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## Drug Users as Social Change Agents: Increasing but Limited Possibilities in Sweden

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This commentary discusses some prerequisites for and potential changes in drug user participation in treatment, decision-making, and policy in Sweden. What possibilities and obstacles are there for drug users to serve as social change agents? To what extent are drug users able to bring about change in social organizations and institutions—changes that are beneficial from their point of view?

Drug use is viewed as a serious social problem in Sweden and the restrictive drug policy adheres to a zero-tolerance attitude to illegal drugs. The overall goal is a drug-free society and the policy includes three pillars as goals: fewer people will start to (mis)use drugs; more

people with addiction problems will be given help to stop; and the supply of drugs will decrease. Both the correctional and the treatment systems are therefore highly involved in the realization of the drug policy.

A moral condemnation of drug as well as zero-tolerance policies, including criminalization of both drug possession and personal use, has left little room for acceptance of drug users' voices in Sweden. Drug users, it has been claimed, have instead "often been treated as second-rate citizens; not as subjects with rights, a voice and an identity, but rather as passive recipients or subjects of help or measures of control, punishment and discipline" (Anker, Asmussen, Kouvonen, & Tops, 2006,

<sup>1</sup>The journal's style utilizes the category *substance abuse* as a diagnostic category. Substances are used or misused; living organisms are and can be abused. Editor's note.

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p. 5). A client perspective has also been scarce in drug use(r) research internationally, not only in Sweden (cf. Hunt & Barker, 1999).

On the other hand, the general policies of central and local governments in Sweden are to encourage active engagement and involvement of interested parties in policy debate and service provision, which can be seen in policy inquiries and legislation that stress the rights of the citizens, respect for the equal worth of all, liberty and dignity of the individual, and citizens' right of integrity and self-determination, as well as the importance of motivation and participation of the individual.

What about the individual drug user's rights and possibilities to participate? Sweden is famous for its universalistic and comprehensive health, welfare, and alcohol and drug treatment systems. The political, civil, and social rights of substance users have, despite that, been limited. Equal and universal suffrage was introduced in 1921 but it was not until 1945 that poor people who needed support from society (often misusers) got the right to vote and became eligible to be elected. The existence of compulsory treatment for drug abuse<sup>1</sup> (up to 6 months), as well as the control and punishment that the criminalization of use brings about, also limits the civil rights of Swedish drug users (see Stenius & Johansson, 2009, for the development of rights in Sweden). Neither are drug users guaranteed social rights (work, housing, etc.). Social rights are often viewed as prerequisites for citizens' possibilities to make use of their civil and political rights. Even though social rights are expressed in the Swedish Constitution, which makes them a guiding principle in social, health, and welfare institutions, these principles only reach the status of goals and they are not legally binding (Nergelius, 2006). As a consequence, social rights cannot be claimed as subjective rights of the individual drug user and such rights seldom come without conditioning. Drug users may have to be and remain abstinent in order to receive help in finding housing, applying for certain jobs, or taking part in work programs to get cash benefits, etc.

Researchers have acknowledged that the individual drug user has an inferior position in relation to professionals. Welfare and health professionals have the preferential right of interpretation, the power to define problems and needs, and to give or withdraw benefits (Järvinen, 2002). Clients' perceptions are often not acknowledged when an intervention is chosen by professionals (Blomqvist & Wallander, 2004). Experienced drug users often learn the rules of this game—how to get what they need and escape what they do not want. This may be achieved by proving that they deserve help, pretending to be motivated, adjusting to rules, withholding information, etc. (Storbjörk, 2007). In some countries, notably the United States, former drug users (“in recovery”) often become counselors in the formal treatment system. They may thereby influence the implementation of policy in the daily provision of treatment. But this is rarely the case in Sweden. The increasing demands for evidence-based treatment imply requirements of formal skills and education among staff (Socialstyrelsen, 2007).

Customer choice is becoming highly valued in Swedish health care and in some welfare sectors, such as eldercare. This development also begins to appear in the field of substance use. For example, a recent comprehensive policy inquiry (SOU 2011:35) presented in April 2011 about the development of addiction treatment suggests a treatment guarantee that may increase substance users' possibilities to choose care providers. The individual drug user's choice may, however, in practice be limited to the choice between one 12-step program and another 12-step program (Storbjörk, 2007).

It is thus fair to say that drug users, despite the expressed importance of respect and self-determination, have a weak voice when it comes to participation at an individual level. Drug users repeatedly stress their unfulfilled right to be related to and treated with dignity and respect by service providers, policy-makers, and government representatives (cf. Bröring & Schatz, 2008).

At collective levels, however, there has been some increase in advocacy for the interests of drug users. There are a number of client organizations in Sweden that are seeking to strengthen the position and voice of drug users. The first one to be established, in 1965, was RFHL (*Riksförbundet för hjälp åt läkemedelsmissbrukare*; the National Association for Aid to People Addicted to Drugs and Pharmaceuticals), composed of intellectual academics, authorities, and former addicts and prisoners. RFHL has sought to influence the development of drug policy and treatment toward less repressive methods, but has had to balance between representation of drug users and distancing itself from its clients' way of life. KRIS (*Kriminellas revansch i samhället*; Criminals' Return into Society) was founded in 1997 with the aim to provide peer support for those who wanted to leave a criminal lifestyle. The association insists on strict adherence to the law (Laanemets, 2006). It is, of course, difficult for active drug users to organize themselves and gain official legitimacy when their shared experience—drug use—is illegal. The first drug users' union, SBF (*Svenska brukarföreningen*; the Swedish Drug Users' Union), was however set up in 2002. SBF is for people in medically assisted maintenance treatment and aims to promote and defend the interests of heroin users (Laanemets, 2006). Anker et al. (2006) argue that the increasing acceptance and expansion of substitution treatment may have opened up for a shared space and point of reference among drug users. This may increase drug users' possibilities to become social change agents.

A user perspective is also increasingly seen as being important in the development of societal institutions. User councils consisting of representatives for different user organizations are more frequently being invited to participate in development projects. One example is that user councils are included in a large national project (Knowledge to Practice, led by the Swedish Association of Local Authorities and Regions) that seeks to implement national treatment guidelines for those suffering from substance abuse. Organizations such as SBF have also been invited to comment on the recent policy inquiry (SOU 2011:35).

We may say that drug users' organizations officially have the possibility to participate in decision-making at a collective or system level, but this claim is problematic. Drug users' opportunities to become social change agents are limited due to the illegal status of drug use. An investigation of the extent to which drug users have been able to influence Swedish drug policy since the 1960s concludes that their influence has been very limited, and that their possibilities to influence have in fact diminished (Johnson, 2006). Neither do we know if the views of SBF and organizations alike will be taken into account when the development of addiction treatment is decided, despite the fact that they have been invited to comment on the proposal (SOU 2011:35).

It should be noted that drug users compose a heterogeneous group and different user organizations have somewhat competing goals. SBF promotes harm reduction, whereas KRIS adheres to drug-free treatment. RFHL opposed substitution treatment for many years but have now changed sides. This aspect is discussed in an article entitled "Soon there'll be a society for every bit of the intestine" (Sellerberg, 1999). Groups arise that become more and more specific to a disorder or topic, and each of them seek to make *their* voice heard. These organizations are, as we have seen, invited to take part in the policy discussions. But this development requires that people organize themselves—*individuals* lose their position as actors when *organizations* are in focus—and differentiate themselves from other groups. We see an increased competition between such user organizations, and those that are not successful in presenting their problem and opinion may lose their voice.

Overall, we must conclude that individual drug users have not had and still do not have a strong voice in Swedish society. The establishment of drug user organizations and their participation in decision-making processes may well strengthen the participation in policy discussions of drug users as a group. Drug users do not, however, have just one voice, and there is a risk that their joint experiences may get lost in the noise if their competing interests are emphasized in the debates. Drug users' possibilities to become social change agents may have increased but they are still limited.

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**Jessica Storbjörk**, Ph.D., is a sociologist at the Centre for Social Research on Alcohol and Drugs (SoRAD) at Stockholm University, Stockholm, Sweden. Jessica has been engaged in quantitative and qualitative research into social aspects of alcohol and drug use, problems, and treatment since 2000. Her work has mainly focused on a client perspective: on substance users' reasons for entering treatment; coercion and social control; the marginalized

position of substance users in terms of poor social situation, poor housing, and weak social networks; clients' experiences of treatment and contacts with societal institutions/authorities; and clients' reasons for changed use following treatment. She has also conducted studies of homelessness and organizational changes in the treatment system and served as the guest editor of a thematic issue on treatment systems research in the *Nordic Studies on Alcohol and Drugs* (issue no. 6, 2010). Jessica is presently analyzing the legislated rights and obligations of Swedish citizens with a special emphasis on the social rights of substance users.

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