



## Commentary

## Coexisting or conjoined: The growth of the international drug users' movement through participation with International Harm Reduction Association Conferences<sup>☆</sup>

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The development of the international drug users' movement has been intrinsically linked to the growth and development of the international harm reduction movement but more particularly with the annual International Harm Reduction Association (IHRA) conferences. These conferences gave drug user activists a chance to meet in an environment where our lives were being talked about and our treatments decided and our views have, over the years, been given increasing consideration. The impetus for us to have a visible presence was extremely important. We had not had much success in making an impact on the drug and alcohol fields in our individual countries. It was the outbreak of HIV/AIDS that gave us our voice in the local situation and led to the birth of harm reduction initiatives, in particular, the provision of needle exchange. However, it was the drug and alcohol arena that had such a big and so often negative impact on the majority of drug users' lives, particularly in the late eighties and early nineties. It has been said that it was learning activism in the HIV/AIDS movement that led to us bringing our newly found voices to the emerging harm reduction movement. It is true to say that except for the Dutch MDHG *Belangenvereniging voor Druggebruikers* (Interest Association for Drug Users) experience of setting up the world's first needle exchange in 1984, in response to an outbreak of Hepatitis B amongst people who inject drugs (Tops, 2006), activist drug users were a rarity prior to HIV/AIDS. They were not seen as having any worthwhile experience or knowledge to give to the wider community. In this crucial respect, it was drug users themselves who kick-started the harm reduction movement. However, in the early years our voices were largely stifled by the increasing profession-

alisation of the field and the marginalisation of people who used drugs.

Certain key elements of modern harm reduction were developed by the drug users' movement, as is evidenced by the Dutch experience described above. This is also evident in countries, as diverse as Thailand and the USA, where drug users have played an important role in introducing harm reduction initiatives and pushing for progress. According to one Thai drug user activist "Thai drug users have introduced community-driven harm reduction interventions since the 1990s, in spite of the ongoing repressive legal and policy environment" (Suwannawong, 2009). Likewise, in the USA, where federal funding for needle exchange is prohibited, drug users have been central to the development of underground and mobile needle exchanges (see for example the work of the Springfield Users' Council in Massachusetts). In the still more hostile environment of Russia, where substitution therapy is illegal, drug users have been organising themselves; in 2001 a group of drug users, who were concerned about problems of drug users in society, formed an organisation known as "Kolodez". During the seven years of its operation, *Kolodez* fought for improved drug policy in Russia. One of their most important successes was their impact on the decree *on amendments and additions to the Criminal Code of Russia* enacted in 2003. They significantly changed the articles relating to drugs and responsibility for the commission of illegal acts (Ovchinnikova, 2009).

At the first *International Conference on the Reduction of Drug Related Harm* (hereafter *International Conference*), in Melbourne in 1992, an international network was mooted. We had an incredibly exciting meeting at the local user group and the International Drug User Network (IDUN) was established. Representatives from Germany, the Netherlands and the UK were amongst the seven countries represented at the inaugural meeting (Byrne, 2000). However this was in the pre-internet and -mobile phone era so

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international communications were extremely difficult. In addition, many of the participants did not have organisations to back them. Ultimately the practical benefit of the organisation was limited, but its legacy proved to be enduring. The notion was imbedded within the movement that we could learn from each other and be more powerful as a united entity.

The 6th *International Conference* in Florence in 1995 marked the low point for the drug users' movement with the recognition that both IDUN and the European Interest Group of Drug Users (EIGDU) had failed. In both cases, this highlighted the difficulty of developing regional and global networks of people who used drugs without strong networks at a country level.

The three post-Melbourne conferences had no real impact on the development of the movement other than to provide a place for user activists to meet and speak our minds, tell of our lives, share experiences, lessons and aspirations. However, people who used drugs were invited onto the programme committee and reviewed abstracts.

In 1996, the 7th *International Conference* in Hobart kick-started the fledgling IDUN and users were becoming able to communicate more efficiently due to technological advances. Further, IHRA had started to listen to our voices and acknowledge that we had a legitimate role to play in the conferences. The 8th *International Conference* in Paris in 1997 had a large and well-supported user presence. ASUD, the French drug users' movement, hosted a side event for people who used drugs, which converted the Eiffel Tower into a syringe as its logo.

For the 9th *International Conference* in Sao Paulo, a drug user representative was invited onto the organising committee and was able to develop a drug user stream. It was an important step for us and how we felt about our contribution. At least one person from the drug users' movement has been part of the organising committee ever since. In the last four or five years, there have been dedicated sessions organised by drug users, and drug users have spoken at both the opening and closing plenaries. This was in part facilitated by funding raised by IHRA and the International Harm Reduction Development (IHRD) Programme to bring drug users to the conference.

The 10th *International Conference* in Geneva in 1999, was a watershed moment, when a drug user activist provided one of the opening plenary speeches, a huge step forward in our collective sense of acceptance and worth. We had an extremely lively activist meeting hosted by the *Drug Policy Foundation (DPFU)* and an internet forum (still operating) was set up for drug users to communicate. This made organisation and discussion much more viable and strengthened our sense of being a community and a movement.

This period saw a key ideological shift from an exclusively public health to a more inclusive human rights focus. This was accompanied by a shift towards more diverse and inclusive drug user networks. This movement was built around the 'To Prevent A Human Right?' paper, which was co-authored by a number of senior leaders of the drug users' movement

Prior to the 11th *International Conference* held in Jersey in 2000, the UK movement hosted the International Drug User Conference, which was one of the largest ever meetings of people who used drugs. Further progress was made on international networking but, learning from past mistakes, an international network was not launched, with priority being given instead to the development of local networks.

In 2005, frustration at the poor facilities for drug users at the 16th *International Conference* in Belfast was a catalyst for an invigorated

international network and led to the inception of the *International Network of People Who Use Drugs (INPUD)*. This formed around a statement endorsed at the 17th *International Conference* in Vancouver in 2006 by the now traditional pre-conference meeting of user activists—'The Vancouver Declaration'. Although this was the product of many activists' efforts, the initial process of transforming INPUD into a legal entity was undertaken by a working group which included representatives from Asia, Europe, Latin America, North America and Oceania. The UK's Department for International Development provided funding for INPUD, as part of a larger grant to IHRA. After some birthing pain, INPUD is developing into the organisation that many of us envisaged all those years ago. In its early phases INPUD encountered some constitutional difficulties and concerns about process. A subsequent crisis meeting was held at the 19th *International Conference* in Barcelona in 2008. This led to a successful re-foundation General Meeting hosted by the Danish Drug Users' Union (*BrugerForeningen*) in Copenhagen at the end of October 2008 where a Consensus Statement and a clearer infrastructure were agreed. Since then a representative from INPUD was invited to give a formal address as part of the UK delegation to the United Nations' Commission on Narcotics Drugs (CND) in April 2009 and several other members attended as part of various NGO delegations. INPUD has now become recognised as the voice of the international drug users' movement by most of the major organisations, NGO's, and donors in the harm reduction and HIV/AIDS fields.

There have perhaps been four major factors that have changed the relationship between IHRA Conferences and the drug users' movement. Most obvious perhaps is the collective growth in our experience, which has led to the maturing of our leadership and the ability to sustain a more assertive and measured engagement with the harm reduction movement. Second, the balance between power and participation has shifted to a more mutually acceptable level. With our sense of becoming meaningfully engaged, listened to and heard, we feel respected as partners. This has a positive impact on our own sense of worth and of that of our movement. Subsequent to this, leaders on both sides have now worked closely together over a substantial period of time and both friendships and strong professional relationships have been forged as a result. Finally, the harm reduction movement has made a firm commitment to the human rights and political aspects of this work, something that we long argued for, with the result that we no longer view the field as purely a network of public health professionals. The human rights abuses that our community suffers and the degree of discrimination to which we are subjected has become universally recognised within the field. On the other side, we have perhaps become more sophisticated in our engagement with these agendas.

Without the support and continued belief in our movement by the IHRA network, it would have been a much harder struggle. IHRA believed we should have input to the conference and the treatments that affected our lives and demonstrated a firm commitment to the idea that we had something worthwhile to give researchers, doctors, and others working in the harm reduction field.

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