

Acknowledgements

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About the Hepatitis C Harm Reduction Project:

The Hepatitis C Harm Reduction Project is a New York City Council-funded technical assistance project initiated in late 2003 based on advocacy efforts of the Injection Drug User Health Alliance (IDUHA).

The project exists to:

- Increase the capacity of syringe exchange (SEPs) and community-based ESAP programs and other allied health care and drug treatment centers serving IDUs to address the hepatitis C epidemic among drug users.
- Develop interventions to ensure that IDUs have access to a full spectrum of hepatitis C prevention, education, health care and treatment services – including hepatitis A and B vaccinations, HCV diagnostic testing and liver disease monitoring, support, and treatment options for those already infected.
- Promote effective IDU-based HCV program models within SEP and ESAP; Adapt models implemented in these settings to community-based organizations, drug treatment, and health care settings that serve current and former drug users.
- Advance policies to improve drug user health; increase hepatitis C prevention, care and treatment options; and advocate for resources to address this epidemic among IDUs.

About the Harm Reduction Coalition:

The Harm Reduction Coalition (HRC) is a nonprofit organization committed to improving the health and wellbeing of drug users and communities affected by drug-related harm. HRC promotes effective harm reduction services and policies at the national, regional, and local levels; through education and training, community organizing, policy advocacy, and publications. HRC locates itself as part of a broader movement for progressive change that challenges social, cultural and economic structures – including current drug policy – that foster and sustain disadvantage, discrimination, and denial of civil liberties and human rights.

Introduction

This guide was developed with the collective input of syringe exchange participants and service providers actively involved in hepatitis C (HCV) support groups throughout New York City. Together we have compiled some 'best practices' for establishing HCV groups within a harm reduction framework. We also offer facilitators practical suggestions and creative tools for effectively maintaining a group that meets the unique and varied needs of former and active drug users.

The majority of existing HCV support groups are connected to hospitals, medical clinics or drug treatment programs. These groups often overlook the physical, emotional, and social realities of drug users, making it difficult for members to talk openly about issues that may impede their ability and/or motivation to pursue HCV care and treatment – like managing their drug use, coping with mental health issues, or dealing with homelessness and a lack of resources. Others simply avoid these groups altogether because of the stigma and discrimination they've had to confront over the years from service providers and the health care system.

Part I of this manual includes some effective strategies for developing HCV groups that accommodate the complex support and education needs of individuals with a current or past history of drug use. We have included suggestions for all stages of group development – from assessing participant needs and identifying gaps in knowledge, to determining the overall focus and objectives of the group. To help ensure the greatest needs of group members are met, it is essential that participants are involved in every stage of the planning and initiation process.

Benefits of HCV Support Groups

Below are some of the positive outcomes we've observed over the years working in HCV groups with current and former drug users:

- By taking the initiative to increase their knowledge about hepatitis C and acquiring practical strategies to better care for their health, group members feel empowered to take a more active role in their healthcare and initiate other changes to improve their quality of life.
- As their awareness around HCV increases, participants act as peer educators within their social networks, reinforcing HCV prevention and care messages relevant to the community.
- Participants' motivation to pursue HCV care and treatment is enhanced through the experience of witnessing others actively addressing their health and wellness needs.
- Group cohesion and support can decrease feelings of personal isolation and create positive social networks for individuals with mutual needs and goals.
- By talking openly about their drug use and injection practices, group members can share practical risk-reduction strategies and methods for managing their use.
- Group involvement facilitates linkages to other supportive services and provides facilitators with a non-threatening means of engaging harder-to-reach participants.

- Trust between participants and service providers is strengthened by setting a collaborative tone within the group and actively responding to the feedback and suggestions of members.

HCV groups can also benefit the community as a whole by evolving into a sort of 'HCV advisory council,' providing guidance on program development and carrying practical messages around HCV prevention, care and treatment to the wider community.

Developing New Approaches

As individual and group needs change over time, facilitators are encouraged to engage participants around developing new and creative approaches for meeting the evolving needs of members. Below are some common examples of projects and "spin off groups" adopted in the past:

- *Peer Education Groups:* offers intensive training opportunities so highly motivated members can fine tune their peer education skills and increase their knowledge on issues related to hepatitis C.
- *HCV Awareness/Working Groups:* participants may be interested in developing creative projects that increase HCV awareness within the agency – like designing an educational 'ad campaign' or starting a magazine to showcase participants' artwork, writing, and other forms of self expression.
- *Treatment Support Groups:* provides a forum for participants undergoing HCV treatment to receive encouragement and support from participants with common issues and concerns.

Activities and Tools for Group Facilitators

Part II of this guide provides facilitators with useful information and tools for exploring some of the central themes around hepatitis C and drug user health. Facilitators don't need to become experts on hepatitis C to be effective educators. However it is recommended they acquire a basic understanding of the key issues outlined in this manual.

For each section we have included a basic overview of each topic, followed by stimulating discussion questions and interactive group activities that engage participants on issues like treatment readiness, substance use management, coping with depression, communicating with medical providers, and working through feelings around stigma and disclosure. Because participants have unique ways of absorbing, remembering, and processing information, we incorporated exercises that involve written, visual, and verbal approaches to exploring these issues.

Refer to the *resource section* at the back of this guide for group activity tools, fact sheets, informational brochures, and a listing of useful websites.

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