

Case Study 2: *The Swedish Drug Users' Union (SDUU) – flourishing in extreme adversity*

The Swedish Drug Users' Union (SDUU), known in Swedish as *Svenska Brukarföreningen (SBF)* is a classic, and thriving example of what I would classify as the third generation in the history of the organisation of people who use drugs in Europe. I have developed this typology as a conclusion of my study, expressed in various publications, of the history of drug user organising in Europe. Briefly, the first generation is comprised of the historic originators of our movement in the late 1970s and 1980s largely, but not solely, in response to the HIV/AIDS epidemic, and to a lesser extent, the spreading of Hepatitis C amongst injecting drug users. The key figures here include Nico Adriaans, Werner Hermann, Theo van Dam, Daan van der Gouwe, and John Mordaunt. The key organisations to develop out of the work of this generation of activists were the Dutch *Junkie-Bunds*. That said, this wave of activism did in fact pre-date the AIDS pandemic: "Theo van Dam credits Nico Adriaans as the founder and chairman of the first advocacy/activist group Rotterdam Junkie Union (RJB) in the Netherlands in 1977. Around this time, van Dam and Daan van der Gouwe also started *Landelijk Steunpunt Druggebruikers (LSD)* to try to get the Dutch government to support users and user groups, reduce stigma and shape opinion around legalisation. Initially, harm reduction was an offshoot of the drug users' movement, notably Dutch activists who established the world's first needle exchange programme, set up by the *MDHG Belangenvereniging Druggebruikers (Interest Association for Drug Users)* in 1984"¹.

The second generation or wave of European attempts to organise people who use drugs include that group of activists directly and explicitly influenced by the achievements of the first generation, and through personal contact with its members. Pre-eminent in this second generation are the French *ASUD (Auto-Support parmi les Usagers des Drogues)*, founded in 1992, and the German *JES* network (*Junkies, Ehemalige, Substituierte — Junkies, ex-users, substitution clients*), founded in 1989, and the Danish *BrugerForeningen*, whose English strapline is "for active drug users". All of these groups are still in existence, though in very different current states of health and vitality. These first and second-generation groups are notable for the fact that they were founded by active drug, typically heroin, users and had explicitly political agendas. High up on

¹ Hunt, N., Albert, E. and Montañés Sánchez, V. (2010), 'User involvement and user organising in harm reduction', in, Rhodes, T. and Hedrich, D. (eds), *Harm reduction: evidence, impacts and challenges*, EMCDDA Scientific Monograph Series No. 10. Publications Office of the European Union, Luxembourg, 369-392, 370.

their list of priorities were combating the stigmatisation, marginalisation, and criminalisation of people who use drugs. All of these groups were explicitly anti-prohibitionist in orientation, and activist in their modes of action. In addition, all were united by a refusal to adopt a patient subject identity and were explicit in the fact that they were active users of illegal drugs, this in and of itself was a courageous step to take in a world that was still dealing with Nixon's 1974 resurrection of the 'war on drugs', memorably reconfigured by John Mordaunt as a "war on drug users". It is a remarkable and often under noted fact that the harm reduction movement was a direct spinoff from the actions of the first-generation of drug user activists².

This brings us to the third-generation of the European movement and specifically to the subject of this case study, *The Swedish Drug Users' Union* (SDUU), known in Swedish as *Svenska Brukarföreningen* (SBF) which, founded in October 2002, was itself directly influenced by the existence, and more specifically, some of the action repertoire, of the Danish *BrugerForeningen*. In contradistinction to the first and second generation of European organisations of people who use drugs, SDUU, was founded by users of Swedish Opiate Substitution Treatment programmes, paltry as they are, to provide a voice both for them and for active drug users not engaged in treatment. That said, SDUU is scrupulously careful and methodical in its use of language to avoid the dominant construction of the drug user in official Swedish drug discourse as a "misuser" or "missbrukare", hence SDUU typically use the word "brukare" or user, both in the context of a "user" of illicit drugs, and also as a "user" of treatment services.

Sweden is notable in Europe for the extreme moralism which underpins its approach towards drug policy, for the severity of its criminal sanctions just for usage of, as opposed to dealing and possession as is the case in most countries, illegal drugs, its utter hostility, and refusal to subscribe nationally, to harm reduction, contributing to estimates that 90% of the country's injecting drug users are hepatitis C positive and in some parts of Sweden, mainly in the smaller cities excessively long waits for substitution therapy. Fortunately according to Damon Barrett "Sweden already has the infrastructure to introduce harm reduction successfully – excellent

² For an attempt to correct this see Albert, E (forthcoming), 'Harm reduction: contribution to a critical appraisal from the perspective of people who use drugs', in Richard Pates and Diane Riley (eds.) *Drugs and Harm Reduction*, Wiley Blackwell; London.

social safety nets, low levels of social inequality and high quality health and education systems”³. There still exists a lot of regional problems in terms of substitution therapy, but things are moving in the right direction. Sweden is one of the few countries in the world where prison sentences for the use (rather than the possession) of drugs are available; in addition, coercive testing and treatment are also utilized – a positive test for any illegal drug is an offence punishable by imprisonment, even though no one has actually been sentenced to prison solely for the use of drugs (a positive urine sample), you get a fine. This is in spite of the fact that Sweden’s own ‘National Council for Crime Prevention’ has stated that “based on available information on trends in drug misuse there are no clear indications that criminalisation and an increased severity of punishment has had a deterrent effect on the drug habits of young people or that new recruitment to drug misuse has been halted”⁴.

The extent of official hostility towards harm reduction and opiate substitution programmes is graphically illustrated by the fact that Sweden has no nationally coordinated programme of treatment for dependent drug users, still less, a coordinated harm reduction programme including needle exchange. As a result, in the whole of Sweden there are only three municipally run needle exchanges, and they are not in the capital, Stockholm, but in the Southern cities of Malmö, Helsingborg and Lund. These programmes ran on an ‘experimental’ basis for over twenty years, but since 2006 have been given legal status. Now more cities are preparing to initiate needle exchange programs, including Stockholm, although the process is slow moving. These programmes provide services for approximately 5% of the total injecting population, a figure far short of the 80% commitment⁵ called for in Article 9 of the *Dublin Declaration on Partnership to fight HIV/AIDS in Europe and Central Asia* adopted in 2004, and ratified by Sweden. As noted, the three local needle exchanges that do exist and used to be experimental are not attached to any national policy as in Sweden provision of needle exchange services remains entirely at the discretion of local government. Paul Hunt, the UN Special Rapporteur on the Right to Health underlined the Swedish government’s hostility to harm reduction when, after a study visit to Sweden in 2006, he remarked that “[T]he [Swedish]

³ Barrett, Damon, ‘Harm Reduction International at The Swedish Drug Users Union’s Seminar in Gotland’, accessed at <http://www.ihra.net/print/303>.

⁴ Quoted in Swedish Drug Users’ Union/International Harm Reduction Association, *Briefing to the Committee on Economic, Social and Cultural Rights on the fifth report of Sweden on the implementation of the International Covenant on Economic, Social and Cultural Rights*, October 2007, 6.

⁵ *Op. cit.*, 5.

Government has a responsibility to ensure the implementation, throughout Sweden and as a matter of priority, of a comprehensive harm reduction policy, including counselling, advice on sexual and reproductive health, and clean needles and syringes”⁶. The extent to which the Swedish government are in dereliction of their international commitments with regards to providing for the health of intravenous drug users is indicated by the following statement “injecting drug use and related harms such as HIV and hepatitis C infection are entirely omitted from the State’s report to the Committee, as are any references to measures taken to address drug use and reduce drug-related harms”⁷, one result of this situation is the fact that SDUU themselves run the only needle exchange in the capital city out of their Stockholm branch. Opposition to needle exchange has been expressed by both the Prime Minister’s Office and Stockholm’s municipal authorities. This means that needle and syringe exchange remain unavailable to people who inject drugs in Stockholm, which as the capital city is not surprisingly the city with the largest injecting population in the country. The concrete result of the different municipal policies and the efficacy of needle exchange programmes are graphically illustrated when one considers that “there were twenty-four new cases of HIV among injecting drug users in Stockholm in the first half of 2007, compared with zero in Skåne, where the needle exchange programmes operate. Professor Paul Hunt stated in his report that harm reduction was too important a human rights issue to be left to local government. Rather it was an obligation of the State”⁸. It is in such a hostile environment that this most remarkable organisation, perhaps the most vibrant of the third-generation, has flourished. As a result of the specificity of Swedish law, actively declaring oneself to be a drug user is simultaneously to declare oneself to be a criminal.

Prior to the founding of SDUU, active drug users and current users of treatment had no organised voice in Sweden. The primary organisation civil society organisation that did exist in the drug policy field was the National Association for Aid to People Addicted to Drugs and Pharmaceuticals (RFHL) founded in 1965, one of its principal aims was to give a voice to a sector of society that it described as “‘care-stricken’ i.e. clients, patients and prisoners”⁹. The organisation however was primarily composed of a layer, social workers and former users and

⁶ *Op. cit.*, 1.

⁷ *Op. cit.*, 3.

⁸ *Op. cit.*, 6.

⁹ Laanemets, Leili, ‘Organisation Among Drug Users in Sweden’, in Jørgen Anker *et al* (eds.), *Drug Users and Spaces for Legitimate Action*. Nordic Council for Alcohol and Drug Research; Helsinki, 105-130, 112.

was committed to abstinence, inspired to a degree by the anti-psychiatry movement, it was hostile to the prescription of drugs by doctors and went so far as to “file a complaint with the state prosecutor against all 600 psychiatrists in the country, claiming that they were handing out prescriptions far too liberally”¹⁰. In direct counter-position to this, the SDUU makes the demand for a nationally coordinated opiate substitution programme one of its priorities, simultaneously it campaigns against the human rights abuses that permeate, and extremely punitive nature of, the various municipal opioid substitution programmes that do exist. They also support the introduction of maintenance programmes for users of amphetamines and cocaine, diamorphine prescribing and safe injection sites.

Ironically the RFHL gave the nascent SDUU a crucial boost and was one of the parties in the discussions that led to its foundation. In the Spring of 2002, fed up with the endemic “difficulties in obtaining methadone, the punitive character of the Stockholm methadone distribution system, the complete lack of needle exchange, and total absence of harm reduction materials”¹¹ Berne Stålenkrantz, a former heroin user, then enrolled in a methadone programme, initiated a discussion with the Stockholm branch of the RFHL. The outcome of these discussions was that RFHL made office space available to Stålenkrantz. By October of that year, the SDUU had been founded, a Board had been elected and a constitution ratified, central to which was the stipulation that all decisions were to be made by active users of heroin or opiate substitution programmes.

To remedy the prior absence of a Swedish voice for the concerns of active drug users, SDUU is thoroughly committed to, and uses prominently on all of its publications, the slogan of the Vancouver Declaration, “Nothing About Us Without Us!” As such, it was the first, and remains the only, organisation in Sweden whose Board consists solely of active users of opiates, whether they be enrolled in a substitution program or not. That only active users be eligible for membership of the Board is fixed in the organisation’s constitution. As Jessica Palm has pointed out, with the RFHL clearly in mind, “prior to the founding of the SBF, most actors on the Swedish drug policy arena were non-users and ex-users [...] there are early indications that it has been recognised as an actor within the drug policy debate and among caregivers. The SBF can be seen as both a product of contemporary discourses and as an actor that could come to influence

¹⁰ *Op. cit.*, 114.

¹¹ Discussion between ERA and Berne Stålenkrantz.

the dominant drug policy discourse”¹². Indeed since its foundation it has grown to a current estimated national membership of 1500, with, apart from its national office in Stockholm, local branches in Stockholm, Dalarna, Gothenburg, Halmstad, Kalmar, Skåne, Örebro, Umeå, Skellefteå and Piteå.

As well as becoming key actors, or at the very least participants, in the Swedish national drugs policy arena, SDUU have made interventions on the international stage, and in 2007 and 2008 Stålenkrantz as the organisations Chairman gave speeches to the UN International Covenant on Economic, Social and Cultural Rights, addressing the Swedish state’s abrogation of various commitments to human rights through its failure to instantiate a national harm reduction policy. Most notable was the joint submission made, in 2008, with the *International Harm Reduction Association* (now *Harm Reduction International*) to the UN Committee on Economic, Social and Cultural Rights as part of the Committee’s review of Sweden’s compliance with its human rights obligations under the International Covenant on Economic, Social and Cultural Rights, the report was a castigating indictment of the Swedish government’s dereliction of its international obligations¹³. The submission was made on the back of Paul Hunt’s already mentioned study visit to the country, and concluded that: “the Committee should reinforce the findings of the Special Rapporteur on the Right to Health and recommend that Sweden adopt comprehensive harm reduction measures throughout the country as an essential element of the State party’s obligations under Article 12. This should develop and expand upon the Committee’s 2006 Concluding Observation on Tajikistan in which it recommended that the Tajik government ‘establish time-bound targets for extending the provision of free testing services, free treatment for HIV and harm reduction services to all parts of the country’” it went on to note that a “specific recommendation should be made to review the recently adopted law relating to needle exchange, and its impact on the right to health of people who inject drugs.”¹⁴

¹² Palm, Jessica (2006), ‘The Consumer, the Weak, the Sick, and the Innocent – Constructions of ‘the user’ by the Swedish Users’ Union’, in Jørgen Anker *et al* (eds.), *Drug Users and Spaces for Legitimate Action*. Nordic Council for Alcohol and Drug Research; Helsinki, 159-182, 160.

¹³ See Swedish Drug Users’ Union/International Harm Reduction Association, *Briefing to the Committee on Economic, Social and Cultural Rights on the fifth report of Sweden on the implementation of the International Covenant on Economic, Social and Cultural Rights*, October 2007.

¹⁴ *Op. cit.*, 8.

When it is not making submissions to international bodies SDUU's core activity and objective is to organize Swedish drug users of both legal and illicit drugs, opioid/opiate users who have or want OST/MMT (opioid substitution treatment or methadone maintenance treatment). As such, the bulk of their work consists of dealing with appeals and complaints relating to the way in which people on substitution programmes have been mis/treated; supporting drug users with such matters as: applications for maintenance programmes; advocacy for patient rights and, the often thankless task of convincing healthcare and social workers to see and understand things from the perspective of people who use drugs. They also maintain a high profile in the Swedish national and regional media through television and radio appearances, the writing of op-ed piece in various newspapers and digital media; in addition they are heavily involved in political lobbying.

SDUU's core commitments are abundantly clear and can be summarised as consisting of:

- Making clear distinctions between prevention, organized crime, and harm reduction. With these clear distinctions it is possible to avoid irrelevances in the work with the issue. Police should fight crime, social services care for help seekers, and treatment must be based on policies of best practices informed by drug users' own experience, science and research. Perspectives and experiences should be drawn from both users and professionals in the field. Cooperation between workers and service users can create the best policy.
- Combatting the 'care ideology' that had permeated Swedish drug policy discourse, in particular that of the RFHL, through a systematic refusal to adopt the position of the helpless patient or sick person;
- Combatting and attempting to neutralise the stigmatization that drug users encounter every day by presenting an image of the drug user as an active, responsible citizen taking initiatives to address issues that affect them.
- A change of focus from the preservation of prohibitionist dogma, and a drugs policy based on enforcement, control and prevention to one based on harm reduction, human rights, scientifically approved interventions, and the preservation of the right to life and health. The focus must change from a drug policy based on zero-tolerance and total abstinence from drugs, to a policy that that preserves individual rights, and dignity.
- Legislative evaluations and steps for change. Sweden needs to identify and change key pieces of legislation that produce, increase and inflict harm on both the individual as well

as on the social level. One of the most pertinent instances here is the law criminalising the use and not just possession of illegal drugs, and that by extension makes the presence of illegal drugs in one's blood a criminal offence, punishable by imprisonment. This is a major hindrance to the implementation of harm reduction measures at any level, and opens the door for human rights abuses in the form of enforced and coercive testing and treatment. The criminalisation of personal use also puts Sweden in breach of article 12 of the *International Charter of Human Rights*, which upholds "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health".

- An ombudsman for drug users. Sweden is a progressive state where the presence of an ombudsman for various interest groups is seen as an important mechanism for upholding Swedish and international law and for overseeing negotiations with the relevant authorities. Such a mechanism should also be put in place for drug users, who are a heavily marginalised, stigmatised and disadvantaged group in Swedish society, and who often find themselves in situations where their rights are abused or overlooked, such cases are common in the treatment system, for example in cases where they are denied access to, or arbitrarily thrown out of, treatment.
- A harm reduction coordinator - Instead of demanding ever more cooperation between municipal organizations, NGOs and other interested parties there should be a national coordinator to oversee the collection of the requisite statistics and information, joint ventures and projects, and can initiate and evaluate projects before making recommendations.

SDUU cooperates with several European and international organizations that support the abolition of the current prohibitionist status quo in favour of a drug policy based upon the principles of harm reduction and human rights. To further these goals, SDUU is a member of the steering committee of the EuroHRN (European Harm Reduction Network) and are the Swedish representatives of INPUD (International Network of People who Use Drugs) and NAMA (the American based National Alliance for Medication Assisted Recovery), they are also an associated partner of the Correlation network.

A key event in the SDUU annual calendar is the yearly seminar they organise to discuss a chosen relevant topic. One part of the seminar, a technique borrowed from the action repertoire of the Danish *BrugerForeningen* (Danish Drug Users' Union) is the presentation of the

”Brukarvänspriset” (loosely translated as the ‘Users’ Friend Award’, an award given to someone, not a member of SDUU and generally not a person who uses drugs, usually a harm reduction professional, politician, or academic, who has most forwarded SDUU’s agenda, and the human rights/public health of people who use drugs in Sweden in the past year). Winners thus far include Professor Lars Gunne - the founder in 1967 of one of the world’s oldest OST programmes, at Ulleråker Hospital in Uppsala; Björn Fries - former drug policy coordinator to the government; a representative of the needle exchange program in Malmö and Lund, the only municipally funded such project in the country; Professor Henrik Tham; Professor Ted Goldberg; a representative of the National Board of Health and Welfare; and four MPs from the Left wing Party for their advocacy of decriminalisation of personal use. The award winner 2011 was the special investigator appointed by the government. A second key event in the SDUU calendar is also one borrowed from the action repertoire of other international organisations of people who use drugs, namely the holding on 21st July of a Remembrance Day ceremony to mark the passing of those who have suffered lethal overdoses and other victims of prohibition, “this originated in Germany more than ten years ago when the mother of a heroin user who had recently died wanted to draw attention to the poor condition in which many drug users live”¹⁵. This event is used to draw attention to issues that contribute to ‘drug-related deaths’, such as deficiencies in service provision, but also the impacts of drug prohibition. They also provide an opportunity for drug users to mark the deaths of friends; this is especially important as so often drug users die alone and their drug using friends are excluded from family burial services. In this respect the day can serve to raise the consciousness of the drug using community as a group.

In conclusion SDUU demonstrates an important lesson for drug user organising, and clearly illustrates what is perhaps a truism in social movement theory, namely that when faced with an extremely hostile environment, powerful movements of opposition are possible if the drive and commitment are present and if the organisational model chosen is appropriate. Clearly, SDUU with their unwavering commitment both to community engagement and activism, as well as an uncompromisingly democratic and inclusive mode of organisation have been able to make an impact on Swedish drug policy that is far more thorough than their membership would suggest.

¹⁵ ¹⁵ Hunt, N., Albert, E. and Montañés Sánchez, V. (2010), ‘User involvement and user organising in harm reduction’, in, Rhodes, T. and Hedrich, D. (eds), *Harm reduction: evidence, impacts and challenges*, EMCDDA Scientific Monograph Series No. 10. Publications Office of the European Union, Luxembourg, 369-392, 382.

That said, with membership at approximately 1500 SDUU are one of the strongest groups in the world of European drug user organising.

Dr Eliot Ross Albers, PhD