

DEVELOPING DRUG AND SERVICE USER FORUMS

CONFERENCE REPORT

9TH NOVEMBER 2006

REPORT COMPILED BY JOHN BENNETT MSC

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Introduction

This is the report of the “Developing Drug and Service User Forums” conference, which took place in the Royal Dublin Hotel, O’Connell St. on the 9th November 2006. The conference was significant in that it was the first time that drug/service users had come together to specifically discuss drug/service user involvement in the drug task force process and drug services generally.

The report contains a summary of the various elements that combined to make the conference such a successful and useful event for all involved, including drug users, LDTFs, RDTFs and the NDST members. Most importantly the report contains a list of recommendations that were agreed by the conference participants. These provide a clear indication of the priority issues for drug/service users and those committed to pursuing this aspect of drug policy in Ireland, and ensuring that the actions contained in the National Drug Strategy relating to the involvement of drug users are fully implemented.

The organisers wish to thank all who participated in the conference and contributed to a very useful day. Thanks also to the Department of Community Rural and Gaeltacht Affairs for providing funding for the conference. Thanks also to Minister of State Noel Ahern for opening the conference. On behalf of all of the Local Drug Task Forces, thanks to those who helped organise the conference:

Emma Keenoy – Finglas/Cabra LDTF

Emily Reaper – UISCE

Ruaidhri McAuliffe – UISCE

Clare Hobley – Ballymun LDTF

Vanessa Hoare – DNE LDTF

Sandra Mullen – Clondalkin LDTF

Geraldine Fitzpatrick – Dunlaoire LDTF

John Bennett – Finglas/Cabra LDTF

Rationale for the conference

Community participation is one of the key principles upon which drug task forces have been developed in Ireland. In the context of the work of Drug Task Forces, a key aspect of community participation is the involvement of those who are directly affected by problematic drug use in the work of Task Forces, i.e. drug users.

The priority placed on the involvement of drug users in LDTFs is reflected in the National Drug Strategy Action No. 96.

“To enable user groups in Task Force areas to play a role in the generation of a greater societal understanding of drug misusers and drug misuse issues. For those misusers who may not be in contact with mainstream agencies, these groups can help foster awareness about support services available e.g. treatment options, needle exchanges etc.” (Action No. 96, National Drug Strategy 2001-2008)

The strategy goes on to state that this action is to be implemented on an on-going basis by the Task Forces.

A survey of LDTFs carried out in 2006 by the Canal Communities LDTF summarised the actual situation on the ground in each Task Force area:

- 5 out of the 14 LDTF areas had a forum or project aimed at developing drug user involvement
- One LDTF has a drug user representative
- All LDTFs were either doing development work, or awaiting the outcome of the conference
- Little happening in the RDTF areas, but a commitment exists to this area of work

With this knowledge in mind a conference was proposed focusing on models of drug user involvement to the LDTF Co-ordinators Network, by the Finglas/Cabra LDTF, early in 2006. At this time a number of LDTFs were seeking to develop drug user

forums in their areas, and the new LDTF project workers were doing groundwork on how this could be achieved. A cross-task force conference on the subject was considered to be a useful way to share knowledge and experience, and put the involvement of drug/service users higher on the agenda of the NDST, the Local DTFs and Regional DTFs.

A proposal to fund a conference was then made to the National Drug Strategy Team (NDST) and was subsequently approved.

Conference organization

The people invited to attend the conference included a mix of members of task forces (5 from each task force) and drug users (5 from each LDTF). As the Regional DTFs are in an early stage of development they were not expected to invite drug users. On the day of the conference drug users from Wexford and Galway areas were present (See appendix 1. for list of attendees).

Involving drug users

As the conference was primarily focused on the involvement of drug users, each Local Drug Task Force was requested to identify five drug users to attend the conference. Guidelines on how this could be achieved were produced by the organising committee and sent to all task forces. (See appendix 1).

A meeting of all project workers was organised prior to the conference to monitor how the guidelines were being implemented and the numbers of drug users that were expected to attend.

Conference Programme

The aims of the conference programme were:

- Use the local preparation process with drug/service users for the conference, as a mechanism for the development of existing and new local drug/service user forums
- Contribute to the creation of a common understanding and approach to the establishment of new drug/service user forums in all drug task force areas
- Share the experience of forums that already exist and promote increased participation by drug users in task force structures.

To achieve these aims John Bennett, Co-ordinator with Finglas/Cabra LDTF made a presentation on the purpose and aim of the conference and summarised drug policy relevant to the aims of the conference.

Individuals from Ireland and England with practical knowledge and expertise in community work with drug users were invited to speak at the conference. These included:

Matthew Southwell

Matthew founded a community harm reduction response to HIV/Aids in 1989, pioneering peer support and community development responses to the needs of injecting drug users and other hard drug users. He was head of service at East London and City Drug Services. He later wrote Guidelines on Involving & Empowering Drug Users for the National Treatment Agency. Matthew was also lead development worker and later the first elected chairperson of the National Drug Users Development Agency.

Rosy Flexer

Rosy has worked in the various aspects of the drug field for over 15 years, initially as a volunteer after recovering from a long-term drug problem. As part of her work with the Stockwell Project, Rosy started a Service User Group. She is currently Service User Involvement Co-ordinator for the Lambeth Drug Action Team.

Ruaidhri McAuliffe

Ruaidhri works for UISCE (The North Inner City Drug/Service User organisation) UISCE began in 1998 based on the guiding principal that “drug users have a right to a voice within their community.” UISCE acts as a voice for drug users in the North Inner City. In his role with UISCE, Ruaidhri seeks to raise awareness of the needs of drug/service users among treatment agencies and at the LDTF. The start-up funding for UISCE was provided by the North Inner City Local Drug Task Force.

Anne Corrigan

Cairdeas is an advocacy service for the drug using community and their families in Clondalkin. Anne is the Co-ordinator of Cairdeas and has been working with Cairdeas since it began in 1999. Cairdeas also employs two project workers. Cairdeas

organises advocacy, training and two drug user forums in Clondalkin and is funded and managed by the Clondalkin Drug Task Force.

Summary of conference presentations

Introduction

This chapter of the report contains the presentations made at the conference. The speech made by Minister of State Ahern is the complete official text provided by the Minister of State's officials. The other sections are summaries of the presentations made at the conference.

Setting a policy context for the conference – John Bennett

This presentation aimed to summarise references relating to the participation of drug users contained in documents relevant to the work of Local Drug Task Forces. It highlighted existing policy which can be used to legitimise the involvement of drug users in the LDTF structures, and in drug treatment services in general. The presentation sought to encourage reflection on what is actually happening on the ground in each Task Force area, and to portray the extent to which guidance already exists for Task Forces in respect to the involvement of drug/service users.

Task Forces and community participation

The Handbook provided to LDTFs by the NDST in 1997 contains clear guidance to LDTFs regarding their general approach to community participation. It states that "Task Forces provide a mechanism which enables local communities to work closely with State and Voluntary Agencies in designing and implementing its strategy." LDTF Handbook, P.9

It also contains specific guidance to LDTFs in relation to the involvement of drug users, where it states:

"There is also scope for drug users to make a valuable contribution through, for example, the use of drug user fora, which can act as a mechanism for consultation between Task Forces and local drug users" (LDTF Handbook, 1997, P.16)

The National Drug Strategy

The National Drug Strategy also contains two actions specific to the participation of drug/service users. [Actions 46, 96] Progress in relation to these was reported on in the NDS Mid-Term Review. (March 2005)

To develop and put in place by the end of 2002 a service-users charter specific to treatment and rehabilitation facilities, which would lead to a greater balance in the relationship between the service user and the service provider.” (Action No. 46, National Drug Strategy 2001-2008)

In March 2005 the NDS Mid-Term Review of the National Drug Strategy reported on progress regarding the implementation of this action:

“The steering group welcomes the drafting of service user charters by many Health Boards, as outlined in Action 46. However, the group is of the opinion that, in the future, where this is not already taking place, services should consult more widely with service users in the drafting of these documents.” (NDS, Mid Term Review, 2005, P.36)

“To enable user groups in Task Force areas to play a role in the generation of a greater societal understanding of drug misusers and drug misuse issues. For those misusers who may not be in contact with mainstream agencies, these groups can help foster awareness about support services available e.g. treatment options, needle exchanges etc.” (Action No. 96, National Drug Strategy 2001-2008)

According to the NDS, this action is to be implemented on an on-going basis by the Task Forces.

In the progress report on this action contained in the NDS Mid-term review it states that this action was completed or an ongoing task of task forces.

Vital Connections Conference

The LDTF “Vital Connections Conference” which took place in 2005 provided a forum for the discussion of the participation of drug users in the LDTFs. The following references are from the presentation made at the conference by Emily Reaper of the drug user’s organisation UISCE which was warmly received by the 400 conference participants. An indication of how well received Emily’s presentation was received is seen in the contributions that follow from the then Chair of the NDST, Mr P. White and Minister of State for the National Drug Strategy Noel Ahern T.D.

“If drug users are not included at the LDTF level, and I think we are just paying lip service to this, the LDTFs are not going to work. The LDTF process needs to get them to say what they think will work for them, and what services they need to be put in place” Emily Reaper, UISCE, 2005

“The LDTFs that are there also need to support the development of drug user forums. I know that a few of them have come to UISCE lately and have asked us how to do this. Well you would love to wave a magic wand that would show how it is done. But they need to go and ask drug users in their areas and involve them in setting up Forums.” Emily Reaper, UISCE, 2005.

“When you use the terms drug users you are talking about people who take drugs, and I think that people are looking for people who don’t take drugs to represent people who take drugs. So that whole quagmire of who do you really want representing drug users needs to be clarified. Don’t be afraid of drug users and what they have to say on life.” Emily Reaper 2000.

“The messages I got from today: We have to keep challenging ourselves, we have to keep asking ourselves are we relevant, are we being effective, are we in touch with what is actually going on. Emily Reaper of UISCE really posed a big challenge to us. How can we make sure what’s going on with our clients, our customers, those who are victims of drug abuse, are they being heard? She posed a real challenge and

that is something that I take away, how do we actually meet that challenge.” Padraig White, Chair NDST.

“Some LDTFs have family support persons and user involvement and some do not. LDTFs should be taking this on board and have a member representing family support, and have a means of listening to users as well. I certainly think there is value in that.”

Min of State Ahern, 2005

These references demonstrate clearly the existence of significant official support and policy commitments regarding the involvement of drug users in the development of drug related services both locally and nationally, and in LDTF and RDTF inter-agency co-ordination structures, underpinned by the NDST. The extent to which further guidance is required to enable the involvement of drug users is debatable. What is now required is more practical action to be brought forward, both locally, regionally and nationally.

Conference opening - Minister of State Noel Ahern T.D.

"I am very pleased to be here with you today to officially open this important Conference on Developing Drug User and Drug Service User Forums.

Developing Drug User / Service User Forums

It is clear that the involvement of drug users can be most beneficial in the planning and development of initiatives to address the problems of drug misuse. Indeed, this matter came to the fore during the Mid-Term Review of the National Drugs Strategy in 2005. Also, Action 96 of the Strategy highlights that user groups are well placed to foster awareness about available support services for those misusers who may not be in contact with mainstream agencies.

Needs of drug / service users

It can be difficult to take the decision to look for assistance and treatment. It is vital that we have appropriate, accessible services to help drug users overcome the many obstacles that they face. To regain their capacity for daily life from the impact of drug use they need medical support, access to education, housing, employment opportunities, advocacy and other social supports. As no single agency has the range of competencies and expertise to cater for all their requirements, we know that this can increase the difficulties experienced by drug users.

In this regard, the report of the Working Group on Rehabilitation, which is expected to be finalised before the end of this year, will include particular recommendations regarding the need for cohesive inter-agency working and enhanced case-management of clients.

Establishment of Drug / Service User Forums

The aim of this conference is to lead to the establishment of Drug User Forums in all Task Force areas. The engagement and support of the Local and Regional Task Forces will be required in order to support the on-going development of those Forums, once established. Given the attendance of so many people here today representing drug users, service users and LDTF and RDTF members, I feel that the support and engagement necessary will be forthcoming.

Conclusion

In concluding, I want to offer a special thanks to the Steering Group and to Finglas/Cabra LDTF for taking a lead role in organising today's event. In particular I welcome the involvement of drug users in the conference today and acknowledge their courage in that regard. I look forward to the increased and on-going participation of drug users in the work of Local and Regional Drugs Task Forces and in the implementation of the National Drugs Strategy.

It is vital for all of us engaged in this work to have real links with drug users. That is why today is so significant."

Models of Drug/Service User participation – Matthew Southwell

Matthew Southwell was invited to make a presentation at the conference on models drug/service user participation. His presentation contained a discussion of 3 models that can be used to inform approaches to this area of work in the drugs field. These he described as:

- a “community risk reduction model
- a consumerist model
- principle led development model

He suggests that these models have emerged over time in tandem with the development of policy and services.

Community Risk Reduction

Public health service engagement with drug users emerged as part of the response to HIV/Aids epidemics in the 1980's. The focus of this engagement centred on the need to reduce the risk of the spread of HIV/Aids arising from drug use.

This engagement utilised organic drug user groups who were self organized around illicit drug scenes to help with fund-raising hustles, for safety and companionship, and to make the most of their buying power. These groups provided public health agencies with opportunities to identify discuss and develop responses to perceived risks and problems.

As with other populations affected by HIV/Aids, drug injectors turned their collective concern into community organizations.' Where drug users formed community responses off their own bat, this was described as “spontaneous self-organization.” The illegal nature of illicit drug use and the scape-goating faced by drug users presented particular risks to peer leaders involved of these organizations.

Organic responses to risk

Other significant examples of self-organized organic responses emanated from New York and in Rotterdam in the mid-1980s. Drug injectors on the streets of New York were identified with the 'walking dead syndrome,' and their experience with Hepatitis B generated an instinctive reduction of syringe sharing. (See research by Sam Friedman from National (US) Institute of Drug Abuse)

In Rotterdam Nico Adriaans set up the Rotterdam Drug Users Union in response to the fragmentation of the local drug scene. Importantly, the Junkiebond campaigned for drug users' rights and opposed negative stereotyping. In response to the threat of Hepatitis B, the Rotterdam Junkiebond set up the world's first Needle & Syringe Programme in 1982.

Contrived spontaneity

Drug users have also self-organized on the recommendation of a trusted or valued professional. This model is referred to as "*Contrived Spontaneity*." The outcome of this form of community action can be as autonomous and dynamic as a grass roots model. The challenge for this model exists around the likely desire of drug users to address both health and political objectives.

The consultant psychiatrists, Prof. Alex Wodak & Annie Madden promoted the concept of self-organization among drug users in New South Wales, Australia. This triggered developments that led to the creation of the "Australian IV League." Both parties highlight the importance of knowing how to offer support, and when to step back and hand over the reins to ensure genuine autonomy of drug users.

Peer workers vs. peer support

One of the key opportunities provided by peer workers is their ability to secure "*Privileged Access*" to peer networks. Community outreach is evidenced to be substantially more effective and efficient than more widely used individual models of engaging hard-to-reach populations. (Researcher: Bob Broadhead)

However, Franz Trautman argues that there is a difference between exploiting and engaging community networks and promotes the use of two different terms to describe different models - peer education vs. peer support.

“Peer” training for professionals,’ i.e. experiential expertise to enhance efficacy of professional experts. An example of this is were “Jersey Respect” (a drug users group) trained local paramedics, this had the dual effect of teaching them practical skills and helping the ambulance officers to overcome their fears of working with drug users.

Viewing drug users as a community

It is important to view drug users as a community of interest like any other. They should be allowed to make use of community structures and players, as a resource similar to the role of gay men’s clubs, pubs and self-help structures and like other HIV affected groups.

Sloboda (NIDA) argued that this can change the professional field’s understanding of drug users’ engagement with risk. It also leads to a new relationship between professionals and drug users, and a valuing of both professional and experiential expertise.

Consumerism

The consumerist model developed as part of the evolution of methadone maintenance services. Drug users began to be engaged by medical and paramedics as consumers of methadone services. This happened on two levels; individual assertion of patients’ rights (patient’s charters). By drug users organizing as consumers of services, to express their voice, to advocate for rights and defend services.

Elements of a consumerist model:

Access - recruiting clients

Assessment – promoting the principle of choice and client centered care

Induction - self-regulation & peer mentoring & community pharmacist

Advocacy - virtual, peer support and professional advocacy groups

Expert patients – working with those with chronic health conditions

Self-Help - NA/AA, support groups, social groups

Professionals have also encouraged service user involvement responses. However, the focus in UK has been on PALS model - limitations of this has been shown in research done by the UK Department of Health.

Service user group model in UK

There are examples of positive experiences when risks are taken to resource service user groups that are not directly linked to specific services, i.e. Walsall - post funded by DAT and not linked to services. With proper resourcing service user groups can begin complex activity such as peer training of professionals, helping practitioners understand the consumer experience and promoting an empathic treatment model e.g. Royal College of General Practitioners Certificate & Alliance. Some service users groups have also facilitated diversity training among professionals. This can address professional's self-concepts and promote change in the management approach of services.

The quality of involvement offered to treatment service consumers is taken as the major measure of a service's commitment to patient and public participation among drug users. Fears about what this can mean for service providers are not substantiated as there remains a significant mismatch between the numbers wanting to complain and actual numbers of complaints.

Although service user groups can make very important contributions, they can also have a serious negative impact by not engaging with non-service users & treatment drop outs.

Principle-led Development Model

Recognizing contribution of each form of expertise (professional and experiential) – this empathic development model contains the following:

This model distinguishes between positive role modeling/imaging of drug users. (Different from promoting drug use) It creates training opportunities for users to become expert patients and peer workers.

It develops supplantive learning experiences for professionals, with diversity & skills training. This change may be termed "supplantive learning," to be contrasted with simple "additive learning", in that instead of just adding new knowledge or skills to an existing repertoire, supplantive learning calls into question previous ways of acting or prior knowledge and replaces them ([Atherton, 1999](#)).

Best Practice in drug user involvement will contain the following into account:

- ✓ Community Risk Reduction
- ✓ Identifying trends and new threats
- ✓ Identifying & evaluating organic responses
- ✓ Community development responses; a partnership valuing professional & experiential expertise
- ✓ Professional training
- ✓ Policy-level developments – operational guidelines for services
- ✓ Development journey is best approached on a step-by-step basis allowing interventions and relationships to unfold, incrementally

Conclusion

When both parties enter involvement programmes from place of enquiry, with willingness to respect each others' expertise and when both groups are tolerant of the steep learning curve that all stakeholders will be embarking on then conditions exist for growth of trust and creative practice.

The work of UISCE – Ruaidhri McAuliffe

UISCE, the Union for Improved Services, Communication & Education has its origins in a local drugs task force initiative in Dublin's North Inner City. Initially UISCE's founding Coordinator was commissioned by the local drugs task force on a consultancy basis, to represent the issues of people who use drugs, or were receiving drug use services in the area. That person was the late Tommy Larkin, who sadly passed away in January 2004.

The origins of UISCE are closely associated with Tommy's work in the preceding years. In these years Tommy facilitated an art group with people who used at Merchants Quay. Tommy used cartoons to engage participants and illustrate the problems drug users faced. These cartoons were then published in BRASS MUNKIE, a simple magazine aimed at drug users.

The first issue of BRASS MUNKIE appeared in 1996. As well as the cartoons, the magazine also contained harm reduction information, interviews with clinicians, lists of NA meetings and needle exchange information. A popular feature was the regular "PHY SPY" series which evaluated methadone clinics from the patients' perspective.

While Tommy played a central role in the production of the BRASS MUNKIE, he was assisted at the time by a loose collective of people known as CEIST (Current & Ex-users for Improved Services and Treatment.) CEIST had developed from Tommy's own networks as well as a previous group known as the "Development Group" comprising of current and former users and drugs workers. This group met about 1990. At this time Tommy was also involved in establishing a "Drug Workers' Forum."

While it is important to acknowledge UISCE's lineage, the common thread was Tommy's pioneering work, the recognition afforded to Tommy, and by extension UISCE, by employing him professionally as a consultant, was a key moment in

UISCE's development. Through hiring Tommy as a consultant, the local drugs task force showed its commitment to having the voice of drug users heard at the Task Force table and within its structures. In early 1999, Tommy sub-contracted Emily Reaper to assist him in his work. Emily had worked closely with Tommy from the time of the Development Group and is still part of the staff team.

UISCE continued to expand, and took on another part-time staff member, plus three additional CE workers. UISCE developed its own regular newsletter, along the lines of the Brass Munkie.

The staff group, plus members of the management team visited Amsterdam in November 2000, to participate in "International Drug User's Day." UISCE developed its links with MDHG and Mainline in Amsterdam. We subsequently collaborated in Europe-wide research with Mainline into the issues of control strategies for cocaine use, and adherence to combination HIV therapies.

UISCE also developed its own research skills in gauging what issues were most important to drug users in the North inner City. A questionnaire was drawn up and drug users were surveyed by peers into what issues were of most concern. From this initial research it was found that "Treatment" was the number 1 issue, followed by "discrimination," and "homelessness."

Of course all these issues are linked. The emphasis on treatment led us to undertake a follow-up survey around the issue of treatment. This coincided with the introduction of the "methadone protocols." Part of the new regime involved a switch from the branded methadone "Physeptone" to generic green methadone. At the time we were hearing that many people receiving methadone were unhappy with the new brand, we were also seeing an increase in poly-drug use. Particularly concerning at the time were the use of large amounts of alcohol and benzodiazepines.

Our research confirmed that the generic methadone was almost universally seen as less effective than Physeptone, and that people were compensating by using alcohol

and tablets. We published a report “Methadone: What’s the Story?” in 2003, detailing our findings. While we did not change the policy on methadone, we did highlight the concerns of those in treatment regarding the lack of consultation in relation to the change of methadone.

The issue of “sanctions” was also central to UISCE’s work. In this case we did eventually manage to influence policy change. People in treatment were having their methadone reduced because they continued to use illicit drugs, or for behavioural issues such as not turning up on time, or smoking in the toilets. In highlighting this issue, we found common ground with the families of people in treatment, and worked together towards a change in policy. Such sanctions do not exist in the North Inner City Task Force area, except in the most extreme, life-threatening cases. UISCE is now part of a community liaison group that meets with the management of the local HSE satellite clinic in Amiens Street.

Working with the families of those in treatment, on the “sanctions” issue, taught us the value of synergy by collaborating with other interest groups in the area. More recently we collaborated with a local GP run family practice on the “Participation and Practice of Rights Group” in researching drug users’ experiences of medical services. The findings were published in a report “We’re People Too.”

Other recent collaborations include working with Chrysalis Drug Project and Dublin AIDS Alliance in a Hepatitis C awareness campaign. Significantly, we involved people currently using drugs in all stages of the campaign, through initial focus groups, design and distribution.

The BRASS MUNKIE newsletter was revived by UISCE in 2005, and is used as an outreach tool for engaging people through street contacts. It is primarily through street contact that we gather information on issues affecting drug users. We supplement this through the hosting of fora in the Dublin AIDS Alliance, where we have our office, as well as organizing fora in other local drugs projects.

We have developed good network relationships with local projects in the North Inner City and beyond. These are facilitated by local Drug Task Force structures, particularly the “Treatment & Rehabilitation” sub-group.

UISCE has been actively involved in national organizations such as the Drug Policy Action Group, and the Irish Penal Reform Trust. We have made presentations to the NDST and NACD, most recently in the area of “Rehabilitation.” UISCE has also developed links with other groups around the country, who are in the process of setting up representative structures for drug users.

We believe there is a very obvious need for drug users to be represented at Local Drugs Task Forces, and at every forum where policies affecting drug users are decided. The Task Force model is a good one, bringing together the community, voluntary and statutory sectors. It is unfortunate that since being established, the concerns and issues of drug users are directly represented on so few Task Forces. It is hard to imagine any other area of policy development where those most affected are as not represented.

Drug users are not a homogenous group. They do not share a set of common personality traits as a result of using drugs. They are as diverse a group as any other in Ireland. The response to drug users has in many cases been too inflexible, and while there has certainly been progress since the 1996 Rabbitte Report, we are still confronted with a largely “one size fits all” approach to treatment.

The issue of “discrimination” is central to the situation. To a greater or lesser extent, people who use drugs are branded as deviant. Negative attitudes towards drug users are entrenched and pervasive. An Irish survey of social attitudes in the 1990’s found severe negative attitudes towards what are termed “Drug Addicts” in the survey:

34.5% would deny citizenship to “Drug Addicts”

(Negative social attitudes towards drug users).....”must militate against the rehabilitation of those who are addicted to drugs. Those engaged in the rehabilitation of Drug Addicts must take the negativity of the Irish public into account when trying to cope with this problem.”

The author considers such attitudes to be:

” A highly unsatisfactory and somewhat unreasonable position, extremely negative and anything but conducive to the rehabilitation of the “Drug Addict” in our society.”

Micheal MacGreil: Prejudice in Ireland Revisited (1996) pp 451-452

Some of the agencies and groups UISCE works with include:

Irish Penal Reform Trust NICDTF- sub-committees NWICN (North West Inner-City Network) ICON (Inner-City Organizations” Network) City Clinic Community Liaison Group National Drug Treatment Centre, Pearse Street PPR Participation and Practice of Rights Project Mountjoy Street, Family Practice Royal College of Surgeons Ireland Ana Liffey Drugs Project Drug Education Workers’ Forum Merchant’s Quay Ireland Drug Policy Action Group Tallaght DUF Cairdeas Project Clondalkin	Urrus Dublin AIDS Alliance Chrysalis Community Drug Project Community Detox Protocols Group Community Policing Forum Family Support Network Citywide (Drugs Crisis Campaign) The Homeless Agency Combat Poverty DROP Dun Laoghaire Western Regional Drugs Task Force SAOL Pathways CDVEC The Homeless Agency De Paul Trust FAST Finglas Ballyfermot STAR Pavee Point
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The work of Lambeth Service User Council

Rosy Flexer has worked in various aspects of the drug field for over 15 years, initially as a volunteer after recovering from a long-term drug problem. As part of her work with the Stockwell Project, Rosy started the project user group. She is currently Service User Involvement Co-ordinator for the Lambeth Drug Action Team.

- Lambeth

Lambeth is a London inner city Borough which includes Brixton. It has a population of 270,000 and is an ethnically diverse community. There are 3,000-5,000 problematic drug users in the Borough. 2,000 of these drug users are in treatment.

Lambeth DAT has been working with IU's for past three years. It began in small way by canvassing service users interested in getting involved. They also canvassed interest among staff teams to take the lead. They developed user groups in services.

A budget was made available for training, expenses and developmental projects. From these service based user groups, eighteen months ago, the Service User Council for Lambeth was established, with representatives from all the user groups.

- Obstacles

It was a new way of working for both service users and staff teams

Service Users were cynical about getting involved

Importance of having achievable goals at the start

Staff teams may feel insecure and unsure about boundaries

Individual members of the user group may want to focus on their own issues rather than the bigger picture

- Lambeth Service User Council - At the service delivery level

Supports the continuation of service based user groups

Monitors the effectiveness of SUI in services

Supports specialist user groups including; Housing User Group, BME UG, Alcohol Forum, Criminal Justice Forums

Supports peer led initiatives and projects

Writes and publishes a newsletter for all SU to use as a resource

Involvement in peer lead education in various mediums; *'Speak out' Film*, *'Fear and Loathing in Lambeth'*, *'Don't be a Tosser' campaign*,

Established a peer led advocacy service

Involvement in the delivery of training to both peers and professionals, including; Overdose Prevention Training, Basic Drug awareness, The Sanctuary Club, Hepatitis C survey

Established a constitution for the Lambeth Service User Council, enabling it to have more autonomy

Lambeth DAT provides office space/premises for the LSUC

- Monitoring, reviewing and auditing services.

Service users attend quarterly monitoring meetings, with service providers and commissioners.

Annual peer led audit of services

Monitoring shared care treatment with peer led audits and liaison with G.P.'s

Participation in a review of a crack cocaine service.

- Consultation and Commissioning

Representation from LSUC on all strategic planning groups including; Women's Action Group, Equalities and Diversity group, Children of Substance Misusers, Criminal Justice Operational Group, Treatment and Care Planning group, Joint Commissioning Group and Supporting People contract allocation group

- Involvement in writing and implementation of strategies including; Alcohol Strategy, Harm Reduction Strategy, Crack Cocaine Needs Assessment, Service User Involvement Strategy

- Conclusion

A lot was learned in the initial eighteen months of the Lambeth Service User Council. A lot of barriers have been broken down. The expertise of Service Users has contributed to all aspects of planning, commissioning, and monitoring of drug related services.

This has raised confidence among Service Users that they can become more involved in service planning. The work of the council has raised awareness that Service Users can be involved in making positive change.

The work of Cairdeas - Anne Corrigan

Cairdeas is a community based organisation established in 1998, as a part of the Clondalkin Drug Task Force area action plan. At this time the Task Force had no direct link with drug/service users living in the Clondalkin area.

The Cairdeas project now employs one worker and it focuses on a number of key pieces of work. These include the Advocacy Service, Step-Ladder Training Course, Drug Users forum.

Advocacy Service

People presenting to the advocacy service with issues related to treatment, housing/homeless, anti-social behaviour, South Dublin County Council are dealt with on a one to one basis. Whether the issue is resolved or not, the person will receive support from staff. People who contact our advocacy service may become members of the forum or join the Step-ladder Training.

Step-ladder Training Course

The need for training was identified by members of the forum who felt it could be a way to get people involved in the Forum. The training course runs three mornings per week from 9.30am - 1pm, for twelve weeks. The modules covered are Personal Development, Computers, First Aid and Health & Safety, Job Club, all are certified.

The objective of the Step-ladder training is to prepare participants to go into further Training / Education or Employment, as well as to make known the work of the Forum. The project facilitates two courses per year, one in North and one in South West Clondalkin.

Drug users Forum

Drug Users Forum is an Advocacy Group. Members use their personal issues to help set the agenda on the bigger issues. The forum is Community Development for Drug Users, which offers training and support to work through issues to come up with solutions. The members get support with their own issues through the Advocacy Service.

Establishment of the Forum

A lot of work was taken on by staff to get the forum up and running. The first piece of work was peer led research on the needs of Drug Users in Clondalkin. The research data was gathered by two drug users who were trained in completion of questionnaires. They then completed the research questionnaires with their peers and while doing this promoted the work of Cairdeas.

Our advocacy service was offered to service users of other agencies and this form of outreach work helped us build relationship with drug service users.

Recruitment of Members

The recruitment of members into the forum is an ongoing process which happens in many ways through the Advocacy Service, Step-ladder Training Course, and work shops on harm reduction, as well as networking with other agencies, issue based work and word of mouth, poster campaigns and leaflet drops.

How the forum operates

The forum operates on a weekly basis and is open to all members of the drug using community, no matter where you are in your addiction i.e. active, stable or drug free. Ground Rules were drawn up with the group and are enforced by the group with the support of staff. The forum operates to a work plan that the members draft every twelve weeks.

Work completed by the Forum

A discussion document for a local treatment centre was one of the first pieces of work taken on by the forum. Members identified a number of issues, then looked at the policies and where things needed to be changed, and then came up with solutions. As a result of this work by the Clondalkin Forum the treatment centre made some changes.

Needle exchange

Forum also identifies local service gaps for the Local Drug Task Force, and has prioritised the need for a needle exchange. The Forum undertook research into where the drug using community felt the exchange might be located. As a result, North Clondalkin now has a needle exchange.

Film script

The members of the forum also participated in proof reading the script for the film "Adam & Paul," great fun was had by all.

Training

The members have participated in training in active participation in which they got the opportunity to do a piece of research into what drug users felt about having service users represent themselves on the management committee of agencies, who provide services for drug users.

Networking

Members of the Clondalkin Forum attend meetings organised by UISCE, in Liberty Hall

Barriers for forum members

Disbelief that you can influence changes for the better by coming together

The time it takes for things to change

Understanding the meaning of the collective voice, as well as the need for individuals to have space to work on personal issues

Each individual's personal addiction and history of drug use

The need to create a safe place for forum members to meet

The area profile i.e. age of the drug users, as the project is asking them to engage in local politics

Staff

Their need to remain focused, whether there is one person or ten people attending the forum, and the challenges this poses on the implementation of work plans.

Not sitting in the office waiting for people to come to you, you need to outreach to them. Seek to find solutions so you are not just complaining. If a member of the forum is ready to move away from the drug issue you need to let that happen.

Service user recruitment

Recruitment needs to be ongoing and done in many ways by offering advocacy, training and workshops on harm reduction. Contact can also be made through networking with other agencies that provide services for Drug Users. Promoting the Forum through "word of mouth" by those already involved in the forum.

Learning to Date

The importance of the collective voice, not only for Service Users, but the service can only benefit from the experience of those using the service as they have a different insight into what may work better. The need for a network of Drug Users Forums to help forum members build their skills and create a bigger voice.

Drug Users Forums are important mechanisms not only for consultation with drug users, but as full participants. In my experience those involved have a good insight into gaps in services, and are good at offering practical solutions to these gaps. The forums are a form of community development for drug users. Enabling them to feed the issues from the ground up, to a level which can collectively bring about change at where it is needed.

Issues and recommendations from the conference workshops

Priority recommendations relating to the LDTFs and RDTFs

1. The conference recommends that a dedicated worker is needed in each LDTF area to drive the development of service user involvement
2. In the interim LDTF Development Workers are ideally placed to continue this work
3. The LDTF Development Workers should continue to organise meetings of the services users who attended the conference
4. Capacity building and training should be organised for the service users attending the conference, who will then use this to develop a wider local service user network
5. The conference recommends as a matter of urgency that places are provided for drug user representation on all LDTFs and at NDST level, and that appropriate training is organised for the individuals concerned. These representatives should be elected by local fora. This representation should not be tokenistic in nature.
6. All Task Forces Local and Regional as well as the NDST, need to prioritise the development of D.U/S. fora and provide adequate funding for this to happen.
7. Treatment and service issues will then be fed into the LDTF from the service user network and where relevant on to the NDST, on the understanding that there will be formal responses

8. Forums need to network and access training to be able to be sustainable and effective
9. Funders (Task Forces) need to stipulate best practice in relation to service user representation and monitor by consulting service users
10. Task Force need to stipulate best practice in relation to service user rep to it's projects and monitor by consultation with service users
11. The conference recommends training for Task Force members regarding service user needs and real meaning of participation
12. The conference recommends that the childcare needs for drug/service users who wish to participate needs to be addressed

Priority recommendations relating to the NDST

1. It is recommended that funding be provided to each Task Force, by the NDST, for the development of service user forums
2. Service user forums need to be made a priority – this needs to be raised with the NDST
3. Task Forces and NDST need to prioritise the development of fora and provide adequate resources
4. Service user representation on Task Force and at NDST level is recommended as a matter of priority. (Elected by Fora) Not tokenistic
5. National standard of best practice – to deal with all sanctions around prescribing systems in place dealing with sanctions

6. Childcare needs to be addressed

Priority recommendations re: new structures

1. An independent agency to advocate on behalf of clients to all services should be established.
2. The conference identified the need for structures to be put in place to engage service users and professionals in dialogue regarding service related issues
3. The conference recommends that community development approaches and methods should be used to train/building capacity of service users and forums
4. All forums in Ireland need to network and access training to be sustainable and effective
5. Need to establish a National Network of Fora. UISCE could be supported/resourced to develop the network

Priority recommendations for service providers

1. The conference recommends that a set of national standards of best practice be developed – to deal with all sanctions around prescribing systems. Drug/service users should play a key role in the development of these.
2. The conference also recommends the establishment of an independent panel to address any drug treatment service complaints by service users (with a time frame for processing complaints)
3. The childcare needs of those using treatment and rehabilitation services needs to be addressed. This an effective bar to treatment.

4. Training of professionals and service users, regarding attitudes, to think differently about users. (Supplantive learning referred to by Matthew Southwell)
5. The conference recommends more peer led information – helpline/leaflets through funding and supporting service user forums e.g. buddy system/peer support, respect expertise of service users
6. The conference recommends the creation of independent advocates in drug related services to ensure drug/service users are heard and issues acted upon. Advocacy workers could accompany individuals when issues are being reported.
7. The conference recommends that the use of oral swabs is seriously considered instead of urines, as the way of taking drug testing samples. The taking of urine samples is demeaning and a human rights issue.
8. There are many issues that need to be addressed by Doctors. Those that manage GP's need to be alerted to the practices relating to the treatment of drug users. Dialogue needs to take place to address the issues involved.
9. It is recommended that drug users involved in hiring staff within services, and more employment opportunities are available for service users within services

Conclusion

To conclude this report and to provide some pointers to progress the recommendations of the conference, the organisers offer the following proposals:

The NDST should seek funding to implement the commitment in the National Drug Strategy in relation to the involvement of drug users in the planning, management and monitoring of the range of drug services, at national, regional and local levels.

This funding should be used to employ workers at local level to support, organise and represent the interests of drug/service users. This work should then act as a foundation for linking into national drug policy structures.

LDTF project/development workers are in some cases, leading the process of setting up representational mechanisms at local level. While this work has made a valuable contribution, it is neither ideal, nor sustainable in the longer term.

At least one worker is needed in each LDTF and RDTF area. The arrangements in regard to employment and work planning for this should be agreed by the interests at local and regional level, for there can be different ways of doing this in each Task Force area.

Following the conference, there can now be no doubt about the obvious need for drug users to be represented on drug task forces. This can be achieved by all local and regional drug task forces actively facilitating this immediately.

Local Drug Task Forces should also set achievable targets and schedules in their revised strategic plans for the involvement drug/service users in their structures.

Finally, considering the lack of representation of drug/service users on Task Forces and other relevant structures to date, there is a need for further discussion as to the barriers preventing this in Ireland.

Appendices

Appendix 1

Guidelines for LDTF staff on preparing drug/service users to participate in the conference

Introduction

The purpose of these guidelines is to provide each Task Force with some practical ideas on how to prepare a group of Drug /Service Users for the conference so that they can share, as much as possible, their ideas and experiences regarding the development and sustainability of Drug User Forums in their areas.

Aim of the conference

The aim of the conference is to act as a catalyst for the a common understanding and approach to the establishment of Drug User Forums in all Task Force areas; to share the experience of the forums that already exist; and to promote increased participation by drug users in the Task Force structures.

Who should participate?

The conference is aimed at drug users ranging from people actively using drugs, to those using drug treatment services, to those no longer dependent on psychoactive substances.

Where can they be contacted?

The individuals concerned can be already active in an existing drug user forum, an interim-funded or mainstreamed project, a HSE or voluntary sector drug treatment service etc.

What preparation can be done with participants in the lead up to the conference?

- Explaining the purpose of the conference, i.e. that the key purpose of the conference is to explore how best to establish, develop and support effective

Drug User Forums. It is crucial to emphasise that the conference will not deal with individual case issues or problems with specific services.

- Discussing how conferences work i.e. speakers, workshops etc.
- Discuss how workshops work and how a summary of the discussion is recorded and brought back to the main conference.
- Discussing why people come together in large groups to think about the topic and the ideas and issues involved.
- Discussing with participants what their role will be at the conference i.e. that it is ok to just listen and learn but also the importance of hearing directly from those who are drug/service users.
- Exploring some of the ideas and experiences they may wish to share at the conference.
- Organise arrangements so that the group from each LDTF travels together.
- Discussing with active drug users how best to manage their drug use during the conference, as illicit drug use will not be permitted at the conference.
- Re-arrange appointments so that attendance at the conference doesn't conflict with drug treatment or family care responsibilities etc.
- Organise how feedback to their local group or Task Force will be done as a follow-up to the conference

What role will drug/service users be expected to play at the conference?

- To contribute ideas and experiences that achieves the aim of the conference
- To participate in workshops
- To network with other conference participants
- To bring back what they have learned to their local group

What resources will be needed? (To be provided by each LDTF)

- Assistance with re-arranging treatment appointments
- Transport
- Family care support
- Pens and paper etc

- General expenses

Appendix 2

LDTF Service User Conference

Royal Dublin Hotel, 9th November 2006

Attendance Sheet

NAME	ORGANISATION
T Gilson	Tallaght LDTF
Rose Dodson	Tallaght LDTF
Gerard Cooke	D/S User
Jessica Smith	D/S user
Paul Quigley	Finglas/Cabra LDTF
Graham Ryall	CCLDTF
Mary Ryder	CCLDTF
Niamh Kinsella	Frontline Project
Shane Dillon	Frontline Project
Rose Dunne	Crossroads
Joan Donnolly	Crossroads
Paul H	D12 LDTF
Alison Rode	Ballymun LDTF
Sandra King	SWICN
Niamh Lyons	CCLDTF
Rory Byrne	TURAS
Cecil Scott	SICLTF
Derek Mooney	SICLDTF
Gemma Fox	NACD
Jen Cronly	ROSIE
Louise Sheehy	ROSIE
Emily Reaper	UISCE
Vivienne Hogg	DENDTF
T O'Brien	DENDTF
Ann Corrigan	Clondalkin LDTF
John Coleman	CLDF
Peter Murphy	CLDF
John Kerrigan	CLDF
Tara Peevoy	CLDTF
Rosie McGone	CLDTF
Ger Cooke	CLDTF
Lorraine Flanagan	RASP
Siobhan Turner	ECRDTF
Amy	D/S user
David Lane	Cork LDTF
Sharon Perry	Bray LDTF

Frank Gilligan	Ballyfermot LDTF
Susan Keegan	Blanchardstown LDTF
Ger Doyle	Blanchardstown LDTF
Emma Keenoy	Finglas/Cabra LDTF
Joanne Doyle	DCR CAT
Mags Carey	Merchants Quay Ireland
Willy Sullivan	DNEDTF
Andrew Diggins	NDST
N Hackett	WRDTF
John Balfe	Probation and Welfare Service
Mary Jones	Wexford Area Partnership
Declan Byrne	DNELDTF
Blathnaid Dunne	BLDTF
Joanne Farrell	Drugs Task Force
Michelle Walsh	RASP
Frank Jones	DRDP
Jay Cummins	BLDTF
Ann Losty	BLDTF
Sandra Dignan	BLDTF
Joan Duffy	Cabra Resource Centre
Bernie Clarke	CR Corduff
Siobhan Swords	DLR CAT
Declan Meade	An Garda Siochana - D12 DTF
Tony May	CCLDTF
Aoife Fitzgerald	D12 LDTF
Matt Davis	UISCE
Anna Quigley	Citywide
Paul Heaney	DCRGA
Tony Roche	Cornmarket Project
Glenda O'Neill	Ballymun LDTF
Doreen Davis	D12 Service Users
Chris Black	Southern RDTF
Vanessa Hoare	DNE LDTF
Phillip Keegan	Blanchardstown LDTF
Justine Horgan	NACD
Jackie Monaghan	BLDTF
Phillip Jennings	BLDTF
Paula Paget	Ballymun LDTF
Clare Horan	Ballymun LDTF
Kevin Piggott	Finglas/Cabra LDTF
Kathy McAuley	Trinity Court
Martina Stritch	Trinity Court
David Guerin	KCCP
Wendy Byrne	Cork LDTF
Erin Nugent	UISCE

Amy Bonass	Cork LDTF
Pat McCormack	Finglas/Cabra
Gerard Fitzpatrick	EC Regional
Loman Conway	NWR DTF
Brian Kirwan	Millennium Carving
Mary McEntee	BLDTF
Eileen Cannon	ECRDTF
Atracta Canny	D/S user
Dolores Duggan	WRDTF
Simon Comer	WRDTF
Jayson Power	Cornmarket Wexford Partnership
Barbara Condon	Finglas Addiction Support Team
David Kiely	Southern Region DTF
Teresa Weafer	RDRD
Simon Groves	RDRD
Kenneth Ronan	RDRD
Katherine Harford	TDTF
Charlotte Chubb	Tallaght Drug Users Forum
Brenda Gallagher	Tallaght Drug Users Forum
Sandra Johnson	Tallaght Drug Users Forum
Andy Ogle	NE LDTF
Sean O'Connor	NW RDTF
Louise Mullen	Dept Public Health
Mary McGagh	D12 Task Force
Darren Wright	CDA
Marlene Donnelly	NE LDTF
Sue Smithers	NIC LDTF
Hugh Greaves	Ballymun LDTF
Angela Birch	BKYR
David Norton	LDTF
Lisa Baggott	SWRDTF
Sharon Harty	CASP Clondalkin DTF
David Guerin	KCCP
Lisa Whittaker	RCDT
John Bennett	Finglas/Cabra LDTF