



Surviving and Thriving: Lessons in Successful Advocacy from Drug-User Led Networks



The International Network of People Who Use Drugs (INPUD) is the premier global organisation for network-driven drug user organizing and advocacy. INPUD members, who are regional peer-led groups of people who use drugs, lead the movement to abolish damaging policies, defend human rights and promote the health of people who use drugs. INPUD is ideally placed, and well prepared to assess its members' needs and fulfil them, providing human, financial and technical resources that optimize the quality, impact and outcomes of their work.

CONTENTS

CHAPTER	PAGE
1. Introduction	05
2. Case Studies	07
2.1 South Africa Network of People Who Use Drugs “I wish that everyone can have it” – Bellhaven Harm Reduction Centre, Durban, South Africa	07
2.2 Eurasian Network of People Who Use Drugs Gains in OAT Access in Eastern Europe and Central Asia: Peers as Experts	14
2.3 Urban Survivors Union (United States) NarcoFeminist Story Sharing: Developing Alternative Narratives, Producing New Knowledge, and Ensuring More Responsive Advocacy	20
2.4 Indian Drug Users’ Forum Budget Advocacy: Ten million dollars for key populations	25

1.0 INTRODUCTION

“Why do I continue to do what I do? Seeing the incredible humans who access [our] services. Friends and colleagues [have] passed away from ways that could have been prevented – time and time again.”

Angela McBride, South Africa Network of People Who Use Drugs (SANPUD)

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INPUD commissioned and launched *Surviving and Thriving: Lessons in Successful Advocacy from Drug-User Led Networks* to showcase what local and regional drug user-led networks can do when they have support from a global umbrella organization – and adequate resources through accessible and sustainable donor funding; the innovative projects they describe can inspire future work, mobilise people to transform harmful stereotypes and policies, and inform donor strategy and decision-making.

Network-based approaches to advocacy ensure that “...issues that affect a variety of lived experiences are represented, rather than one; and (networks) can select their own representatives, which ensures a more democratic process of self-representation.”¹

Well-resourced and organised networks create a supportive, self-sustaining environment that can influence policies, laws, or program changes. But funding is needed to develop, support and sustain networks so that their power and influence is not lost.

...there’s this corporate-esque culture that’s infected some organising, where you think, ‘Oh, well, we can just do a day-long presentation, we can just do a workshop,’ No! This, this material is way too incendiary, it’s way too deeply rooted, and you leave people triggered and traumatised and vulnerable then, with no community to come back to, to figure it out together. You need

1. Belle-Isle, L., Pauly, B., Benoit, C., Hall, B., Lacroix, K., LeBlanc, S., Sproule, R., Cater, J., Johnson, M., & Dupuis, G. (2016). *From One Ally to Another: Practice Guidelines to Better Include People who Use Drugs at your Decision-making Tables*. CARBC Bulletin #14, Victoria, British Columbia: University of Victoria.

to have long-term investment and commitment to people if you're going to go through this storytelling process.

Caty Simon, Urban Survivor's Union

Despite their power and achievements, drug user-led networks are not well-funded or valued. INPUD notes that key population networks, including those of people who use drugs, continue to be under-funded and are treated by disease response programs as vectors, instead of valuing them and investing in them as equal partners. For example, a paltry 7% of the total international donor funding for harm reduction goes to community-led organizations, while only 2% of overall funding for HIV programmes targets key populations, including people who use drugs.^{2,3}

The networks featured in these case studies took on projects that confront the most pressing issues of our time, such as COVID-19, government crackdowns on human rights activists and gender power imbalances. Having directly experienced and survived harms that include discrimination, incarceration, police violence and overdose, people who use drugs and their advocacy networks are uniquely positioned and motivated to implement community-response work.

This report aims to show how and why peer-led networks should be given primacy by donors and recognised for their work. It demonstrates how peer-led drug user networks have strategised and mobilised to leverage limited resources to positive effect, and how they are thriving in adversity and crisis, in the context of insufficient and unstable resources. Highly restrictive funding, underfunding – and unsustainable funding for drug user-led networks – undermine their ability to do transformative work, are anathema to the universally-held value of the meaningful involvement of key populations, and detrimental to social justice and human rights.

Achievements highlighted here – forming the first regional community advisory board (CAB) to ensure opiate agonist therapy (OAT) in Eastern Europe and Central Asia; providing medical services during COVID-19 lockdowns to homeless people using drugs in South Africa; disrupting stereotypical narratives about women, transgender and non-binary people who use drugs in the United States – were supported and enhanced by INPUD.

These projects have restored dignity and purpose to the lives they have saved. Many individual service users, such as Menzi, who is a peer worker at Bellhaven Harm

2. AIDSfonds. (2020) Fast track or off track? How insufficient funding for key populations jeopardizes ending AIDS by 2030. Available at: <https://aidsfonds.org/assets/work/file/Factsheet%20general.pdf>.

3. Ibid.

Reduction Centre in Durban (see South Africa Case Study), have channeled their gratitude at being seen, embraced, and served, to become next-generation leaders, providing their peers with the same compassion and appropriate, quality care that once lifted them up.

A smart investment in drug user-led networks is essential for the achievement of shared global health and equity goals, such as those under the UNAIDS-championed campaign, “10-10-10.”⁴ Effective network projects, such as the ones highlighted here, urgently require adequate and sustainable support, so that they can be optimised, maintained, scaled, and shared. Widespread adaptation and implementation of these innovations have the power to change individual lives and transform policies and society.

Dedicated funds for networks of people who use drugs, and removing illicit drug use-related barriers, namely criminalization, that limit or prevent access to funding and the meaningful participation of people who use drugs -- are essential to support extraordinary community-led programming, such as those highlighted here. Bolstering this work will help build new generations of activist leaders, for a more inclusive, dynamic and effective global health and human rights movement that includes, and benefits from, the capacities of people who use drugs.

4. In which less than 10% of countries have punitive legal and policy environments that lead to the denial or limitation of access to services, less than 10% of people living with HIV and key populations experience stigma and discrimination, and less than 10% of women, girls, people living with HIV and key populations experience gender-based inequalities and all forms of gender-based violence (UNAIDS).

2.0 CASE STUDIES

2.1 BELLHAVEN HARM REDUCTION CENTRE

“I wish that everyone can have it”

Bellhaven Harm Reduction Centre, Durban, South Africa

Durban’s Bellhaven Harm Reduction Centre was “...birthed from one of the most traumatic experiences in all of our lives - COVID,” says Angela Mc Bride, Executive Director of the South African Network of People Who Use Drugs (SANPUD). SANPUD was founded in 2015, with support from the International Network of People Who Use Drugs (INPUD), Mainline and TB/HIV Care in Cape Town. “After seeing the work that other drug user organisations and allies have been doing across the world, it was vital that people who use drugs in South Africa have the same representation; as a result, SANPUD was born. We have progressed from seeing and bringing experiences to actioning what we’ve learned and what we’ve seen, with the intention to mold it to a South African context,” says McBride, adding, “It is such an incredible collaboration. It was only by having multiple actors with the same dedication coming together and collaborating that this could be possible.”

Bellhaven Harm Reduction Centre, which has become a national and global example of a successful evidence-based solution to challenges facing people who use drugs, such as access to opiate agonist therapy (OAT), started as a public-private partnership. “Lockdown was really an opportunity in many ways to shift the narrative in Durban, from a very prohibitionist stance to one that is much more understanding and supportive of harm reduction,” said Michael Wilson, the Executive Director of Advance Delivery and Access South Africa, one of Bellhaven’s co-founders.

Left: Prepared care packages handed out at Bellhaven.

Right: Members of the Bellhaven team.



As South Africa was going into a strict lockdown, Belinda Scott, Durban's deputy mayor, approached Michael and Professor Monique Marks, the Director of the Urban Futures Centre at the Durban Institute of Technology, because the city needed an intervention to help people and take them off the streets; 40 to 60 percent of the city's homeless people were going through forced withdrawal. "People from government, including the police, and the broader community became very, very aware of what OAT was, and how withdrawal needed to be managed in a more medicalised and also more humane way," says Monique.

Monique and Michael, with their collaborators (see Box, "Creating Bellhaven") launched a short-term OAT programme in an underground parking lot in the Moses Mabhida Stadium, which became a temporary homeless shelter during lockdown. People were also offered tuberculosis (TB) and HIV screening and testing; they were re-initiated on antiretroviral therapy, TB treatment and other medications for chronic illnesses, and linked with public clinics and Bellhaven. Michael says it has been "...a really important public health opportunity for a group of people who often fall through the cracks of the traditional public health system."

Monique explained how Bellhaven developed from a short-term OAT programme into a harm reduction centre, because of: "...the impact that it had on transforming people's lives - and allowing people generally to feel safer, because there weren't a lot of homeless people wandering around looking for drugs during the lockdown."

The short-term OAT programme had an impact on the surrounding community- and the city, leading it to support a solution for everyone: a more permanent place for people who use drugs. Monique said that "As we got to lockdown 'level three,' when people were allowed to leave the safe spaces [shelters], the municipality did something astonishing: that was to say, 'Here is the building, we want you to run a full-time harm reduction centre.' It was something that we had been contemplating for a very long time, but

CREATING BELLHAVEN

- The **eThekweni Municipality** provides the building, utilities, and 24-hour security
- **Advance Access and Delivery** provides staffing
- **TB/HIV Care** provides the needle/syringe programme and psychosocial support
- **SANPUD**, which advocated for Bellhaven; is the fiscal agent and is involved in its governance; it works on sustainable funding and registering Bellhaven as an independent organisation.

Left: Bellhaven provides a short-term OAT programme.

Right: Peer support workers play a lead role in running the centre.



it sort of sprang out of nowhere, almost as an imperative, from a municipality which had previously been very abstinence-based, and is now very supportive,” adding, “You need partnerships – support to feel safe moral authority to go forward with a program like this.”

Bellhaven provides comprehensive peer-led services; nurses and social workers provide back-up support. Homeless and low-income people who use drugs are welcomed into the centre and its programmes by trained peers, who work closely with nurses and social workers to develop processes and create a user-friendly environment. “I got help,” said Menzi Mavundla, one of Bellhaven’s peer supporters, “Now I’m helping others. So, I’m very, very proud. I got the chance and I used it. Now I’m helping others get the chance... help[-ing] those who have been where I’ve been.”

Peer support workers play a lead role in the day-to-day running of the programme, service delivery, and they work on cultural, social, and wellness events with Bellhaven’s community of people who use drugs. Two other peer supporters run a home-based care programme, delivering psychosocial support, methadone, and other medications to beneficiaries who are unable or unwilling to access services at the Centre.

Monique describes the Centre’s leadership structure as “instinctive - this place could not be governed by people who don’t use drugs... there were so many situations and issues that we could not find solutions to, and if we did, they may not be the right solutions. If we don’t have the input and the support of the beneficiaries of Bellhaven, it will never work.” Bellhaven’s governance structure includes Michael, Monique, the nurses or social workers, our peer support people, three people who are currently part of the methadone programme or have been part of it, and a SANPUD representative. “At the forefront, at the core of it, we as people who use drugs are leading it,” says Angela.

Right: Peer support groups are a critical component of Bellhaven's services.



to talk about drugs, to share with one another, what are our thoughts? What are concerns? What are preconceptions about drugs?”

Monique describes Bellhaven as a low-cost, frugal institutional space. “We could run this program from a tent, we could run it from an underground parking lot - which is what we did, for the first 10 weeks of lockdown. It’s about thinking about how you can, with very minimal resources, run something like this with peer supporters and with very little medical support. You don’t need medical experts, you don’t need psychiatrists, you need a general practitioner, and you need nurses that are responsible for dealing with the medication... it’s low threshold in the sense that we’re not dealing with it as a very highly medicalised program. It’s much more a community-based program, which has a medical component to it, which is essential, but it’s integrated, the space.”

She adds, “The university runs a homeopathic program twice a week, so people have an opportunity to uptake non-allopathic medical routes in combination with what they already taking from Bellhaven. So, it then becomes a training ground or transdisciplinary groupings across a variety of different health sectors... you use it as a service learning, community engagement, continuing professional development space, it becomes very, very powerful.”

Bellhaven has already won a number of prestigious awards since opening, including an Inaugural Team Award from the University of South Africa’s Human Science Research Council and Universities South Africa for an intervention during COVID-19, the 2020 Community Engagement Project Award and recognition as a top “Good Hood”⁵ initiative by the South African Cities Network, which profiled Bellhaven for a national audience.

5. Available at <https://www.youtube.com/watch?v=1SV2FCmmCzI>

Despite the awards and attention that Bellhaven has attracted, it struggles with funding and sustainability. Monique explained that Bellhaven's ceiling is around 200 people; "It's a funding restraint, rather than a space restraint. The main challenge is to be able to afford the medication, which is completely out of our control. Methadone is very expensive in South Africa – it is 10 times the price in the U.S., because it's not on the Essential Drug List yet, and there's only one supplier, Equity Pharmaceuticals. And because this began almost organically, rather than in a very planned way, it's been a real struggle to keep going on a month-to-month basis. We're in the process of applying for a whole number of different grants." Angela adds, "I don't think donors realise how impactful their expectations are directly on us, the community. With restrictive funding there are targets, and a target just means you are meeting a number, not a human...it can't be about that. The mechanisms to link resources with centers like this are a problem. Funding is available but because it is restricted, it is unattainable, especially for spaces that need it. Donors should be looking at the work being done already, the impact being made and the need for sustainability, and tailor their expectations accordingly."

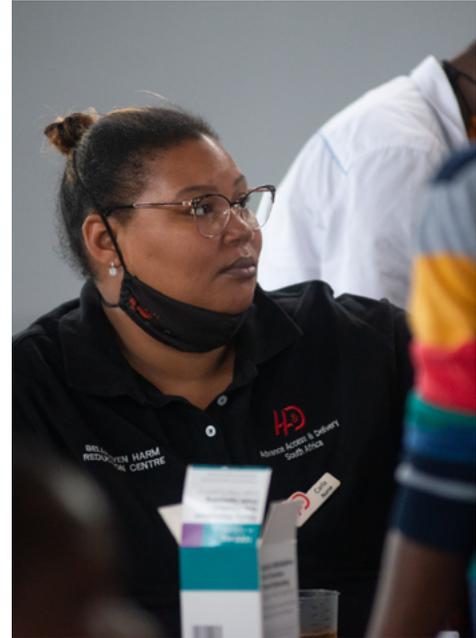
Bellhaven faces other challenges, as Monique explains, "The program has to be understood within a sort of political economy, which is very unstable. These kinds of moments are going to happen, and we kind of have to constantly walk alongside and over them. We had a failed insurrection [in 2021]; everything was completely upside down. And we almost had to start from scratch because it was a week of complete chaos - there was absolutely no food, no petrol, no nothing - everything shut down. After that, we really had to start again, but we stayed open throughout the entire insurrection. We were the only healthcare facility that did – we were proud of that – but some people had to be initiated back onto methadone, and then back into the psychosocial individual and group support that they were participating in before. Melloh and Menzi have tried really, really hard to get people back in, I think now we are back to capacity in terms of groups, but it's taken a while to get there."

"We feel that this is really a model not just for South Africa, but probably for the continent as well. And it's been recognised as such, particularly by the Department of Social Development, who are really wanting to promote Bellhaven as a model for harm reduction across the country. Those are our strengths."

For those who want to replicate the programme, Angela suggests, "Start small and aim high; with a small team, a few people who can give, and who are clear about what they can bring to the table. Ensure that people who use drugs are involved in each of these discussions and that we guide it every step of the way; we should be the ones implementing whenever possible. Start in a welcoming space where you can stay and build. If you want to start Bellhaven, or something like Bellhaven, do it because you

Left: Community vigils are led by peers at Bellhaven.

Right: Peer workers at Bellhaven.



love it and do it because you want to make a difference; do it slowly, like one human at a time, not when it just becomes about the money, the numbers, and the targets.”

Plans for Bellhaven’s future include establishing an overdose prevention room, where drugs can be consumed safely. “The fact that we have government support at a local level, I tell you is a massive thing, because they were very prohibitionist.” Monique explains, “The support that we get from the Metro Police, or our local police is also amazing. They do not come anywhere near Bellhaven. They know our beneficiaries, many are still active drug users - they do not harass people, which is extraordinary. They should only come to Bellhaven if we request them because there’s a real policing problem, like violence or some conflict going on, which is unrelated to our services, but affects our services.”

She adds, “They will bring people to us that they feel would benefit from the services. Now that is a remarkable outcome. It sounds like a small thing. But across the globe, this is very, very unusual. We refer to the police as architects of production because they know the street better than anyone else. So, as we move forward into developing a drug consumption room, they will come on board as trying to help us figure out what this will look like. They are going to have to be the experts.”

“We’re going to continue doing now the things we are doing now, because they are bringing back hope to people who have lost hope, hope to the hopeless,” said Menzi, adding, “I can also relate to that. I thought I was gonna die in the streets... So, a place like this is life-changing.”

Tracy Swan

2.2 GAINS IN OAT ACCESS IN EASTERN EUROPE AND CENTRAL ASIA: PEERS AS EXPERTS

The Eurasian Network of People Who Use Drugs (ENPUD) was started in 2010, and officially registered in Georgia during 2020. It has 142 representatives from 14 countries in Eastern Europe and Central Asia.

ENPUD is particularly interested in ensuring that people who use drugs are represented in conversations and decision-making on access to high quality opiate agonist therapy (OAT) at national, regional and international levels.

ENPUD convened its Community Advisory Board (CAB) in 2020, with support from the International Network of People Who Use Drugs (INPUD), who facilitated funding for the group through a grant from ViiV Healthcare. ENPUD also received institutional support in 2021 from the Robert Carr Fund (RCF), including for a program coordinator. The coordinator convenes the CAB, taking the lead in fundraising, administration and fostering connections with peers and experts.

The CAB has been a mechanism to develop community expertise and for community members to be in close contact with other activists in their countries. In a group consultation, CAB members spoke about how they don't have an academic background, but they have developed expertise and have learned by doing. During some of their first meetings CAB members arranged the "ENPUD CAB School," where they brought in experts to share relevant knowledge.

The ENPUD CAB team meets weekly, with each member taking on some of the work to sustain the group (e.g.: arranging for expert training, reporting, outreach, and communication with pharmaceutical companies). At each meeting, CAB members discussed the current situation of OAT access in their countries, and when relevant, the intersection with other treatment access issues, such as HIV. During the second half of the meeting, CAB members brainstorm solutions to the problems they have identified together. In their joint advocacy work in the region, the group refers to themselves as the ENPUD Expert Council on Treatment (ENPUD ECT).

By 2021, the ECT had representatives from seven countries: Belarus, Georgia, Kazakhstan, Kyrgyzstan, Moldova, Russia, Ukraine and Tajikistan. The ECT's goals are to:

- Mobilise people who use drugs to advocate for access to quality OAT;
- Initiate dialogue with pharmaceutical companies that produce OAT to increase access;
- Monitor the procurement of medicines for OAT programs.

The ECT routinely prioritises representing the needs of people who use drugs in each country. ENPUD CAB School and ECT meetings are open, so anyone can join, even just to listen. Each country sends a focal point to the ECT; when it's not clear who should be the person to join, the focal point is elected through an open competition. Olga Belyaeva, the ECT's coordinator, spoke about the ways the group has prioritised true community participation and input, saying that although many groups claim to incorporate the voices and perspectives of people who use drugs, they may not have true representation. She said, "No... you have an expert with community background, but it's not [a] community voice", meaning a person who has deep, on-going connections to and understanding of communities of people who use drugs and can represent their interests.

The ECT structure enables drug user activists to exchange information about their local contexts and draw on international experts to push for change. Such cross-regional collaborations are useful to other drug user networks for establishing connections that can be leveraged to address common and entrenched problems, including barriers to OAT access.

Historically, access to OAT has been an uphill battle in many countries in Eastern Europe and Central Asia. In some countries, governments refused to implement OAT, while in others OAT is only available in major cities without take-home services, which severely limits access. In 2019, people who use drugs and their advocates reported widespread drug stockouts, as well as insufficiently effective and subtherapeutic OAT drugs paid for by government budgets. In many cases, OAT was initially supported by international sources, such as the Global Fund for AIDS, TB and Malaria (the Global Fund), and it has been challenging to get effective treatments consistently included in state budgets.

Several ECT members now sit on decision-making bodies in their countries, such as the country coordinating mechanism (CCM) for the Global Fund. In October 2021, ENPUD's program coordinator raised resources from the Global Fund to support activists from Kazakhstan and Kyrgyzstan in joining the ECT. In the beginning of 2022, the ECT anticipates welcoming several new members, including representatives from Armenia and Uzbekistan.

During the COVID-19 pandemic, the ECT has continued to ensure access to, and delivery of, quality OAT drugs for communities. Some of the key achievements of ECT members related to OAT access in their countries include:

Right:
Representatives
of the ECT come
from seven coun-
tries in Eurasia.



Georgia

Before the COVID-19 pandemic, OAT was only available at medical facilities, where it was directly observed by a medical provider. During the pandemic, this became a barrier to OAT access for many people. Georgian activists, with support from the ECT, met with government stakeholders and were able to secure access to methadone for outpatient use, a change that positively impacted 14,000 people. After an emergency intervention of the ECT, 3,500 people gained access to quality buprenorphine. ECT members reported that examples provided by members in Moldova and Ukraine helped to inform their advocacy.

Kazakhstan

In Kazakhstan, people taking OAT were arrested for administrative infractions and placed in temporary detention where they were unable to access their medication. Many were experiencing withdrawal symptoms with no recourse. Over the course of six months, Kazakh activists, with support from the ECT, wrote letters and held two meetings with the Ministry of Internal Affairs, which includes the police who oversee temporary detention facilities. As a result of their advocacy, the Ministry of Internal Affairs altered their internal guidelines to include access to methadone for people detained after arrest.

Moldova

When the ECT started their work, buprenorphine was only available in Moldova's capital, Chisinau. Moldovan activists brought together experts and healthcare workers to expand access to other parts of the country. To date, they have secured access to buprenorphine for 36 people outside Chisinau. In addition, they have developed transparent stock management systems for OAT, which have proven helpful for advocacy to expand access to treatment.

Belarus

In Belarus, activists secured a signed protocol for distributing OAT on an out-patient basis, an advocacy issue they had been working on for five years, but were able to make progress on in large part due to COVID-19. The rise of COVID-19 cases, including isolation and quarantine restrictions made it difficult for clients to obtain OAT and made the argument for out-patient access more compelling. Although the protocol is now in place, implementation remains a challenge. Activists are currently working to defend a doctor who has been persecuted for prescribing OAT.

Ukraine

In 2020, the state started procuring OAT directly, paying for it through the state budget. In moving towards national procurement, the government's primary concern was cost; in Ukraine, only lower-priced OAT drugs became available. Ukrainian drug user activists have noted many complaints from across the country about the lack of active substance in state-procured drugs. Initially, the government refused to respond to these complaints and investigate drug quality. Patients reported being shamed and/or sanctioned by healthcare workers for bringing the issue to their attention.

Ukrainian activists, supported by the ECT, were able to convince the Ukrainian government to take the concerns of clients seriously, and test the quality of OAT drugs across seven sites. Support from the ECT made it safer for activists to complain and helped push the government to respond to drug quality issues. Recently, the government public health center responded to activist complaints, claiming that the available drugs meet quality standards, which directly conflicts with the experiences of people who use drugs. Activists will now begin efforts to get an independent, international entity to test for drug quality.

At the same time, the Ukrainian activists and the ECT are working to influence the tendering process for OAT drugs, to ensure it is happening in a transparent way and that effective drugs are reaching the people who need them. Currently, only domestically produced methadone is available in Ukraine, but activists would like to see OAT drugs from other parts of the world, such as Italy and Serbia, become available. They are in the process of negotiating with both government stakeholders and pharmaceutical companies to enable a more competitive market for drugs from outside the country. At the same time, they have also started conversations with domestic producers of methadone, to address issues with quality.

Russia

Russia has one of the most challenging contexts for drug user activists to operate in; even saying the words "opiate agonist therapy" is prohibited by the national criminal code. Russian activists have focused extensively on building relationships with

international experts and have filed complaints about lack of access to treatment in European courts. Activists see clinical trials as a tool to access treatment for the few people who can participate, as well as build an evidence base to help them advocate for access to OAT in the future.

Recently, AIDS Foundation East-West has secured funding to work with ENPUD to identify healthcare providers in three areas of the country that would be supportive of a clinical trial testing the effectiveness of supportive services and treatment support (i.e.: tramadol) for drug users living with HIV, tuberculosis and other conditions. Once stakeholders are identified, ENPUD will do qualitative research to understand the context and build stakeholder relationships. Based on the findings of the initial study, Russian activists, with support from ENPUD, plan to seek private funding to implement a clinical trial that would include 150-200 people, comparing those with treatment support to those without treatment support.

The ECT has made some collective gains that span across the countries members represent. In particular, members have mapped the procedures for drug registration in all of their countries, including mechanisms for quality control and tendering. They created compiled an internal index of registered medicines and formulations (i.e.: liquid, tablet, etc.), narcotics regulators, the procurement process and what information is public. This information has helped ECT members to identify specific bottlenecks that impede OAT access and it informs productive conversations with government stakeholders, pharmaceutical companies and healthcare providers.

For example, in Kazakhstan, activists were able to identify and predict delays in OAT supply, bringing them to the attention of authorities. At the same time, activists initiated a conversation with Molteni Farmaceutici (an Italian company that supplies methadone and oral liquid morphine) about securing an uninterrupted supply of OAT. As a result, activists were able to secure a continuous drug supply earlier this spring, at a time when they feared drug stockouts. However, concerns remain about the supply and distribution of OAT, and activists remain vigilant.

ECT members reflected on why the group was formed, noting that it came directly from community needs and a desire to connect with one another and share experiences. The ECT coordinator spoke about how the group continually revisits how they can best represent community needs. Part of the group's success is due to demand from its members and the personal responsibility each member takes for contributing to the work. A clear delineation of responsibilities, such as taking the lead in negotiating with a pharmaceutical company or arranging for training of ECT members, and frequent meetings have helped the group develop a cohesive structure, where members felt accountable for progress.

As country representatives deeply embedded in communities, ECT members spoke about how access to regional and international experts was useful, enabling them to tap into a variety of perspectives on advocacy strategies, as well as the tools to enact them. At different times, ECT members built on conversations with regional and national experts, experiences from other countries in the region and their conversations with pharmaceutical companies to make progress towards their goals. In many of the examples described in this case study, activists drew on the ECT to highlight an unacceptable situation, to provide good practice examples from respected neighbors (e.g.: Georgia drawing on Moldova and Ukraine regarding outpatient use of OAT) and/or to support activists behind the scenes in their negotiations with government stakeholders. The group's flexibility and the variety of ways the ECT could be involved enabled activists to select the strategies most likely to succeed.

CABs such as the ECT can be effective at developing community expertise, fostering peer connections, strengthening resources and developing and implementing national advocacy strategies. They are most effective when the impetus to form comes directly from activists at the national level instead of using a "one size fits all" approach to providing support for advocacy. The presence of a paid coordinator enabled the group to make connections with one another and ensured that the follow-up steps that the group identified were realized. Historically, support for CABs has been piecemeal and inconsistent, without taking into account the time the coordinator(s) and/or focal points may be spending on CAB-related tasks. Also, CAB members come from various backgrounds, some without full-time paid work or access to needed health services or insurance for themselves or their families. Providing consistent and holistic support for a paid coordinator and stipends for CAB members can reduce these pressures, enabling members to focus on the work.

In environments where it is not possible to form an ECT, support for regional peer learning spaces can help to build relationships between activists and encourage peer exchange. In some cases, these relationships may eventually result in demand for a CAB and/or allow activists to draw upon each other as resources for advocacy without a formal structure. Regional and global networks of people who use drugs are effective vehicles for creating these spaces for peer exchange and providing regional and international expertise to national activists.

Erin Howe

2.3 NARCOFEMINISM STORYSHARE PROJECT: DEVELOPING ALTERNATIVE NARRATIVES, PRODUCING NEW KNOWLEDGE, AND ENSURING MORE RESPONSIVE ADVOCACY

“These stories are so complex that they manage to touch people... [in] the places where people have carefully hidden what remaining stigma they have.”

Caty Simon, Urban Survivors Union

When marginalized communities come together to tell their own stories, it can turn stigma on its head by exposing myths and replacing negative images with ones of agency, nuance, and dignity. Brilliant innovations emerging from spaces for people who use drugs can drive change by keeping movements accountable to the needs of their constituents, and guiding policymakers, funders, and service providers to direct their resources.

Women, transgender and non-binary people who use drugs often face stigma and/or neglect from the general population, including other people who use drugs. “Many drug users don’t fit the White male narrative of drug use; this is what we talk a lot about,” says Caty Simon, a leadership team member and sex worker liaison at the Urban Survivors Union, who facilitates NarcoFeminist Story Share groups. She underscored that women, transgender and non-binary people who use drugs, especially pregnant and parenting people, are often marginalized within both the women’s rights and people who use drugs advocacy communities: on the one hand, women who use drugs do not always feature in the sexual and reproductive health policy agenda; on the other, the harm reduction community tends toward a somewhat de-politicized public health perspective, and often fails to adequately address gender, reproductive or parenting issues.

“The narratives we see reflected of ourselves are so reduced, so stereotypical. The only narrative that is left for us is, ‘It’s a good thing that they took my kids,’ or ‘it was the best thing for me that I went to prison.’ These are the stories we have to tell if you want your freedom, if you want your kids, if you want your methadone. Unfortunately, when we tell them so often, they become the stories we believe.”

To address this, groups of women, transgender and non-binary people who use drugs have been gathering to tell their own stories through the NarcoFeminist Story Share project of the North Carolina Survivors Union (NCSU). “We couldn’t create these versions of ourselves like ‘the me outside drug use;’ we had to look at ourselves as whole people,” says Caty, “Lived experience with all this trauma, without any sort of lens with

which to understand it wasn't helpful, so we started to have... these larger conversations within our groups about our trauma and, and started to try to understand it in a broader context before we could tell some of these stories."

Within the NarcoFeminist Story Share's safe, supportive and facilitated spaces, women, transgender and non-binary people who use drugs develop new narratives about their lives that disrupt shaming tropes, and place intersectionality front and center. They are breathing life into what it means to be "NarcoFeminist," a new and evolving term referring to feminists who use drugs. Adopting this term is a political move, promoting feminism that demands greater inclusivity from women's and drug users' rights movements.

At NCSU, trained facilitators - who are women, transgender and non-binary people who use drugs - support program participants to craft personal narratives. "There's no monolithic or homogenous story for women, transgender and non-binary people who use drugs, so we had to think a lot about the dynamics to the group in terms of racial and class equity, and the power dynamics that come up; it's a culture project - yes, we're developing stories, but they also become healing justice spaces," says Caty.

Over the course of the sessions, people whose stories, motivations and knowledge often remain unseen are offered a platform to tell their stories, in their own voices. Typically, groups of up to 15 people gather once a week over a period of weeks to months, engaging in storytelling and dialogue around a specific theme. Subjects have included overdose, reproductive harm reduction, HIV and hepatitis C, and more. "We've been working on launching NarcoFeminism Masculinities - which would be for the men among us, discussing ...issues of gender and looking at their lives from a feminist lens, talking about issues like race among men; also, talking about issues of incarceration and how that impacts on gender. We've been thinking of doing a module on sexual assault and domestic and interpersonal violence against women, transgender and non-binary people who use drugs."

Through storytelling, women, transgender and non-binary people who use drugs take control of the language and imagery shaping their lives. Telling one's story - free from judgment or reprobation - is a radical act, especially in contexts where criminalisation and social stigma have silenced people.

Storytelling can provide a powerful antidote. The use of affirming and powerful terms is a step towards reclaiming identity, and re-setting often damaging narratives about one's life. Embracing the term "NarcoFeminist" announces, unflinchingly, that "I am a woman - and I use drugs" - with all the nuance and complexity implied therein. Storytelling is a vehicle for reframing narratives. For example, group participants

Internalized stigma

“One mother was telling a story about how she’d overdosed on cocaine right after putting her daughter to bed. This story was supposed to be about her greatest mistake and how much she’d [screwed] up as a parent, right? And as she told this story though, the rest of the group were picking out the details, like, “You have this gorgeously painted and appointed room; you spend 45 minutes with your daughter on this story-time, bedtime ritual, right?”

Throughout this story, there are all these little details demonstrating how much incredible care this mother also gave to her daughter... Things that she hadn’t even realized, until she’d read the story over herself and we’d pointed it out to her. These were the kinds of processes that were so important within Narcofeminist StoryShare, because so many of us were also experienced drug-user organizers, who’d been doing this work for decades – yet, we still had so much internalized stigma within us.”

recount how they will opportunistically invoke the language of “getting clean” to satisfy people in power, such as probation officers or social workers. People who use drugs often use this language purely to serve their needs, even when doing so reinforces rather than disrupts prevailing norms.

Through their stories, people give a human face to the concept of intersectionality. As Caty explained, ‘coming out’ as pregnant or sharing a story about one’s child can be extremely complicated and painful – given the significant stigma associated with mothering and drug use. “The storytelling process revealed, for so many of us, there had not been space for these stories. NarcoFeminism Story Share actually goes beyond a simplified politicised analysis into the kind of messy, nitty-gritty, nuanced and complex pieces.”

“We’ve been working on creating trainings out of these stories,” says Caty. “The trainings came easily because we have this narrative, story-based piece and we have this evidence-based piece, from Ria Tsinas ‘s work with the Academy of Perinatal Harm Reduction.⁶ The formula where the evidence-based material is combined with these stories is the part that works, because if it was just a question of presenting the evidence, then so many policy battles within harm reduction would’ve been won decades ago - because we have the evidence. Unfortunately, evidence doesn’t really convince people. The (Personal) stories are just so visceral and affecting that people can’t help

6. Ria Tsinas from the Academy of Perinatal Harm Reduction: <https://www.perinatalharmreduction.org>

Right: A Narcofeminism Storyshare project session of NCUSU.



but react. Even the most radicalised allies might not understand how they've held on to their stigma until they are confronted with this highly charged, emotional material."

Many pregnant and parenting people who use drugs needlessly suffered self-blame, while stigma and misinformation prevent service providers and researchers from understanding the full range of issues women, transgender and non-binary people who use drugs must navigate, and what their needs are. "We knew about the crack baby hysteria - and how that was based on nothing- and how poverty is much more determinant of negative outcomes in children than any prenatal drug use, but we didn't really know how limited the harm was, in so many of these very criminalised drugs, with prenatal use."

Storytelling is a compelling, powerful tool for revealing, examining, and transforming expertise – especially among people and groups who have been stigmatised. Many people who use drugs remain hidden, which diminishes access to accurate information about their lives and experiences. This allows falsehoods to circulate in ways that interfere with personal safety and even compound stigma.

The impact of NarcoFeminist StoryShare is evident, demonstrated by the demand for NCSU's training. For example, NCSU is developing a training for social work students, which will equip people entering the mental health field with a more appropriate and nuanced understanding of the people they are likely to encounter; this training has the potential to transform the mainstream healthcare system's historic hostility toward people who use drugs.

Emerging narratives from storytelling can shift discourse at a broader level. 'Changing hearts and minds' is integral to, and one of the main advocacy goals of, anti-stigma work. Story-telling generates alternative language and imagery for wider circulation,

which can shape popular imagination, and provide people within movements and in broader society - whether the media, policymakers, program designers or funders – with access to more positive and accurate perspectives to use in their work.

Storytelling seeds critical ground for collective action, by building trust and promoting greater accountability within and across movements. Facilitators craft the protocol in such a way that ensures the safety, privacy, and healing of all participants, specifically recognising that individuals may be disclosing and even re-living experiences involving considerable trauma as participants engage in deep listening and peer support. The bonds developed through this work are quite intense and fuel the trust required for collaborative political work.

Indeed, inspired by their participation in the reproductive harm reduction module, NCSU members joined an ongoing campaign to defeat proposed legislation that would have had devastating impact on pregnant people and new parents who use drugs. In 2021, North Carolina's House Bill 918 included a provision for expedited termination of parental rights following a positive drug test, and defined fetal substance exposure – regardless of effect -- as child abuse. A cross-section of NGOs from both the reproductive justice and drug user rights communities mobilized and fought hard against the bill. Eventually North Carolina's governor vetoed the proposed law; the Governor's remarks announcing the veto, referencing racially disparate impact among other possible consequences, were a clear nod toward the messaging from NCSU and partner organizations.

In addition, NCSU recently participated in Take Root, a reproductive justice conference held annually in the southern United States. One of NCSU's Board Members was invited to present on the profound challenges faced by pregnant and parenting people who use drugs, specifically within child welfare systems.

Greater investment in Healing Justice – through projects like NarcoFeminist Story Share – can have a significant impact on advocates' ability to perform and thrive in their social change work. Storytelling goes beyond individual healing. Its process and outcomes are powerful, benefiting individuals, building and strengthening movements, improving programs, informing policymakers and the media– and changing damaging stereotypes. Safe and informed spaces, such as those created through storytelling work, are necessary to generate the kind of 'lived expertise' that is increasingly sought after by funders and policymakers alike.

2.4 BUDGET ADVOCACY:

“IDUF brought community voices directly into this proposal, to ensure that resources will reach those who need them most, and be used effectively.”

The Indian Drug User’s Forum (IDUF) played a strategic, essential role in securing a US \$10 million Global Fund, grant addressing emergency needs among key populations (gay and other men who have sex with men, people who inject drugs, sex workers, prisoners and transgender people) who during COVID-19.

Frontline, key affected populations are often excluded from grantmaking despite their lived experience and first-hand knowledge of what communities need. To ensure the meaningful participation of people who are members of key populations, IDUF engaged representatives from their organizations and networks to create a collective advocacy platform for developing a key population-led and informed Global Fund proposal. These representatives worked closely with other stakeholders and technical experts to provide information for, and discuss the proposal’s development. IDUF supported the proposal development process, enabling communities to provide their expertise and perspectives; it also built their capacity, by translating international and/or national guidelines for health services providers into in clear and actionable language to inform the proposal; engaging a consultant to focus on co-development of sections on budgeting and monitoring and evaluation and worked closely with the Country Coordinating Mechanism, the National AIDS Control Program, and the six networks in the platform.



The International Network of People who Use Drugs (INPUD) is a global peer-based organisation that seeks to promote the health and defend the rights of people who use drugs. As an organisation, INPUD is focused on exposing and challenging stigma, discrimination, and the criminalisation of people who use drugs, and their impact on the drug-using community's health and rights. INPUD works to achieve its key aims and objectives through processes of empowerment and advocacy at the international level; and by supporting empowerment and advocacy at community, national, and regional levels.

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Olga Belyeva, Alexey Kvitkovskiy, Sergey Kryzhevich, Roman Ledkov, Sergeay Shchetnikov, Vitaliy Rabinchuk, Zaza Karchhadze, Ernesto Cortes, Angela McBride, Monique Michal Marks, Menzi Mavundla, Charanjit Sharma, Bongiwe Sibiyi, Caty Simon, Hassan Turaif, Michael Wilson

Written by

Karyn Kaplan (lead author), Tracy Swan (Bellhaven Harm Reduction Centre), Erin Howe (Gains in OAT Access in Eastern Europe and Central Asia), Rachel Yassky (Narcofeminism Storyshare project) and Kanya Benjamaneepairoj (Budget Advocacy)

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