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## What we do not know about organizations of people who use drugs

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## Introduction

The focus of this special issue is about programs that incorporate active drug users as change agents for promoting their own goals and those of public health. Many active drug users have a wealth of talents and skills they can use for themselves as well as for others. Some of them find that their own drug use impedes their skills. Many more find that they are impeded by stigma against drug users, by the criminalization of drug users, and often by issues of social or economic status. Many countries, including the United States, make it legally difficult or impossible to employ drug users in projects that receive government funding; and many programs exist that encourage employers and others to ban drug users so they will "bottom out."

This issue focuses on the positive roles that drug users take as change agents. It focuses on programs, some of which are research based. Some focus on the role of active drug users in establishing and increasing access to drug user treatment. It is commonly assumed that in order for active drug users to function in society they must first stop using drugs, which usually occurs through drug user treatment. Other papers in this issue focus on "users groups" that are organizations of active drug users that engage in public health or political

<sup>&</sup>lt;sup>1</sup>Treatment can be briefly and usefully defined as a unique, planned, goal directed, temporally structured, multi-dimensional change process, of necessary quality, appropriateness and conditions (endogenous and exogenous), which is *bounded* (culture, place, time, etc.) and can be categorized into professional-based, tradition-based, mutual-help based (AA,NA, etc.) and self-help ("natural recovery") models. There are no unique models or techniques used with substance users- of whatever types and heterogeneities- which aren't also used with non-substance users. Whether or not a treatment technique is indicated or contra-indicated, and its selection underpinnings (theory-based, empirically-based, "principle of faith-based, tradition-based, etc. continues to be a generic and key treatment issue. In the West, with the relatively new ideology of "harm reduction" and the even newer Quality of Life (QOL) and wellbeing treatment-driven models there are now a new set of goals in addition to those derived from/associated with the older tradition of abstinence driven models. Treatment is implemented in a range of environments; ambulatory as well as within institutions which can include controlled environments Treatment includes a spectrum of clinician-caregiver-patient relationships representing various forms of decision-making traditions/models; (1). the hierarchical model in which the clinician-treatment agent makes the decision(s) and the recipient is compliant and relatively passive, (2) shared decision-making which facilitates the collaboration between clinician and patient(s) in which both are active, and (3) the 'informed model' in which the patient makes the decision(s). Editor's note.

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activity. And still others focus on the roles of drug users in HIV outreach efforts or other projects, some of which have research components.

Being involved in key social roles such as employment or membership in a drug users' organizations may provide structures and rewards that have a positive impact on the lives of drug users and others. Some drug users may find that this helps them control their drug use, well being and quality of life. On the other hand, sometimes these roles may have negative consequences. They may be stressful. For those who have quit using drugs, involvement in roles that involve working with active drug users may lead them to take up harmful drug use themselves.

Without empirical data on both the positive and negative impact of drug users' involvement in different organizations and inhabiting different social roles we are left with stakeholder opinions, principles of faith and ideologies about the impact of these activities on drug use and drug users. It is our hope that this special issue of *Substance Use and Misuse* can both provide data on the role of drug users as change agents and can help facilitate programs and research that expand the availability of pro-social roles for active drug users and systematically document the impact of these roles on drug users, their significant others, social network members, and the larger community.