics – they claim that they get 97% of the syringes they give out back, which is against all odds. To everybody who works in the field, that's highly suspicious – but to everybody out in the community, we get calls all the time saying, "Why can't you do what they do?" Because we get back – sometimes 70%, which I think is incredibly high for a needs-based program…. when other programs are making speeches about not doing needs based, and we're having to defend what we do over and over again, it gets hard.*

Others described the difference between independent, standalone SSPs and other programs that integrated syringe services into their other offerings, recalling situations where *"you had to give your whole life story to even get 5 syringes"* or *"absurdly long or inappropriate intake processes when the person wasn't even looking for any other services."* Recognizing that SSPs should exist primarily for the purpose of distributing sterile syringes and improving drug user health overall, attention must be paid to SSPs that have supplemental service requirements causing barriers for participants in achieving these primary goals.

Not all relationships with other SSPs were challenging, however. One stakeholder explained,

> *We’ve never had a problem getting supplies because of incredibly generous other programs. And now we’re able to be that for other programs. One of my favorite things is if someone comes in from far away to get some naloxone or something, and they leave not even being able to see out of the back window of their car because we’ve convinced them they can start a syringe exchange and we’ve given them a bunch of supplies.*

Relationship with Researchers

Relationships with researchers was an area with wide variation of response among stakeholders. Some had little to no experience with researchers. Some worked closely with health departments or other organizations to gather and analyze their own program data, to better understand services – including naloxone distribution, overdose reversals, and geospatial analysis of program services.

Others had generally negative experiences with researchers, and as a result were careful about research partnerships:

> *We’ve been approached by a lot of students that have projects and things like that, and we’re very very selective with who we work with…to make sure that their project aligns with our mission, and with how we carry ourselves.*
>
> *Oftentimes I don’t get the information back, which I do ask for all the time. So that’s a little annoying...this is the hot du jour moment for harm reduction researchers so it’s like, “Oh, let’s try to parachute in and not have relationships…I don’t like that.*

However, some had very positive outcomes from researcher relationships:

> *We also work with someone who works on hepatitis C treatment navigation. They are part of a study to look at different types of treatment methods, so they utilize some of our programs to recruit individuals for those surveys. And that’s been very beneficial, because some of those participants would never have been able to get into treatment without the incentives and opportunities of that study. Now that doesn’t mean you don’t have to be cautious, and…make sure the people who are participating in the research are really going to be protected.*
>
> *The people that use our program benefit greatly from the fact that researchers are interested in what’s going on. The big grant that we won to offer onsite PrEP versus navigation to the community is one of the benefits… there’s a large group of people who use are program who will end up getting PrEP and getting cured of HCV at no cost because we’re doing this as an NIH trial. Or [another project we’re doing is] the onsite naltrexone versus buprenorphine, [which] has made it so people have access to medication-assisted therapy. These pathways didn’t exist before these trials came so I think it’s been good.*

While most research comes with minor incentives for the research participants, compensation for the SSPs, who also bear a burden of the work, is more challenging. *“It…builds our credibility when we have these relationships so I can call on these folks if we need them to back us up,”* said one stakeholder. *“[But] it would also be easiest if they just paid us. There’s all kinds of ways they try to compensate us…loan us an intern, whatever, and I’m like, ‘Just cut us a check.’”*

Methods of data collection

Stakeholders reported four common ways that their SSP collected service data:

1. Minimal data collected during each encounter on paper forms; in this case forms were manually entered into Microsoft Excel, REDCap, or scanned for data entry,
2. Electronic data collection at each encounter, where data were collected via an app on a staffperson or volunteer's mobile phone, uploading to a central database once the phone connected to wifi,
3. A longer, one-time intake form at the time a client enrolled in the program, followed by extremely minimal data collection (simple counts of service) at each encounter, and
4. Very minimal ongoing data paired with longer surveys conducted periodically. Variations included a 15-minute survey every 3 months, with same questions to allow for monitoring of trends, and a subject-specific point-in-time survey every 3 months or so, only containing 4-5 questions each time.

Exceptions to this included people using Ryan White funds or offering low-threshold buprenorphine, both of which come with additional (and sometimes onerous) data requirements.

In most cases, SSPs use a unique code identifier to ensure anonymity, especially when a code was needed in jurisdiction for legal reasons. However, stakeholders noted that this code must be comprised of things that are always remembered, and can be recreated correctly each time, both for simplicity for the participant and integrity of the data collected. At the in-person meeting, several stakeholders argued that using unique identifiers is unnecessary, unreliable, and potentially harmful. Alternatively, some SSPs did not use unique codes for services and instead insisted on only collecting aggregate service data, nothing tied to an individual; this varied by jurisdiction and regulation. Everyone agreed that it was important to silo services so SSPs aren't bound to HIV testing requirements for collection of names, and all data needed to be anonymized for participant safety.

Stakeholders were clear that whatever the exact method of data collection, data should *never* get in the way of receiving services:

- Participants should never have to provide personal data in order to obtain the syringes they need, and data collection is never a reasonable excuse for prohibiting secondary exchange programs.
- SSPs need to create data policies to protect participants. Data is often used as a tool to criminalize clients, especially if it is shared with a health department or other government agency.
- Individual data collection should be opt-in only, with truly informed consent – be clear with participants about how and when data will be used, and what trade-offs there are if they choose not to share data.
- Do not compromise on data ownership. It is critical for community agencies to house and control their data, including who and when the data can be shared, and in what form.

Minimal data

Data collection requirements can be overwhelming for SSPs, and typically satisfies requirements of funders, rarely taking into consideration what's best for program participants. *"We want people to be able to walk in and out within 60 seconds if they want,"* said one stakeholder. *"So we're really focused on making sure that any information we're collecting is worthwhile, that there's a point. We don't want people to have to feel burdened with having to give up anything extra we honestly don't need."*

When asked about the data they thought was essential to collect in some form (whether during each encounter, in aggregate by program staff, or through cross-sectional surveys), stakeholders generally agreed on the following:

- **Demographic data: age, ethnicity, and gender.** This allows programs to know whether they are serving the right people, and who might be falling through the cracks. For programs using a unique code identifier, these demographics can potentially be incorporated into the code, making it easy to track them each time without a separate effort to gather the information at each encounter.

- **Number of people coming in for services**. Both number of unduplicated participants and number of duplicated encounters are valuable to collect, as well as number of new people enrolled.
- **Number of syringes distributed**. Some also thought it was important to track the number of syringes collected for disposal, though there was much disagreement among stakeholders, with some thinking this data was inaccurate, biased, and frequently used against a program.
- **Naloxone kits distributed, overdose reversals.** When applicable, information about drug tracking equipment distributed (e.g. Fentanyl strips distributed, whether used, and results) was also considered beneficial.
- **How many people you are exchanging for.** Many participants work as secondary exchangers, whether officially or unofficially, and collecting this information can be useful to a program especially when community politics are pushing for 1:1 exchange, not a best practice.

Some stakeholders suggested that HIV or HCV status was also very important to collect, especially if testing was offered on-site. During the in-person stakeholders meeting there was strong opposition to this idea, suggesting that while conversations about HIV and HCV status were important, recording that information as a program metric could potentially be used against program participants. One stakeholder specifically recommended having HIV or HCV testing available on site, but only from an external provider who does not share results with the SSP, so the *participant* owns the information about their status and can decide whether to share it.

Stakeholders also emphasized the importance of qualitative data collection, about service provision in general and participant satisfaction in particular. While not usually required by funders, this type of data is often the most useful for continuous quality improvement of the program itself, and should be valued.

Examples of data that SSPs used to collect but stopped, either because the items were deemed too onerous or not useful include:

- Invasive questions around risk behavior
- Sexual orientation/sex-related questions
- Provision of condoms
- Syringes in
- Hygiene kits out (number out still collected, but not to whom)
- Drugs being used
- Zip code/street where participants hang out
- Actual linkage of referrals (as opposed to providing the referral)
- Preferred syringe sizes
- Mood/mental health

However, in addition to the minimal data, some stakeholders did report the supplemental data they had found particularly useful in their service provision or advocacy over the years. Several stakeholders noted that this information need not be collected at every visit, but could be obtained through periodic (i.e. quarterly, annual) surveys. Examples of these data include:

- Whether the participant has witnessed an overdose, or overdosed themselves
- Housing status, especially current or former homelessness
- HCV status
- Naloxone usage reports (if used, did the person survive, how many doses were needed, how much time passed between doses, whether anything was strange)
- Behavioral data around sharing of syringes or injection equipment
- The physical location and type of setting (e.g. car, house, park) where a participant last used and last shared equipment (particularly to drive site selection)
- Primary language (for hiring)

- How many times a participant injects per day
- How many years a participant been injecting
- Whether the participant is in a methadone or buprenorphine program
- Number of vaccines provided

Definitions of program success

In each phone conversation and during the in-person meeting, stakeholders were asked how they defined success of an SSP. Some had quantitative answers typical of the data measured by funders: number of people served, number of syringes distributed, number of naloxone kits distributed, number of HCV tests performed, number of people referred to treatment, reduction in overdose fatality rate, fewer overdoses, lower HCV incidence in the jurisdiction. One broadened the description to "a reduction in morbidity and mortality associated with injection drug use." Another summarized their program's outlook, saying that the only real measure of success was, "Are participants able to access all the equipment they need to be as safe as possible?"

However, most stakeholders immediately underscored the point made by one: *"We tend to think in those quantitative terms, but you can't miss the qualitative benefits, either."* Customer satisfaction is one piece of that:

> *If somebody isn't happy with the service we're providing, we want to look at that, look at what we're doing. I mean, really, it's almost like sales. You go to the place with the best burger – I think it's really like that for this type of work.*

Examples of ways these types of success, which stakeholders argued are perhaps more essential than measures related to reduction of infectious disease, include:

- Number of participants who have evolved into volunteers and staff
- Proportion of staff who are former participants
- Proportion of staff that have lived experience with homelessness, incarceration, substance use
- Whether participants are more empowered, able to tell their stories, share resources, and develop skills for leadership and self-efficacy
- Whether participants feel ownership of and satisfaction with the program
- Whether participants feel an increased sense of their own human rights and connection with others
- Whether participants feel staff treat them with respect, and honor their confidentiality
- Any positive interactions with law enforcement, as a result of having an SSP membership card
- Documentation and procedures that work well and result in positive site visit findings

One stakeholder reminded that success might look very different for each participant, but each success is meaningful:

> *There are so many levels of success with harm reduction. If someone says, "I used to use heroin, and now I use marijuana," that's a success story. "I got into care, I got my kids back," that's a success story. "Since I have to be at work at 8, I've learned to get up an hour earlier so I can use and still get to work on time and not get fired." Everything is a success story. There are so many different angles and vantage points, for the participants who are coming in. All of this is success.*

Funding

There were two clear themes from all discussion of funding for stakeholders during this project: 1) Diversification of funding sources is critical, and 2) There is never enough funding. Stakeholders described funding sources from CDC (typically for HIV prevention), SAMHSA (typically for mental health services or low-threshold buprenorphine), HRSA/Ryan White (Early Intervention Services funding, which can be used to pay for almost everything but syringes), and various federal, state, local, and private grant opportunities. Some have had success with funding from churches, beer and cannabis clubs, and rotary clubs. These sources of funding all usually come with “strings attached,” not all of which are aligned with best practices, or benefit participants. Many funding sources do not pay operating costs, and most do not allow for purchase of supplies, especially syringes, naloxone, and drug testing kits (e.g. Fentanyl strips). Sometimes when these supplies are allowed, it is only in a very limited fashion; one stakeholder noted, *“The health department pays for our Narcan – it’s in health department statute that they have to. So then they started trying to limit it, where it was limited to one per person, and all the other exchanges agreed to that. They were saying if you give them more than one then they won’t call 911.”*

Sources and types of funding matter, because in addition to the money itself there are other implications. Funding usually affects data collection, including both the data required to be collected and the ease of data analysis and reporting (i.e. sometimes the data reported to a funder never comes back to the program at all). When contracts flow through city or county departments before reaching the SSP, often 1/3 or more goes to indirect costs and never make to the program, which is likely stretching every dollar to maximize service provision in a resource-scarce environment. So many SSPs operate without the funding to purchase enough supplies to meet demand or to staff adequately, which means programs grow without infrastructure and capacity to support, spreading staff thin and causing high turnover and gaps in service.

Advocating for appropriate funding support is important for SSPs. Recommendations from stakeholders to improve money flow included:

- Health department funding should <u>not</u> be reimbursement-based. All funders should minimize the financial accounting burden on SSPs, recognizing how much people are doing for so little.
- Provide technical support for grantwriting – it is unreasonable to expect people with lived experience to compete with highly staffed development departments in other agencies, yet independent SSPs staffed by people with lived experience are most often the best ones to do this work. They need support to be competitive in a funding environment where expensive grantwriters are often the ticket to success.
- Cities and counties should consider paying for medical waste supplies or transport, which is a large drain on resources for many SSPs. Some jurisdictions do this and it is very beneficial for SSPs.
- SSPs should not change programs in response to funding opportunities; however, they should consider adapting their narrative to bring in new opportunities (e.g. frame their work as violence prevention, rather than drug user health or HIV prevention).
- Funders should offer resources to fund mental health support for SSP workers experiencing trauma in the workplace, which is common and typically unaddressed due to lack of funds for professional intervention

Stakeholders also acknowledged that funders can be powerful allies of SSPs, and it is good practice for SSPs to connect funders who don’t “get it” with funders who do. During the in-person meeting there was a robust discussion of funder relationships; themes included the importance of keeping funders close to the work that’s happening; educate, advocate, and build relationships with as many funders as possible; and send thank you notes whenever you can. Funders can also support capacity-building among SSPs, as one stakeholder noted:

> *We’ve had a lot of funders send people from red and purple states to us to learn about how we hustle and do our thing. So sometimes what would be helpful with the funders if they can’t do a large investment is to invest in helping new programs that are interested, and potential future groups that could be funded, to provide them with some kind of mentorship to help build up programs’ capacity to hustle and to help build up programs understanding of how to do things with very little money. They should constantly be helping programs to learn.*

Wish list for program expansion

When asked about how they would expand their programs if more funding were available, stakeholders easily generated a wish list:

- An abundance of supplies, to increase volume of service
- Increased staffing to allow expanded hours, especially outside the 9-5 window
- Low-threshold buprenorphine and suboxone access for participants on-site
- A drop-in center, allowing for programming that connects to people’s humanity and meets their basic needs
- Purchasing (another) mobile vehicle, either a mobile van or even just an organizational car
- More clinical services for people who use drugs (including primary care)
- Safer smoking and snorting kits
- More HIV or HCV testing
- More outreach services
- Drug checking services, including dosing infrared disks
- Opening of an overdose prevention site (a.k.a. supervised injection site) – though this would require more than just funding to make possible
- More streamlined data entry
- Legal aide at every site
- Case management services
- Legislative advocacy
- True supportive housing for participants, or at least a harm reduction-based shelter

It is worth noting that during the in-person meeting, several representatives from SSPs with a longstanding history of service were worried about going too far in terms of program growth and undermining the progress that was made. Some programs have experienced debilitating community backlash from one misstep or a changing climate, and this has jeopardized the ability to provide all participant services. This is a good reminder of the extremely challenging and unpredictable political environment in which all U.S. SSPs operate.

Role of advocacy

> *That’s the thing with syringe exchange, you have to defend it all the time! And you’re speaking for people that can’t speak for themselves in many ways, or don’t speak for themselves, or people don’t want to hear. So there’s a heavy burden to make sure that you get it right.*

Given the constant political and legal challenges for SSPs, it is no surprise that advocacy is a constant part of SSP providers’ work. Typically SSPs must agree to extra scrutiny and overregulation just to get laws passed that will allow them to operate legally, in any form. Agreeing to restrictions in order to start an SSP where none exists may be logical in the short-term, but stakeholders were uniform in their assertion that this must be paired with advocacy to change policies and ultimately modify services to meet best practices. Needs-based distribution was the most commonly-cited version of this. However, other policies including restrictions on service location. That SSPs cannot be within 1000 feet of a school or childcare center was a common one, which presents a problem for many SSPs in urban areas and those that utilize a backpack-based outreach model. However, one stakeholder couldn’t be within 50 feet of any dwelling in her jurisdiction – this essentially made service provision impossible. Changing this regulation was essential, and required her to invite each city council member in the city to come see what they were doing, which was ultimately a successful strategy.

There were other examples of SSP advocacy resulting in significant changes to harmful policies: one stakeholder helped shape the new statewide legislation. The resulting successful legislation stipulated that SSPs do not need to ask anyone for approval to operate in that state; rather, they simply notify the government that they plan to operate, which provides legal cover. Another example involved an SSP's response to their health department's position on naloxone:

> *They wanted us to open the boxes and give one dose per person. We refused and they cut us off. It somehow got to the media. And that fixed it. We've been able to give out whatever we need, and when they cut us off, Dan Bigg sent us Narcan…The box says do not open or separate. So we just plowed forward and said we would not open or separate. Eventually it worked.*

In general, making compromises to get an SSP off the ground was seen as a reasonable course of action. However, as one stakeholder said, *"It's really important to not allow for this slippage into 1) minimizing and demonizing needles, and 2) posing that SSPs are this super human, Mary Poppins kind of operation that can not only help people avoid HIV programs but can help them find [themselves], repair relationships, get into recovery, and get a PhD."*

Along the same lines, two stakeholders spoke about the importance of remaining true to the tenets of harm reduction, and not compromising the core activist nature of the work:

> *If we do SSPs right, we need to keep harm reduction at the core of it. This is about the message of empowering drug users to take care of their own health, both at the individual and the collective level. If we're not doing that, we're missing it. It's about empowerment … Sometimes I think in the drug user world we've kinda lost that edge, and we need to go closer to it. We need to do more of the political. Otherwise we become this technical, evidence-based intervention, HIV prevention world. Which is not necessarily harm reduction.*
>
> *Syringe service programs should offer syringes and be unapologetic about it. I feel like a lot of times syringe service programs are like "We're really out there to connect people to social services and do testing. And we kind of use the syringes as this thing we have to do to get people in." I think that's really dangerous. We need to own our rhetoric and not be apologetic because it's incredibly important and people should be thanking us. We shouldn't be apologizing for what we do, they should be thanking us. And giving us money.*

In the end, stakeholders offered a series of recommendations for supporting advocacy on behalf of SSPs:

- Default to the most liberal or permissive policies first, then work backward to reach compromise if really needed. Don't yield more than will absolutely be necessary to succeed.
- Develop a community response plan right from the start. A NIMBY response from the community is entirely predictable, and should be planned for.
- Be open to strange bedfellows – sometimes allies come from unexpected places.
- Consider hiring a strong public relations person, or someone with media experience – or see if anyone is willing to provide those services to your SSP pro bono.
- Plan a high-profile, regular syringe pickup event, where you wear your organization's t-shirts and publicize widely. This helps raise awareness of your work and tells the community you care about safety.
- Be brutally honest – speak up in as many venues as possible about the ways in which policies harm you and your participants!

Keeping up with changes in the field

One of the biggest strengths of the harm reduction community is the connections that harm reductionists have with each other. Almost universally, when asked about ways they keep up with changes in the field and stay aware of best practices, stakeholders responded, “I keep in touch with national partners!” or “I attend the harm reduction conference every other year.” Stakeholders also mentioned the *harmred* and *OSEN* listservs and social media (especially Facebook and Twitter) as ways they stay abreast of new trends and information, as well as connections and resources supported by the Harm Reduction Coalition. One stakeholder explained:

> *A lot of it is constant conversation with other partners all around the country, nationally. I have relationships with people all over, just because I’ve been doing this so long…And sometimes somebody has come up with such a unique idea, and we’re like, “Could we implement that? If we did, what would that look like? How would that operate?”*

The sharing of information in order to benefit others is a cornerstone of harm reduction work. The generosity with which stakeholders shared their time for this project was evidence of that, with their passion and insights driving the development of a performance standards document that will guide future SSPs around the country.

Appendix A

Stakeholder Participants

First Name	Last Name	Agency Affiliation
Christopher	Abert	Indiana Recovery Alliance
Aaron	Arnold	Prevention Point Pittsburgh
Alice	Asher	CDC
Danae	Bixler	CDC
Dita	Broz	CDC
Heather	Bush	Utah
Lauren	Canary	CDC
Robert	Childs	JBS International
Haley	Coles	Sonoran Prevention Works
Natalie	Cramer	NASTAD
Donald	Davis	Volunteers of America Mid-States
Sarah	Deutsch	Washington Department of Health
Maya	Doe-Simkins	Chicago Recovery Alliance
Nora	Fuller	AIDS United
Rebecca	Goldberg	New York State Department of Health
Carol	Helwig	Boulder County Public Health
Mary	Howe	Homeless Youth Alliance
Grace	Keller	Safe Recovery
Michael	Kilkenny	Cabell-Huntington Health Department
Paul	LaKosky	NASEN/Tacoma Needle Exchange
Pamela	Lynch	Harm Reduction Michigan
Kerry	Nolte	New Hampshire Harm Reduction Coalition
Kiefer	Paterson	Harm Reduction Coalition
Laura	Pegram	NASTAD
Mary	Pounder	Comer Family Foundation
Lisa	Raville	Harm Reduction Action Center
Daniel	Raymond	Harm Reduction Coalition
Amanda	Reese	Open Aid Alliance
Patrick	Rezac	One Voice Recovery
Monica	Ridgeway	Kentucky State Health Department
Christine	Rodriguez	Behavioral Health System Baltimore
Hansel	Tookes	IDEA Exchange
Rafi	Torruella	Intercambios Puerto Rico
Shoshanna	Scholar	Los Angeles County Department of Health Services
Gretchen	Weiss	National Association of County and City Health Officials
Jasmine	West	NASTAD
Brandie	Wilson	Humboldt Arena Center for Harm Reduction
Sarah	Ziegenhorn	Iowa Harm Reduction Coalition
Dominick	Zurlo	New Mexico State Health Department
Miss Ian		San Francisco Drug Users Union