Empowerment – Models of good practice: Heroin use and peer support

What lessons have been learnt?

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Colophon

This article is part of the reader ‘ empowerment and self - organisation ofdrug users’

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Twenty years of harm reduction practices in Europe have already passed since the mid-1980's, a consequence of the connection between HIV infection and the intravenous use of heroin.

What lessons have been learnt, in particular with respect to the empowerment of users, considered one of the most important and also one of the most delicate and controversial tools of harm reduction? More specifically, in what terms has the active role of the user managed to play the part of essential resource for

1. a)the assumption of self-protective behaviours of use
2. b)advocacy for their rights
3. c)the direct management or co-management of certain services for drug users?

The World Health Organization (WHO) has more than once affirmed the importance for achieving changes – in particular regarding a series of questions where health issues are grounded in social problems – by working simultaneously on three aspects:

- lifestyles of individuals or groups;
- the environmental context that induces this;
- and the current health and social system.

The work of peer support, activation and self-help between users, meet at the crossroads of the three areas for change identified as strategic by the WHO:

- There is the “community” that learns to protect itself, to produce behaviour change and self-propose a lifestyle that is safer and compatible with social integration.
- There is the “initiative group” that tries to have impact through a different social representation of the problems surrounding drug use in terms of the environmental context.
- Finally, there is the “peer-operator” who has influence regarding better access and relevance to needs from the specific socio-health services, modifying work methods and organization.

The mechanism activated by peer support is that of research-intervention. The actions produced in interaction with the surrounding environment determine the acquisition of new knowledge. This is translated into new work practices that in turn re-interact with the social context and on services.

1. The role of the active minority

The first lesson learnt concerns the crucial role interpreted by the active minority in terms of change. The data identified through social research, that quantifies 2.6% of the general population as the number of people willing to involve themselves objectively for a more general purpose, is also valid for peer support amongst injecting heroin users.

At first glance, this percentage appears very low and could be discouraging and depressing. However, seen through the eyes of a social epidemiologist, it is not to be ignored. According to figures provided annually by EMCCDA the problematic use of heroin involves less than 1% of the population in Europe, which means a total of a few million people, spread out across the States of the Union today.

If it is with these numeric dimensions that the phenomenon of problematic drug use is depicted, then it is hugely amplified at a symbolic level. Drug addiction is linked to questions of public safety and plays the role of scapegoat in the exploitation of fear during political debates.

In a population of a few million consumers in Europe, even allowing for some excess in the 2.6% calculation due to the specific difficulties connected to the problems of heroin use that can cause further preclusions from participation, it still signifies thousands of consumers that can be activated as protagonists for social change regarding this phenomenon. These can act as users, as ex-users, as clients who use health services or those who don't, as activists, volunteers, or peer-operators. Their personal involvement and their contribution represent a social capital that is either unrecognised or totally underestimated but which however is worth counting on

The effort spent in these years in harm reduction programmes and strategies - first in some northern European countries and then in others in the south and now the east - has demonstrated that involving users, even problematic users, is a realistic objective. The process of activation comes about in many varied and diverse ways, due to the cultural specificities of each national cultural reality. This in turn is influenced by important variables that can be placed along a continuum that goes from the types of legislation to the significance of social stigmatisation in each country, to the types of use and the lifestyles of the consumers. It also includes the personal history and background of each user.

However, what best unites the experiences of empowerment in peer support between problematic heroin users is the trajectory of the life experienced: from the phenomenon and the marginalized practices of a stigmatised group to becoming resources for the local community; from unsatisfied and quarrelling clients to integral partners in a social and cultural movement.

2. The multiform nature of the results of peer support work

The results achieved from peer support work have gone beyond the effects expected, leading to surprises compared to initial expectations. Above all, this is because they have reversed, like the many rivulets of a waterfall, with respect to differentiated needs, deviating with different effects on various levels: personal, social, health, cultural, political.

The level of acquired knowledge is widespread with respect to risks and harm associated with certain drug practices, and the determination put into action by the active minority of users, have had strong effects both in terms of the social representation of problems of dependency and with the organization of services.

It may be useful to recall the different areas where results have been achieved:

a) Personal change

Change can occur in terms of a more prudent mode of consumption, the self-limitation of episodes of abuse, the avoidance of risks of infection, but also a major attention to the legality of one's own behaviour, an improvement in relationships with health and social services, an increase in the motivations for change and initial and partial changes in lifestyle. Some of all of these, or a little of each one, translates into greater stabilization of user behaviours and lifestyle habits of people, that render them or re-render them compatible with heroin use. This includes intravenous use with existential choices and a project in itself not overwhelmed solely by the importance of the drug.

The real value of peer support, at a personal level, consists in amplifying the possibilities of individual choices, increasing the number of possible options, with which to measure oneself, making use of new social networks which s/he has become part of, and further opportunities, of which use can be made For some, peer support is the stimulus - via knowledge, imitation and identification under pressure from peers - for the assumption of more attentive drug behaviours; for others it is an opportunity to meet other people, make contacts, develop relationships, have different experiences from those strictly and habitually determined by the world of drug use. Still others see peer support as an occasion for personal commitment, the acquisition of a different sense of identity, an almost militant practice or a semi-professional one such as peer-operator. For each of these, peer support, while stated personally, nevertheless signifies an experience of empowerment.

b) The social normalization of drug use

Normalization means treating the phenomenon drug use as any other socio-sanitary problem that society takes care of. It is precisely the opposite of the logic of continual emergency and a strategy that uses criminal law as the primary resource.

The stabilization of drug use and the maintained or re-established compatibility with a social, emotional and working life - an objective where the different harm reduction interventions and treatments converge - testifies to the fact that it is possible to live with even the hardest of psycho-active drugs, heroin, and at times with the most destructive method of use, intravenous. Not always and not everyone, but the fact that a consistent number of problematic users manage to not let drug use interfere in their social integration, is something that the social representation of the phenomena can not ignore.

Social representation and social normalization are close relatives: if the perception of the phenomenon is stereotypical and if a simplified image of the problem prevails in public opinion – one that uses rigid and dichotomous interpretive categories that adopt binaries such as on/off, dependency/abstinence – drug use becomes identified totally with “hell” and abstinence with “salvation”. Black and white become the only two colours possible to describe the facts. The wide range of grey is ignored, which in reality constitutes the larger part of the phenomena that can be articulated between use, harmful use, abuse, problematic use, dependency and pathological dependency. Scientific evidence has difficulty making headway with public opinion and consequently with the institutions that

should support it and which instead remain paralysed by the generalized opinions of the people they represent.

To represent the “normality” of drug use and to let emerge the prevalence between users of responsible behaviours for themselves and with respect to others, requires the effort of social visibility. To modify a useful stereotype, one whereby the dynamics of scapegoat converge, utilized socially in the worst sense of the word, requires the user to choose public visibility and maintain his/her reasons and to testify to what he/she is and the life he/she leads. The drug addict who is high, behaving delinquently and socially in a highly dangerous way, is today a reduced component of the entire problem, often even the result of the way the question is dealt with. He/she is a small part but one that will most probably represent the whole issue.

The gap between the expansion of stabilized drug behaviours in reality and their reduced social representation constitutes perhaps the greatest obstacle to normalization.

The politics of normalization by institutions, or their duration over time are difficult to put into practice if they do not occur in parallel with a change in the perception of the problem by the general public. Much has been done over the past years and has been followed on in terms of normalization and integration. However, still little has been done with respect to communication and the efficacious description of scientific evidence and the results achieved. These can offer a different interpretation of the phenomenon, indispensable for the start and the consolidation of a policy of de-stigmatisation.

c) The modification of services

The drug users movement has managed to influence services and to make them - at least in part - closer to the needs of their clients, more receptive to their requirements and more contractual. As was expressed in a Correlation seminar, at least in the dedicated and specific services, the objective to be treated with dignity and respect on par with other clients has been achieved. The right to receive information, first aid medication and treatment has also been attained, at least in those countries that have been European community members for a longer period of time. Many specific questions are still to be “perfected”, remaining in closed envelopes.

Nevertheless the network of outreach interventions has expanded, both for harm reduction interventions and for selective preventions. The threshold for access to health and social services has been lowered and treatment options have been both extended and strengthened. Above all, a dialogue has been triggered between users-clients and service providers, which has facilitated not only the need to consider different points of view but in the best of situations, to bring together reciprocal knowledge and competencies, capitalized in new initiatives or “adjustments” in service operations. On occasions it has even been possible to jointly plan and manage innovative interventions.

In certain exceptional situations official representation of users has occurred within institutional bodies more frequently, working in a consultative capacity with respect to service project planning or, alternatively, predisposed to undertake programme evaluation. In other situations that concern in general research, research-interventions or experimentation, users are involved, either individually or in virtue of the associations they represent, with ethics committees, where they function as a guarantee and to ensure that rights are respected.

3. The methods and the difficulties involved in starting initiativ users groups

Innovative groups of users are rarely “wildflowers” that grow spontaneously. Today they are more often “greenhouse flowers” that start up with the help and willingness of certain service operators.

The type of beginning of a group, the method with which it begins, is very relevant to it’s future development, to what it will become, to it’s actual identity. The imprinting of the origins conditions the evolution of the group, at least for all of the initial period, connotating it’s characteristics and above all highlighting the fragility of the group.

The experiences over the years enable the identification of at least three modalities, three prototypes for the start of a group:

a) Users self-made groups

Often their origins arise from a spontaneous reaction to sometimes dramatic events and therefore of great symbolic value that, in terms of their selective significance, are experienced as the straw that broke the camel's back. This in turn reveals a condition of daily subordination towards a chain of overwhelming institutional and social events that is no longer tolerable. Born from this very intense emotional impact - which gives rise to spontaneous meetings in response to the open "wound" - they are organized as self-defence groups. This occurs rather at a local than at the national level, with the aim of protecting themselves against discriminatory practices, carried out by policies, institutions, society and services These groups arise in a manner totally external to services. Most users in these groups are not clients of therapeutic programmes. At times, users approach drug services but they soon stop frequenting them. Some remain in contact for methadone maintenance or for some social benefit payment. Mostly these groups express the conflicting relationship with services, which are perceived as institutional offspring and which are treated with suspicion and distrust, as they are generally incapable of safeguarding user's rights. These antagonistic aspects structure the group and feed the sense of belonging of the participants. The complete autonomy of the group is also its expression of strength, one it self-provides, often with good organizational abilities, pride in its independence and entrepreneurship concerning its own needs.

The major risk for the life of the "self-made" group is represented by the danger of isolation, often the result of the assumption of hard and radical positions and the determined willingness to refuse almost any negotiation with institutions, which in turn precludes the possibility of confrontation and constructive exchange.

Apart from a few national situations, and with some exceptions, this type of user group represents a reality more from the 80's and the early 90's rather than today. These groups were characteristic of the pioneering phase, fated as they were by difficult conditions, at the beginning of the politics of harm reduction and within a repressive and stigmatising context.

b) Spontaneous client groups

These are client groups that, finding themselves in therapeutic programmes run by drug services, decided to autonomously agitate regarding a number of issues: improvement of the allocation of services that regarded them; the request for a space not strictly rehabilitative; the need to be protagonists, but not rigidly confined to the role of user. The involvement of users in group initiatives was more or less the consequence of good clinical practices but also the establishment of accessible services, open and negotiable, aimed at not focalising only on the problematic aspect of who had made a request for help, but on valuing the resources, the knowledge and the competencies present. From this came a request for involvement and the search for a role where motivations and aspects of oneself could be expressed, which had until that moment often been silenced or had had no opportunity to emerge.

Even for the spontaneous users groups the conflict, in this case focalised on the care/cure system, can constitute an evolutionary step of the process. It can almost be considered physiological for the consolidating function it has on the identity of the group

Roger Coleman, a client of psychiatric services in England, describes eloquently his “voyage”, first within the evolution of the mental illness that afflicted him, and then within the psychiatric services. He recounts how, after the obligatory treatment he underwent in the first repressive phase of the therapy, he was then able to access a less cruel treatment method. This method was much more caring and respectful of the person and he was able to have the useful experience of participating in self-help groups. Developing that experience as a psychotic patient who “heard voices”, Coleman became an activist for self-help groups for people who hear voices, then a trainer of patients and professionals. He attempted to help other people with the same condition to control their symptoms better and to prevent the escalation of a psychotic crisis that could subsequently occur. Coleman is an example, as he himself relates, of how the methods used by professionals and the organization of services can favour the start of spontaneous initiative groups of clients.

c) “Greenhouse” groups or mixed groups

These occur where the service providers do not only play the role of midwife for the initiative group but are also the incubators. In these situations the users groups do not come about spontaneously nor as a consequence of good clinical practices, but necessitate a rather long period of working side by side, and it is not a foregone conclusion that they will evolve finally into the formation of an autonomous group. These groups arise from a proposal by drug services, and as such denote a high level of “ontological” vulnerability. They are a fragile matter, to be handled with care. In reality they are conceived by operators, not as groups artificially predisposed to the initiatives of the services, through which pre-chosen users are called up to undertake some kind of already determined activity. Instead they are the outcome of an invitation to participants to develop together with the services a debate, a reflection of joint interest, at times a research project, an experiment, or whatever initiative that could be of interest and useful. The methods and the reasons for the start of such groups can also be very different.

Nevertheless what constitutes the common denominator of these experiences is that the initiative is exogenous. It comes from the services, and necessitates a phase of working with the invited members of the group, which is not yet autonomous and does not yet express a spontaneous capacity for initiatives. Furthermore, the participation and the “control” of the group are sustained by the presence of professional operators. The professionals do not have the paradoxical burden of “conducting” the group towards independence because such an event can be nothing but spontaneous. Rather the effort is in constructing a mixed working group of users and operators. This happens on equal terms with a combined participation that brings together different points of view, different knowledge and competences, and is not characterised by the asymmetry of a relationship that is generally found in the therapeutic setting

The weakness inherent in the origins of these types of groups consists in the hetero-conception rather than the self-conception of the group. Nevertheless, the opening of such an innovative building yard constitutes a true laboratory, where the gamble on fertile creativity, produced from a reciprocal contamination of knowledge, can be won. What is required is sufficient conviction to be instilled in the objective to develop a willingness to “stay” with the new relationship, and to maintain a constant curiosity and openness with respect to the research.

The constitution of mixed working groups where user-clients, operators and volunteers participate, appears today to be the most realistic path to follow.

4. The importance of umbrella organizations

For each of these groups, umbrella organizations play an indispensable part, including the self-made groups. The umbrella organizations, both public and private or volunteer, can be defined on the basis of their willingness to offer refuge and support to all mutual self-help groups and local initiatives that have as protagonists the same people who directly live and experience the problems.

The material resources and the institutional credibility that the umbrella organizations benefit from enable them to undertake two fundamental functions: trampoline and protection, both of which users have need for, not only at the beginning, for continuity and development of their initiative.

The “refuge” that the umbrella organisations provide is above all, even if not only, material and concrete help, which is indispensable for the start and for the consolidation and reinforcement of planned actions This means the possibility of using spaces for activities, to have communication and information resources available, to be able to undertake “consultations as necessary” with respect to a wide range of problems to resolve; to know who to go to for eventual assistance for those individuals temporarily in difficulty.

The “cover” provided by the umbrella organizations also concerns the work of mediation with respect to institutions and public opinion. This consists both in the social and cultural legitimisation and in the recognition and the valuing of the experiences carried out by peer support. These aspects are not easily understood and shared, above all when they are at the limits or “extreme”, and challenge the stereotypes and the prevailing prejudices locally where these interventions occur.

The European network *Correlation* is a good example of an umbrella organization. It strives, through a network of relationships between the north, southwest and east of Europe, to identify the tools that sustain peer support, aiming at a double objective with respect to the empowerment of consumers:

a) to re-launch initiative groups as protagonists in each single country;

b) to try to construct a network capable of giving voice, visibility and international representation to the consumer movement active in defending their rights.

5. The role of the service providers

Professional operators, but also volunteers, play a key role - more today than in the past - in stimulating, working together and strengthening the protagonist role and the initiatives of users. Deciding to work with the resources a client has to offer and not just the "pathology" that has brought them to the drug services, is a choice that hardly needs mentioning and that today concerns a consistent minority of professionals. Furthermore, the difference is in what is intended by valuing the resources of the client: not resources that can be mobilized in direct connection to treatment, finalized solely in terms of the treatment and therefore completely subordinate to compliance with the therapeutic programme, but resources vice-versa available in settings where personal involvement frees the individual from the role of client. He/she acts as a citizen, as a militant for a good cause, as a person who in doing so, acquires dignity and a sense of self-esteem.

What is necessary for the operator, in order to work with peer support, is to be able to at least momentarily abandon or put aside his/her clinical perspective on the issues and therefore leave the therapeutic role behind from the moment he/she gets ready to collaborate with consumer initiative groups. This is the only way that an equilibrium within the relationship can be reconstituted, by leaving behind the asymmetry of the actual power inherent in the operator-user relationship.

This operation constitutes a preliminary act and it is through this act - that is required by the professional - that a totally new and diverse adventure is embarked upon in the relationship with the consumer. The relationship, finally freed at least formally of its roles, obeys a statute of parity. Together, each with their own competence, they form a new group that defines an objective to work together on. The user is no longer the work objective of the therapist. Now they are two subjects, equal and allied in undertaking a third task.

For many operators this "side-step" wrongfoots them with respect to the usual frameworks and upsets the hierarchies of roles. This is seen as a loss, and not a small one at that, nor one to be renounced. The loss is above all that of power, and touches those aspects

of security and certainty of image and professional roles, all of which have profound and authoritative connotations when they are closely connected to the more personal aspects of one's identity.

Loss of power means adventuring into a work field where one's professional specialisation is of no help and is actually out of bounds. When you have to keep the rudder straight in open seas and when insecurity prevails over assuredness, your true nature is directly called upon.

Only a choice made clearly and calmly protects the operator from subsequent betrayal. The "betrayal" is manifested in a thousand ways, if unease is displayed with respect to the choice made: in the work ally the user only is seen and therefore the asymmetrical nature of the relationship is perpetuated; in dividing up the tasks the dirty jobs are delegated; the operator is less willing to step aside to favour the user as protagonist; energies are expended in the competition for the leadership of the group.

What is required is to recognize in the user the existence of a knowledge totally his/hers; to have the intellectual curiosity for all that is unexplored, even that which appears to be the most obvious; to know how to talk to people outside of their roles; to share the battle against the stigmatisation and discrimination of users. There is a premise, a prerequisite in this battle for the development of a good partnership between professionals and operators. If the partnership is real (and not a camouflaged reprint of the therapeutic alliance), anything and everything can happen: divergence of opinion, conflict, escalation of same, methods of resolving confrontation, even separation and splitting off, if this is considered necessary or inevitable. After the experience of partnership, nothing will be as it was before.

Empowerment that has been experienced leaves a mark; it constitutes a point of no return, above and beyond the different shapes that the commitment can assume after this. The user knows and feels that if he/she wants, he/she can play a different role and be the protagonist in his/her own social context and with respect to his/her relationship with services. He or she is no longer the client that asks for help, no longer the stigmatised drug addict, but an active subject with acknowledged resources that he/she can useful contribute to a reciprocal relationship.

6. Today's tasks

Empowerment strategies for users in Europe are widespread and consolidated, and the international situation appears "patchy". A few work priorities are proposed for the future:

- The first objective consists of spreading the experiences of empowerment to those countries that today have had less exposure. This needs to occur in such a way that the new eastern countries can incorporate these experiences, adapting specific strategies to the characteristics of their own diverse contexts. The capitalization of the acknowledgement and the visibility of the user as an active subject, who takes part in policy and service provision debate, have only been achieved in part. What is required is the organization of a national assembly of users that at a consultative level is listened to first hand, without mediation. This is not an easy objective to be reached but neither is it unrealistic.
- Also necessary is a direct European representation of users, not mediated by operator associations. It would be important if a presence was identified within the one foreseen for civil society in the "green paper" that contemplates a consultative discussion at European level, at least for the more accredited international networks. It is crucial that the voices of users are not mediated by networks of operator stakeholders but that they can participate by direct representation.
- Considering the variety of national legislation regarding the use of psychoactive substances and the specificity of each single country, it is important to define a charter of minimum rights for users, of non-discrimination, of access to health and social services and their provision, all of which can be promoted by users themselves.
- To sustain the diffusion of empowerment strategies, it is essential to exploit good practices in order to make use of experiences already put to the test and to avoid repeating errors or taking unsuccessful directions. It should be possible to circulate simple and immediately applicable information. New drugs and new methods of use require continual research and continual up dating of the most efficient practices.
- The implementation of focus groups has proven to be particularly productive for starting up mixed working groups of users-operators in diverse and multi-task services. These groups have enabled the involvement of users, the acquisition of user

points-of-view and knowledge, the sensitisation of operators and the establishment of new ways of relating and collaborating.

- The practice of involving users to manage or co-manage certain harm reduction interventions, as peer-operators, is a very useful opening, both for the contribution of new competencies for services and for placing value on the user as a protagonist.
- The formation of professional operators as facilitators of the empowerment process becomes the characteristic of an essential and priority practice to favour and extend the opportunity for user involvement.

This article is part of the reader ‘empowerment and self-organisations of drug users - experiences and lessons learnt’.

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