

# Greater Meaningful Involvement

of People Who Use Drugs

in 7 Key Principles and 13 Examples of Good Practice



# Colophon

This brochure is a Correlation Network product.

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# Introduction

This brochure highlights some of the examples of excellent practices in peer involvement in Europe. The collection of personal stories and organisation descriptions show brilliant leadership, in combining courage, perseverance and building partnerships.

25 years ago, the first peer initiatives were started as innovative means of providing HIV prevention education. Since then, the scope and capacity of peer involvement has significantly increased beyond HIV prevention and health promotion interventions. Today peer involvement is becoming a critical component in numerous types of activities that include client advisory boards, peer employment, peer-based overdose prevention initiatives, peer research units, high-profile global advocacy and internet-based networks.

# Peer Work in Europe

Many peer initiatives' share similar experiences, that starting a peer initiative is not easy, and sustaining a peer initiative can be even more challenging. A survey conducted by the European Harm Reduction Network (EuroHRN) in 2010 showed there have been significant changes in drug user organizing over the past four decades. The survey shows up to 30 peer initiatives were reported in Europe, including a number of new peer based networks. Whereas peer initiatives in some countries in Western Europe struggled in sustaining, new peers initiatives were emerging in other regions in Europe. For example in Eastern Europe and in countries like Finland, Belgium, Portugal and Greece.

Some of these new initiatives are included in this brochure. From new initiatives that are developed and motivated by drug users to independent self standing organisations with regular staff and government support.

# Peer involvement

As a working definition for peer work, and describing main aspects, we will use the following description:

"Peer work is a freestanding initiative or a collaboration between community members and an agency, aiming at meaningful involvement of peers and based on principles of mutuality and empowerment."

Peer work as described and promoted by the Correlation Network is based upon on a strong commitment to:

- **public health**
- **social inclusion**
- **empowerment**
- **and meaningful involvement**

# Peer Partners

The Correlation Network has historically consisted of activists, community based groups, grass roots initiatives, researchers, policy makers and low threshold service providers. This combination, inclusive of integrating various backgrounds, experience, expertise and disciplines, has been the foundation of the Correlation Network. From its early days to present, drug users groups and other peer initiatives have been steady and strong contributing partners of the Correlation Networks' programmes and mission.

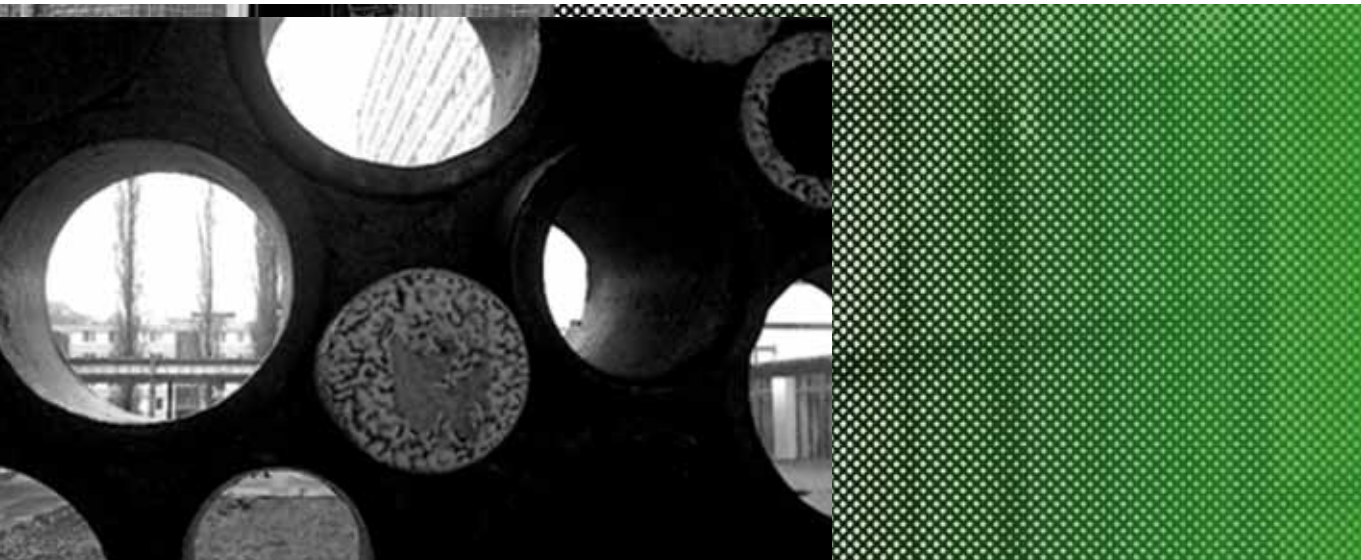
Another example of Correlation's dedication to peer work is a training on developing community activism that is been developed in partnership with the International Network of People Using Drugs (INPUD) and the Swedish Drug Users Union, and with support from many peer groups in Europe. The training and feedback event was conducted in Porto in 2013, and 30 peer trainees from 13 European countries collaborated in partnership during the 5-day course on hepatitis C (HCV) activism and action planning.

The 13 stories clearly illustrate that meaningful peer involvement should be an essential and guiding ethical principle and a cornerstone of modern social and health policies. Because it's ethically right, it works and it contributes to improving people's lives.

If you want to know more on meaningful involvement and how to develop peer initiatives: please visit our website [www.peerinvolvement.eu](http://www.peerinvolvement.eu). The website is entirely dedicated to support initiatives that want to work on peer involvement. The website also shows the excellent examples of peers powerful work, the diversity of experiences and of cross-fertilisation for individual, collaborating partners and agencies involved.

We hope this brochure, the website and the stories of recent European peer collaborations will be a source of inspiration and will be a support to expand current peer involvement activities and to start new initiatives.

**The Correlation Network team**





# Meaningful

Correlation endorses meaningful peer work. 'Meaningful' as to meaning that peers are fully acknowledged and respected as key/equal partners in all areas of an organization. This can include participating in core management processes and feel ownership for the initiative and its' work.

When there is an increased demand for greater and meaningful involvement: peers should be at the forefront whereby having a significant role in drug services and policy development.

We must also be careful to avoid the dangers of tokenism', where peers become mere ornaments in a consultation or communication process. The aim of participation and involvement is not simply to give people a voice, but to offer opportunity for their recommendations to be put into action, and to empower individuals to take responsibility for their own health and lives.

Three examples of good meaningful involvement are distinguished:

- 1. people who use drugs participating in decision-making about programmes and services**
- 2. recognising and respecting the expertise of drug users who know about drug-use patterns**
- 3. people who use drugs implementing and providing services or programmes as peer educators, evaluators and programmers.**

# Lessons Learned

- Is there an ideal model? No, each country and each community; each type of collaboration will have different opportunities for meaningful peer involvement.
- Is there a minimum level of 'involvement'? No, any type of participation can provide support somehow, or support someone to improve self defined quality to someone's life.
- Is more independency always better? In principle; yes. In practice: certainly not always, actually seldom. Depending on the local settings and individual's and communities experience and qualities. There are plenty of examples where support from an agency is essential to offer administrative support and other support during challenging periods of an organizations start-up and development period. As a matter of fact some of the most well-known and successful peer initiatives started with the support and inspiration of a non-user and some of them might have such a person still present on the board of directors.



# Key principles

We consider the following principles as essential elements for meaningful peer involvement:

1. Equality
2. Self determination
3. Genuine and Full Involvement
4. Build on Strengths
5. Support Community Development
6. Meet People Where They Are
7. Respect



# 1. Equality

Peer work programmes are firmly grounded on values of equality. Peers share experiences, background, recognise (parts of) a common identity and lifestyle. Although every individual is different, with different personal characteristics, people in peer groups generally recognise their fellow peers. **Not as identical, but on an equal basis.** An equal or common working partnership is essential in peer work.

Peers who are involved in a peer support project may work within a hierarchical structure. They may have different personal or professional characteristics than some of their fellow peers, but their work is based on equal relationships and common mission. Including equal and respectful partnerships among their peers in the target group, with Peer Support colleagues and with professionals without the same personal expertise.

The principle of equality in Peer Support highlights the significant difference and alternatives to the traditional client-provider model. Peer Support offers both professionals and peers a different health promotion approach and method, based on equality and mutual respect, providing an opportunity to tailor services to the specific needs of the members of that community.





## 2. Self determination

**Peer work aims to offer people to be in the drivers' seat of their own life.** Being able to decide your own daily life actions and destiny. Having the opportunity to decide how the process goes, where it can lead and what it can bring. Using this approach, self determination, to determine your own life aims to also seek personal ownership and is closely linked to emancipation and empowerment processes.

Many peer programmes focus on empowerment within projects, whereby peers have meaningful roles, decision making power, and are directly involved in program development as well as program delivery. This principle is even more important because this starts balance between the two key stakeholder groups - professionals and target audience. Peer support seeks to achieve community level change and objectives. However, it is recognized that individual peer workers may receive personal benefits that help them progress in their life and also can address personal drug-related problems.

## 3. Genuine and Full Involvement

Peer work programmes encourage open dialogue and discussion based on principles of genuine and equal participation. Participants in peer work programmes and their peer colleagues within the target group must be meaningfully involved in the development and implementation of policies and delivery of services. Peers should be involved in decisions that directly affect their lives and not only feel, but be part of **the ownership of the initiative, its work** and it's mission.

In general we tend to say: it's better to focus on maximum implementation of the 'meaningful', whether this is achieved through in free standing initiative or in a collaboration with another supportive agency.

## 4. Building on Strengths

Peer work programmes are more than a response to a technical need or specific problem. Meaningful peer work has offered a positive focus and builds upon strengths, experience and skills of both peer workers and the target group. It **principally builds upon people's capacity and not primarily on their limitations**, needs and problems. Peer support can be an organised way of extending what is often already happening in daily life. What people know, and experienced, has provided capacity to solve and deal with many life situations. Peer work can be seen as empowering and extending organic learning to utilise these skills.

What we have seen is the main source of peers' capacity to communicate and provide support is their shared experience and shared identity with (other) members of the target group.

## 5. Support Community Development

Peer work involves **individuals, families, relatives and wider social networks**. Peer support programmes are closely linked with involving community, and about creating possibilities that empower communities towards active participation and decision-making processes.

Peer support programmes are embedded in an approach that historically addresses root causes of marginalisation and exclusion of vulnerable communities from essential rights, opportunities and resources and aims to strive for **social** inclusion of these communities. Especially through support and strengthening peer initiatives within the community.

Peer work covers a wide range of factors that influence change. It is not only handing over a message what to do, to an isolated individual. Peer programmes offer benefits from the existing individual social networks and to the (informal) infrastructures of a community.

Peer support is bigger than the sum of the individuals relationships, it is about supporting community action and strengthening community networks and relations.

## 6. Meeting People Where They Are

An important element of peer support is to provide options and realistic alternatives to meeting one's personal goals. A range of different support for people to meet people at whatever stage they are at might be asking a question or dealing with a dilemma; which can be a technical issue (e.g. 'How can I check the quality of my drug?') or assisting with a request for support on another more reflective and personal level. (Like 'Should I continue with injecting', 'what can I do for my peers?').

### **Good peer support provides a range of alternatives for people**

From smaller improvements (a change in behavior, a voluntary contribution to a service) or to a more complicated step like contributing to a self organisation.

Each alternative offered could be a valuable improvement of a person's situation. A small step forward. Aiming for second best options (or even third or fourth best options) may sometimes be a considerable improvement in a person's life or current situation. When entering a drop-in centre and having a cup of tea may be an important step in a person living on the street, so may having the job of serving of that cup of tea become an important step to a peer worker. This just a few examples of support towards incremental changes in one's life.

## 7. Respect

An important underpinning of peer support is related to respect. Respect of individual's life style, personal choices and experiences, illegality and vulnerability. Every initiative, peer-based or non-peer based, will acknowledge these aspects of vulnerability, and has to operate with non-judgement, delicately, and respectfully. Everyone needs to be treated respectfully and with dignity. Additionally, every individual's information and identity must be treated confidentially and with strict privacy.

The keynote of the acceptance model is about paying respect to another individual, that person's dignity and rights. The same goes for recognition of the drug user as a human being with the same rights as any other human being. That means for instance that s/he has the right to choose the way how s/he wants to live; if and how s/he wants assistance. One consequence of this idea is to offer assistance without formulating prerequisites, or hidden agendas such as stopping the use of drugs.





# 13 Examples of Good Practice





# ASUD France

*"Today we are supported  
who once were our*

**"ASUD is one of the oldest user groups in Europe, and probably the longest active network of people using drugs in the world.**

The first words of the full name 'Auto Support et réduction des risques parmi les Usagers de Drogues' is self-support. That's what we are: a self-organisation of users and ex-users. We are a self-standing initiative and, although we spoke a lot on collaborations with professionals or other non-users, we keep stuck to our earlier roots of community activism.

We were formed in 1993 to fight against AIDS. France at that time was dealing with large populations of heroin users and large infection rates of AIDS. Even before the formal launch of the organisation we had a magazine ASUD with articles on drugs, consumption, health protection measures and drug policy. Today we have a website: [www.asud.org](http://www.asud.org).

Over the years ASUD has developed into a solid organisation with staff of a dozen employed, including 50 activists, and 3 local chapters. With strategic plans, representation in, for instance the French national commission on narcotics (Commission Nationale des Stupefiants), and more solid financing. We have been formally acknowledged by the government for representing people engaged in drug treatment.

One of our recent successes is the establishment of the virtual Rights of Drug Users Observatory (Observatoire du Droit des Usagers) on the website which allows users to report bad conditions of poor treatment, or an occurring situation of stigmatization. The Observatory has a monitoring,





*by the same people  
opponents years ago"*

and a mediating and advocacy function. Over time many of our health arguments have been accepted. In the beginning we were on our own, standing for our own rights and lives. Later, we got supporters among doctors and among the influential social and political levels. Also nowadays we are even supported by people who once were our opponents in the earlier days.

France is still an ambivalent country on drug policy. On the one hand there is a wide and sophisticated network of harm reduction services such as OST services with buprenorphine and other treatment for



people who use drugs. However there are also enormous numbers of drug arrests, increasing from a couple of thousand in the 70s to 160,000 drug consumers in 2012. Drug use has become a social issue. The lower class is still the most affected, especially among emigrants of the 2nd and 3rd generation who have been deeply effected by heroin, the AIDS epidemic,

crack/cocaine use, and now, in drug trafficking with very high levels of violence. Guns, and the rising number of crimes and killings among young small level drug dealers and traffickers in Paris, and Marseilles is unlike what we have witnessed before in France. This new situation shows perfectly too how the total failure of global drugs prohibition and that all the countries, rich and poor are now involved in the bad effects of this choice."

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# BADD Bucharest, Romania

**Our group is called BADD, The Brigade of Activists in the Drug Domain.**

We are an informal group of users and ex-users, currently under the umbrella of the NGO Carusel. Upon being created, there are 10 members in the group, former and active drug users, including specialists working with drug users.

This initiative came to existence by observing the need for a voice that is representative for drug users in our city Bucharest. We felt the need to create a group that can speak on behalf of the drug users, and provide correct information including an inside look and information about drug users' life. This is extremely important, especially in our country where we are witnessing a recent outbreak of HIV among injecting drug users. The national reports show that, only in Bucharest, in 2011 there were almost 20.000 injecting drug users and a recent study showed that 52.4% of the injectors that participated at this study are HIV positive. Also, more than 82% of the injection drug users (IDU's) have hepatitis C (HCV), and more than 25% of them have hepatitis B (HBV). Although the latest reports show a reduction of the estimated group of injectors in Bucharest, the situation is still very critical.



Some members of BADD are in charge for Carusel's Association, Caracuda-Ferentari (the needle exchange & drop-in center). This is the first drop-in center that is coordinated by a former drug user and also has peer educators working or volunteering in this center, most are being former or active users of heroin or substances like 'legal highs'.

BADD members who are helping with Carusel Association, are also participating in different trainings for police officers, students, volunteers and other NGOs. With topics such as: stigma and discrimination that drug users are facing, HIV and harm reduction services addressed to drug users.

The Brigade of Activists  
in the Drug Domain



*'We felt the need to create a group that  
can speak on our behalf.'*



Right now, we are gathering members to our group from all around Bucharest, in order to have a better understanding of the situation throughout our city, including the trends regarding drug use and to be able to provide better responses to the needs of injecting drug users. In order to have a better recognition and to be able to fully represent the needs and the voice of drug users, BADD, needs to become a legal entity, and creating BADD as an NGO will be the first step in this direction.

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# CASO Portugal

## 'Plenty of plans

**"At the moment there are 5 persons actively involved in CASO's work.** Although CASO aims to be a national Association but at the moment we mainly work in the North of Portugal and the city that we know best is Porto. Currently all of us do this work voluntarily. Two of us also work as peer educators in harm reduction teams, and the other two are unemployed and do occasional works. We work on a regular basis in the street, attend meetings and represent the users' where possible.

We notice that authorities start to seriously. Recently we were invited to informally joint the committee that will be responsible to implement and monitor drug policies in Portugal. CASO's (Associated Users Survive United) beginning was inspired by the visit from a Dutch drug user activist, Theo Van Dam to Portugal in 2007, organized by APDES, the local harm reduction organisation. We are the first Portuguese drug users and former drug users association and our formal beginning was on April 9th, 2010. One of our main goals is to fight against stigma and prejudice towards drug users. APDES is one of our main supporters, without ever interfering with our desires and opinions. Sérgio Rodrigues is the current president of CASO and usually he is the one that most often represents the Association in public events.

Portugal has two types of drug services: high threshold treatment or harm reduction. In treatment centres, people have to go to a first consult with a doctor (waiting time sometimes a month), then do a series of medicals check-



## Plenty of plans f

# for a young organisation'

ups and only after this process is done, it is possible to start taking methadone or buprenorphine. In harm reduction teams the access is easier, but still not perfect as most outreach services rely on the referral to the doctors of treatment centres. Recently, due to governmental changes, pharmacies had to stop with we've also lost one needle exchange programs. Nowadays we can only count on outreach teams to do this work.

One of the success of our organisation is that we were able to stop the closure in 2010 we found out that one of the main treatment centres of the North of Portugal (with approximately 300,000 habitants). We started a petition, met with policy makers to discuss this matter and were able to keep the treatment centre is open till now.

Currently we also are working on having our own space in the centre of Oporto, a kind of drop in centre) with services like needle exchange, information on services available, overdose prevention workshops, information on drugs and safe using, civil rights and so on.

Lots has been achieved and there is still plenty to do. Plenty plans for our young organisation."

## **CASO**

**(Cosumidores Associados Sobrevivem Organizados)**

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**<http://www.casoportugal.com/>**





## Peer involvement revival with municipal support

**“At the end of the 1990s the first initiatives on harm reduction started in Antwerp that really involved drug users.**

In our city the pioneer and main supporter of harm reduction has been, and is the Free Clinic, the main service provider organisation in town. They introduced the concepts of harm reduction and peer support and continuously hammered away on the fact that drug users must be at the front and centre of services and policies. They also made a strong point that users can make the difference. That recognition of our expertise by the Free Clinic triggered our desire and wishes to be heard in a more structural way. We started a user organisation, received some funding, and were able to contribute to the work and debates that related to us. After 4 years the funds dried up and the organisation became silent.

Newer initiatives had similar and more instable success. They came and went.

At the moment there is revival of peer involvement in our city. Experienced people are now hired by the municipality to support services and to work on greater, genuine participation of people using drugs. The initiative was on the side of the City, and they wanted a counterpart. This resulted in





our current initiative Gebruikers Overleg Andwerpen (GOA), comprising on users getting noticed. We received practical support from other activists, supporters of our work and other individuals, including agencies that sympathise with our work. Next to that we were also invited to take part in the municipal advisory body on drugs.

The current shift in priorities in Europe, away from social and health policies and with a more growing focus on security and safety, is also clearly visible in our city. (The mayor of Antwerp recently announced that his city will revitalise the War on Drugs with strong police investments). That makes our peer involvement even more important. We are presently part of significant municipal debates or we initiate them ourselves. For instance we plan to have a couple of meetings on drug consumption rooms and we are working on dedicating an afternoon on hepatitis C information, that includes information on testing and treatment. We also plan to have a questionnaire among the Antwerp drug users, like we did in former times, to let everyone know that we are here again, what we are gonna do, and



# organiseert een Gebruikers-DAG

**OPEN DEBAT**  
met de Antwerpse  
Politieke Kopstukken

**OVER...**  
de verloren strijd tegen drugs,  
cannabis-gebruik en -teelt,  
gebruikersruimten.

**MODERATOR: Robert CRIVIT**  
Algemene Coördinator vzw 'UIT DE MARGE'

**DEUREN:**

\*vanaf 12:30u  
(voor (ex-)gebruikers)

\*vanaf 15:00u  
(buurbewoners, politie,  
geïnteresseerden en pers)

**START: om 13:00u**

in het VERMEKE-Auditorium  
De Grootsteplein - Antwerpen

we will check on the needs of our community. The basis and foundation for a solid initiative is laid, and with support from other agencies, and from other peer initiatives like INPUD, we are ready to build our organisation. 2014 will be vital year for us, that's for sure."

## GOA

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# Greek Drug & Substitution Users Union / Greece

**"In 2013 Greece had been in the centre of attention.** Things like the austerity measures, public health service cuts and the social costs of all these measures draw a lot of international media attention. One of the most significant aspects of the social crises was the impact on health systems. Greece is has been witnessing a HIV crisis, especially among vulnerable groups like migrants, sex workers and injecting drug users (IDUs). The conditions among these groups have worsened severely over the last few years and their condition is now reflected in the statistics. The number of new HIV cases among drug users has gone up from a couple of people in the years before 2010, to 250 people in 2011, and 350 people in 2012.

However, during these difficult conditions, drug users seem more prepared than ever to support advocacy for their rights and contribute their experience and practical knowledge. Our initiative, the Greek Drug and Substitution Users Union, started in 2011 out of the need to advocate for our peers' rights. Rights which were completely abolished and to stop letting others decide for us without us. We just felt we were ready to take action and let ourselves, not professionals, speak for ourselves.

"Nothing about us without us". Our initiative is a movement at a national level. We have 213 members registered, and a basic board of 5, with 3 alternate members who all work as volunteers.

An important target of our work is the board of the public OST program called OKANA. We want to increase treatment and the quality of treatment for people who use drugs. An important item for our group is the OST waiting list. Until recently an individual drug user had to wait 8 years before they could enter OST treatment. Now that's been reduced to 4 years. But still, can you imagine 4 years? No medical and social care, legally. Causing many who want OST to depend on illegal street drugs, in the middle of police raids, in the middle of a HIV crisis.





# Successful rallies in front of the Ministry of Health to prevent closing OST services

Advocacy for policies that will enhance access to quality health services is also a top priority. We will show our face on every occasion. From drop-in centres and OST clinics to media and public events like World AIDS Day and the Anti-Prohibition festival or even in the parliament.

We work closely together with our partners POSITIVE VOICE (Union of people living with HIV) and Prometheus (Union of patients with liver disease). A large part of our work is accelerated by our presence on the Internet. We have a very active Facebook group that ethically supports user-to-user discussions and we also have our webpage: [okanatherapevomenoi.blogspot.com](http://okanatherapevomenoi.blogspot.com).

A great success of our initiative was stopping the planned methadone reduction at the OST programmes when they ran out of methadone supplies on May 2013. We rallied and held demonstrations in front of the Ministry of Health, which resulted in a supplementary methadone order from Italy. Another success was the formation of a Unified Framework of Function where several of our suggestions and proposals were included by OKANA. Finally, we have managed to have a meeting with the national coordinator of drug policy in Greece, and helped to set the themes for the Greek representation in Brussels.

Until recently our action was in isolation, we had no other ideas on involvement other than activism on our own. Since some months ago we have received lots of support from the international user communities and other supportive networks overseas. Now we hope that others might be inspired by us as well."

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# Infoshock, Turin, Italy

**“I’m part of an Italian initiative in Turin called Infoshock, located in the northern part of Italy.** The organisation is partly activist, and an anti drug prohibition initiative which provides information and health services at parties in our region.

We are part of a larger movement, the free festival movement, we urge for ‘free parties’ and are present at raves; in squats and other self managed places. We are on the edge of political activism, anti-drug war and pro-harm reduction. We are inspired by Hakim Bey, an American anarchist author who wrote on Temporary Autonomous Zones that exist outside regular social and legal control and regulation systems. ‘There can be no change without culture.’

Infoshock is part of a network of social/health structures in the region of Piemonte.

We started our political movement committed to the anti prohibition and we recognised the lack of proper policies and support for other people who where using drugs. Personally I work at Csoa Gabrio, a self-managed social centre in a squat in Turin, where I am involved in the substance-related part of the work. Our service is self-managed and self-supported; we receive funds from a sound system that supports us. There is a similar organisation like ours in Bologna, Lab57.





“There can be no change without culture.”

The substances used at the parties we go to are cannabis, alcohol, little heroin, some cocaine, but also widespread ketamine and stimulants. There is no proper harm reduction for people at the parties. The organisation with which we collaborate with is Neutravel. They are the regional specialists sticking to the regulations that do not provide them permission to deliver hands-on services on the spot. So Infoshock provides the services at the parties. We organise pill testing and give out prevention materials and provide a chill out room where we can offer advice and provide medical support if needed.

People at parties like our work because we are part of the party atmosphere and culture, and because we provide honest and fair information. For instance our friends at Lab57 were the first who alerted people on methoxetamina intoxication whereas the formal channels of the national anti-drug agency preferred to follow the international flashy news alerts regarding incidents on substances that were never seen Italy.”

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# JES Germany

## „Junkies, Ex-User, Substituierte (JES) is a relatively old organisation, found- ed in 1989.

We are a National Association of drug users, former users and people in opiate substitution treatment. It was during the middle of the HIV epidemic among drug users, when the organisation, together with the Deutsche Aids Hilfe (DAH), started to conduct workshops and seminars on prevention measures and safer drug use. We saw ourselves as representatives of the interests of people who use drugs, and of former users who live in Germany. Overall, JES covers a network of 15 regional groups that include around 200 activists. JES is special because all users are considered equal: no matter if people are currently using, have quit, or are currently in treatment. However, there are series of common aspects and common principles all of us stand for: 'For a life of human dignity with drugs'.

The German drug policy at the time we started was purely based on prohibition, prosecution, imprisonment and illegality. JES opposed this policy and fought for new comprehensive policies that also included harm

reduction. Finally, by the year 2000 the government formally included harm reduction in the national drug policy and started supporting the implementation of low threshold services, e.g. drug consumption rooms. The number of people in OST also increased from 30.000 to 75.000, and because of that the number of drug related deaths decreased from 2000 annually to 1000. The HIV prevalence rates also dropped to 4% among current injectors.

As of 2000 the national JES coordinator was paid by DAH and presently the federal JES office is under the roof of DAH in Berlin. DAH provides JES financial, structural and organisational support with directing JES. Furthermore JES works closely in cooperation with AKZEPT a major harm reduction network in Germany.

Currently the government considers us a respected actor. JES was for instance part of the development and implementation of working groups for the heroin programme, drug consumption rooms and on hepatitis C services. The

'Action group for HCV and drug use' just developed the first German manual on HCV prevention, treatment and rights. The manual has already been requested 800





# 25 years of building alliances

## without losing ideals



times. Hepatitis C (HCV) is a big problem in Germany. 8 out of 10 drug injectors are infected and only a few have access to treatment. That's gonna be our next target, to increase access to HCV treatments

Other planned activities include: client surveys (for instance on HAV and HBV vaccination and treatment). Our drug user magazine called "DROGENKURIER" (drug trafficker), has been available 4 times a year since 1989; and also our flyers like "Safe storage of opiate medication in domestic environment."

Despite all these results, our main success is that JES still exists after 25 years. JES has changed from a radical opposition group into an independent national association, capable of and willing to form alliances without losing our goals and ideals.

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# Ex-User, Substituierte

# Joost Brantas Rotterdam, The Netherlands



**“Self organising is my second nature.** Since the early days of my drug using career I have been involved in all sorts of drug user organisations. In the early 90s, I was involved with the Rotterdam Junkie Union, and represented the local initiative at the national platform. I am currently on the client board of the municipal health service, have also worked at the union of people living with HIV (where I co-ordinated for sometime the section on HIV veterans ‘the Die Hards’), and have been in anti-prohibition groups, including many other of initiatives.

Holland has had a strong tradition in drug user advocacy. Especially in the 80s and 90s. For over the past two decades there has been a strong movement of users and individuals who supported our case. Including people like academics, some religious leaders, and critical service providers. The Junkie Union in Rotterdam was one of the first drug user self organisations in the world. It was driven by a charismatic drug user activist, Nico Adriaans. Later, after Nico died, it was supported by and managed by non-users, and the ideas of the users union got carried on by some other agencies as well.

I have worked in many initiatives in my town. Some were extremely important and were very effective getting the ‘junky-issue’ on the agenda. But I also witnessed many personality clashes, the rise and fall of talented advocates, often refelcted in the rise and fall of their initiatives. A dreadful drain of energy. So many initiatives vanished, and nowadays I work together with all kinds of organisations.



# ,Veteran activist still going strong'



Personally I'm good at advocacy. A fancy word, but to put it simple: I'm not afraid, and when I see any injustice I simply raise my voice. I'm vocal. Vocal on my rights. If I see any neglect, or unjust or unfair treatment, I step up and raise my voice. And there is much injustice in the life of us drug users. Police controls and beatings, no proper treatment, bad informed doctors, lack of proper medications, urine checks, mafia dealers, social stigma and so on and so on.

Some months ago I was invited to an international Correlation training on hepatitis C and activism. That was another boost for my activism. I learned about the importance of early testing and early treatment. Now I still do whatever I can. I am no longer in an organisation but simply on my own supporting people and initiatives that can use my energy. Last week I gave two lectures on HIV and drug use, one of them in a school. So in fact I'm on my own. Actually I'm a one-man pressure group. Not by principle, but by character. I don't give up. During a recent presentation I wore a T-shirt with the text: 'I am HIV positive, but I will outlive all of you.' That says it all."

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# Scottish Drug Forum Scotland, United Kingdom

**“The Scottish Drug Forum has had a long history of involving people who use drugs.** Since the early 1990s, SDF has worked to involve those receiving services for their drug problem so that service users can influence how services are planned and organised. Over a number of years, we struggled to create an effective role for SDF in supporting user involvement. In 2003, we developed a model of User Involvement that focused on social/peer research. During the past 10 years this has proved to be a very sustainable model, and one that has been successful in urban and rural areas.

The aim of the group is straight forward – it is to improve the quality of the Scottish response to the problems of people who use drugs.

We do this through undertaking a range of peer research on different aspects of drug use and associated problems. Members of the group are trained in conducting surveys, interviewing techniques and are then supported to deliver the research.

SDF's peer research model has been running for the last 10 years and during that time we have had hundreds of people working with us. We currently have 20 people involved.

Over the past 10 years, SDF has delivered a significant body of work, providing 2-3 surveys a year – most of the studies have involved interviewing 50-100 people. Undertaking this amount of work also allows the group to have a good overview of the issues facing people with drug problems. The group, SDF is therefore in demand with key policymakers. Over the last year there was 10 separate meetings with policymakers including; the head of the Government's Drug Policy Unit and influential members of the Scottish Parliament.



# Peer research at arms' length

Our model is not free standing but a way of embedding user involvement into SDF's work and the planning and delivery of services. We have two full time staff working to support this work – without dedicated staff the research work could not function effectively. The host organisation is a crucially important aspect of whether or not such a project can be successful. Our opinion is that it should be an organisation sufficiently at arms' from the services themselves.

As highlighted the ultimate success of the initiative is that it has influenced improvements in the quality of responses both within services and at a policy level. Although the group has undertaken a large amount of work over the years regarding drug related deaths, this work has directly influenced the development of the national naloxone programme.

The success of this initiative can also be measured through the building of skills, knowledge and self-esteem of it's members. Over the years a majority of our members have moved on returning to education, training or employment. Indeed in the last few years significant numbers have moved into paid employment as part of our Addiction Worker Training Project and subsequently becoming long-term members of the work force; further improving quality through this route. Therefore people don't become stuck with a 'user representative label'."



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SDF



# Suomen Lummery Finland

**“Our initiative started some years ago in 2006.** The Swedish user union, Brukarföreningen, has been a wonderful example for us, motivating Finnish users, to start our own union. As you might notice, the Finnish union has copied the logo from Sweden. At the moment our union has around 100 members, but actively involved are around ten people. The professional agency A-Klinikka foundation has supported and promoted our work, since we started.

Society is often dealing with users in a very cynical, prejudiced, and accusing way. Our goal is, that users of substances are treated with respect and dignity, as human beings, not as patients, madmen, aliens or criminals. We ask for an individual approach. Our task is very difficult. Bad attitudes on users are deeply rooted in the minds of the society, all caused because of wrong information and a couple of bad examples. Our aim is to prevent substance abuse problems arising, and if people are up to it, support them in a substance abuse-free life. Lumme produces a magazine with stories on our lives, health and culture. We also work in international context with other similar initiatives.

One of our activities is that we regularly clean certain areas where there are used syringes and needles, and other drug use related garbage. It is one example of where we think that we can contribute to the living environment and to the wider society. Next to that we keep on communicating with other users on issues that are of our common concern: we talk on health promotion measures, prevention techniques and ways to improve your health and personal well being.



# Fighting the bad attitudes on drug users in society



Helsinki is predominantly characterized by mixed use, with opioid-based pain-killers (like Buprenorphine), benzodiazepines, amphetamines, alcohol and cannabis. The prominence of prescription drugs, other medications and so called 'legal highs' as MDPV has become a growing concern in our city Helsinki. The drug scene has changed a lot over the last years, with younger people and more chaos.

In the future Suomen Lumme will do hepatitis C education courses for municipal health clinics and social offices. We will also produce HepC educational video, to support the courses."

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# Svenska Brukarföreningen (SBF) Sweden

**Sweden is well-known in Europe for their position on drug use.** The existing moralism, rooted in the post-war progressive social-democratic traditions, considers all drug use as deviant behavior and sees users as sick, mad or criminal individuals. There are criminal sanctions on drug use, even usage of drugs, coercive testing and treatment are utilized and there is national refusal to subscribe to harm reduction. The few existing health care for drug users are local and do by no means provide any adequate coverage of services.

In this moral climate and hostile the Swedish Drug Users' Union (SDUU), known in Swedish as Svenska Brukarföreningen (SBF) has become an example of an outstanding peer initiative. The organization was founded in 2002 by Berne Stahlenkranz out of dissatisfaction with the stigma and discrimination and the lack of access for drug users to proper health systems: "And by the lack of having any kind of peer organization that could represent active users. The existing agencies were consisting of family members of users, ex-users, but no active users. And all of them were speaking on our behalf. That's a mistake: they are no users. We are users. So that's why we organized ourselves. And we took the motto from the Vancouver-declaration of the establishment of INPUD: 'Nothing about us, without us'."

From the moment of establishment the organisation grew and expanded. There are local branches in more than 10 cities with in total more than 1500 members and the organization has become the main actor in Sweden urging for better and more inclusive policies. The organization represents the users in



various governmental platforms and urges in all these for a for better drug policies which are based on public health and human rights. Also on international fora the SBF criticized the Swedish policies. SBF's work includes appeals, complaints, support users with different matters such as: apply for maintenance treatment, advocate for patient rights and to convince the healthcare and social workers to see and understand things from the users perspective. They also write op-eds and carry out lobbying.

# Networking, advocacy and bridge building champions



The straight-forward work on community engagement and activism is recognized among many stakeholders in the country. The annual SBF conference is visited by over 200 participants from various professional and experiential backgrounds; varying from politicians and parliamentarians to peers and professionals from many agencies. SBF's continuous advocacy and bridge building makes them an extraordinary example of peer involvement. According to the SBF is collaboration by drug services and community groups essential in creating the best policy.

One of their last successes has been the production of a 50 minute documentary on hepatitis C: „The Hidden and Forgotten Plague“. The documentary is one of the activities in a wide range of HCV information and advocacy events that the organization is organizing. The work on hepatitis C among people using drugs, as can be seen on the portal <http://www.hepatitportalen.se/>, is ground-breaking and an inspiration for many other agencies and communities in Europe.

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**‘Nothing about us, without us’**



# UISCE Dublin, Ireland



**"Our organization started as a result of a radical overhaul of the national drug strategy in 1997-98.**

This created the establishment of a 'Task Force' in areas most affected by drugs, and also in areas of relatively high social deprivation. The idea was to bring together representatives of the community (community leaders, often people centrally involved in anti-drugs street protests and borderline vigilantism, plus parents of drug users), including Statutory (Police, Government departments) and NGO sectors. We lobbied to have a seat for someone to represent drug users. Tommy Larkin was this person, and our organization grew from Tommy being given a budget to develop the role.

Currently we are two employees, a Coordinator (35 hours per week), and a Development Worker (20 hours per week). We have a management committee of four, which should really be larger. It used to include UISCE staff, but now just the coordinator, plus four others.

The kind of work we do is represent drug users on local forums with community groups and service providers. We have organised focus groups on particular issues to assist with external or our own research into for instance Hep C, crack use, Mephedrone use, and 'patient satisfaction'.

UISCE produces a newsletter 'Brass Munkie' with articles on current drug issues and health promotion as well as poetry and articles by drug users. We have spearheaded a network of similar groups in the Republic of Ireland, and have developed links with groups in Northern Ireland and internationally.



# Together with active local communities, family members and government



UISCE has received a lot of support from NGOs like Dublin AIDS Alliance and the local drugs task force. Our group is 100% financed by the Irish Health Service (HSE). We have received a lot of support from the HSE in their inviting us to participate in policy level committees, both nationally and locally. We have collaborated with community groups in the local area and with the FSN (Family Support Network- families, but in effect parents of drug users).

One of our successes was getting methadone treatment providers to stop reducing or suspending treatment as a means of social control, often unconnected to drug use at all. A key element in this lobbying was UISCE working in cooperation with community and family organizations. It was also our alliance with the Family Support Network that helped in identifying that these 'sanctions' affected not just the person in treatment, but also punished that person's family and community. Working towards a common goal helped address a lot of distrust that existed between our community and family members, many of whom were involved in what is still referred to as 'Anti-drug Activism' (i.e. street marchers and quasi-vigilantes). It was some time ago now and the situation has greatly improved in Dublin since those days."

## *“We’re people too”*

Views of drug users on health services

Report by Eilish O’Riada, Emily Rogers and Sam Rodmond  
June 2006

The Shannon Street  
Family Practice

Union for Improved Services  
Communication & Education

The Participation and  
Practice of Rights Project

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# Unity Amsterdam, The Netherlands



**"In the mid-1990's, it was evident that substance use among young people attending clubs and dance parties in Amsterdam, and surrounding regions was increasing.**

Information collected via the ecstasy 'pill-testing service', located on site, also provided insight into new drug trends in the dance/club scene.

Most drug information for people in the dance-scene occurred via traditional health promotion methods such as posters and information brochures. The prevention department of Jellinek, (the local drugs and alcohol agency in Amsterdam), established informal relations with key informants among the clubbers which over time developed into a partnership involving participation of the target group in 1996.



Unity is a peer education intervention that is aimed at providing information to the dance going public about 'party drugs'. The project has 6 departments in different regional parts of the Netherlands and attends approximately 100 high profile festivals or dance events per year. Unity is supported by Jellinek Prevention, and 6 other institutions for mental health care. These institutions host the project and provide the administrative infrastructure and resources to implement the project.

Unity currently consists of 144 fully trained volunteers who are recruited from the dance scene. The volunteers are trained to spread objective information on various substances, potential risks that their use entails, and methods to reduce the risks to a minimum. The project utilises harm minimisation strategies to provide information to the target group with the aim of reducing drug related harm.

Think for yourself

# Peer work on the dance floor

We work at festivals and dance events through a 'shop-front' or information stand. Written information is distributed and myths and risks associated with drug use are discussed. Visitors to the stand are encouraged to fill out an alcohol and drugs knowledge test. When finished, feedback is given by the peer educator who often prompts for a further conversation about drugs. Through its network, Unity is also able to disseminate 'Red Alert' information about high risk or contaminated drugs. In addition to the fieldwork Unity is very active online through her website and social media.

Since it's humble beginning in small clubs in Amsterdam, Unity as expanded and now attends 180 festivals and dance events per year, talking to almost 20.000 party goers. Excellent contacts have been made with festival and club promoters, and Unity is welcome and supported at all major events and many smaller underground parties in the Netherlands."

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yourself care about others



