

6

Tapping Into the

Viral Hepatitis Community

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In the last few years, the media have focused on newly emerging health threats—SARS, West Nile virus, monkeypox, drug-resistant bacteria, and others. In addition, other high-profile, health-related issues such as bioterrorism and prescription coverage for the elderly have been the focus of policy-makers at the national level. In the course of health-related discussions, whether they are at the local, state, or national level, viral hepatitis rarely receives a mention. However, viral hepatitis, which for the purpose of this document refers to hepatitis A virus (HAV), hepatitis B virus (HBV), and hepatitis C virus (HCV) infections,¹ is a significant public health challenge for various reasons, some of which are listed below.

- Both hepatitis B and C viruses are highly infectious, blood-borne viruses (much more infectious than HIV).
- Infection with one or more of the three types of viral hepatitis can have serious health consequences. Infection with chronic hepatitis B or chronic hepatitis C can lead to cirrhosis, liver cancer, and death.
- All three types of viral hepatitis can be prevented through behavior change, and hepatitis A and B are also vaccine-preventable.
- Many people who are infected may have never heard of viral hepatitis. Some people infected with hepatitis B and/or hepatitis C were infected 10 to 20 years ago and no longer engage in the behaviors that put them at risk. Because they are not currently at

¹Hepatitis A, B, and C are the most common types of viral hepatitis in the U.S.

risk of infection, they may not respond to awareness efforts and are probably not accessing HIV or STD prevention services. Specific outreach strategies are required for these individuals.

- Viral hepatitis affects multiple, diverse populations, necessitating various prevention strategies.

Hepatitis A, B, and C share many similarities with HIV and other STDs, as they affect many of the same populations. They all can pose a serious health threat, either separately or in interaction with each other.

Hepatitis A is caused by an infection with HAV. HAV is transmitted primarily by oral contact with the feces of an infected person. This occurs most often by sexual or household contact with an infected person. Hepatitis A can also occur through ingestion of HAV-contaminated food or water. Men who have sex with men (MSM) and injecting and noninjecting drug users are at increased risk for contracting HAV infection. Hepatitis A vaccination is recommended for these high-risk groups. Increased rates of HAV infection are common in some areas of the world, and vaccination is recommended for travelers to those areas.

An estimated 3.9 million Americans have been infected with HCV, and 2.7 million Americans are chronically infected.

Hepatitis B is a blood-borne disease caused by infection with HBV. HBV is transmitted primarily through sexual contact with an infected person. Populations at risk of infection include MSM, persons with multiple sex partners, persons with an STD infection, injection drug users (IDUs), household contacts of persons chronically infected with HBV, and infants born to infected mothers. As with hepatitis A, in certain areas of the world, hepatitis B is endemic in the population, and infants or immigrants from these parts of the world may be at higher risk of infection. The risk of infection among health care workers has substantially declined, due to large-scale vaccination programs. Like hepatitis A, hepatitis B is vaccine-preventable, and vaccination is recommended for all persons at risk.

Hepatitis C is the most prevalent type of chronic viral hepatitis in the United States; an estimated 3.9 million

Table 1. Disease Burden From Hepatitis A, B, and C in the United States

	Hepatitis A		Hepatitis B		Hepatitis C	
	2001	2000	2001	2000	2001	2000
Number of Acute Clinical Cases Reported	10,616	13,397	7,844	8,036	no data	
Estimated Number of Acute Clinical Cases	45,000	57,000	22,000	22,000	4,000	5,700
Estimated Number of New Infections	93,000	143,000	78,000	81,000	25,000	35,000
Number of Persons With Chronic Infection	no chronic infection		1.25 million		2.7 million	
Estimated Annual Number of Chronic Liver Disease Deaths	no chronic infection		5,000		8,000-10,000	
Percent Ever Infected	31.3%		4.9%		1.8%	

Source: Division of Viral Hepatitis, National Center for Infectious Diseases, Centers for Disease Control and Prevention (http://www.cdc.gov/ncidod/diseases/hepatitis/resource/dz_burden02.htm)

Americans have been infected with HCV, and 2.7 million Americans are chronically infected. HCV is transmitted through blood-to-blood contact with an infected person, and injection drug use is currently the primary risk factor for transmission. In the past, persons with specific medical conditions have been at high risk of infection. These include individuals who received a blood transfusion or organ transplant before July 1992, persons who were ever on long-term hemodialysis, and persons who received clotting factor concentrates before 1987. Other persons who are currently at risk of infection include health care and public safety workers who are exposed to HCV-infected blood, and children born to HCV-infected mothers. Studies have found that African Americans, Latinos, and incarcerated individuals are disproportionately affected by HCV.

Despite the magnitude of viral hepatitis in the United States, the public health response to this epidemic

Role of Hepatitis C Coordinators

CDC's Division of Viral Hepatitis (DVH) funds a national Hepatitis C Coordinator Program. In each state, the Hepatitis C Coordinator serves as a liaison with other public health programs, including HIV/STD, substance abuse, immunization, and corrections. The goal of the coordinator position is to help integrate viral hepatitis services (hepatitis C counseling and testing, hepatitis A and B vaccines) into existing prevention programs.

Hepatitis C Coordinators must play various roles. Perhaps most importantly, they must provide leadership and increase the visibility of viral hepatitis as an issue of importance. They must also identify stakeholders and recruit them to the cause. Finally, they must become adept at identifying resources at the local, state, and national levels.

remains insufficient, in large part due to the limited federal resources available for hepatitis services (e.g., prevention, screening, vaccination, referral for medical evaluation). For over 10 years, there have been recommendations to vaccinate MSM and other high-risk adults against hepatitis B, but without federal dollars to support vaccine purchase and infrastructure development, immunization rates among MSM remain low, and the virus continues to be transmitted. Similarly, the Centers for Disease Control and Prevention's (CDC) 2001 Hepatitis C Prevention Strategy outlined a comprehensive plan for the prevention and control of HCV, but without a substantial increase in resources, state and local public health programs have been unable to fully implement the recommended actions.

Several state legislatures have responded to the hepatitis C epidemic by appropriating funds, but with the current fiscal crisis in most states, many have seen the hepatitis appropriation decreased or cut. It is unlikely that in the current fiscal climate, state and local health departments will be able to tap into sufficient state funds to address needs.

The lack of resources has created something of a dilemma for service providers at the local level. Charged with creating awareness among at-risk populations, providers worry that resources will not be sufficient to meet the resulting demand for services such as screening and appropriate follow-up.

Given the lack of resources, most state and local public health programs seek to integrate viral hepatitis services within existing services, such as HIV,

STD, and immunization. Through integration, hepatitis programs can capitalize on existing programmatic infrastructure and experience in reaching populations at risk. Coordinating and consolidating these activities within a health department can be a challenge. Taking the next step to involve the community in the response to hepatitis also requires considerable effort. However, given the scarcity of resources, involving community-based organizations (CBOs) and affected populations in the state and local response is one of the few options available to local health departments for expanding services in response to growing demand.

THE ROLE OF CBOs AND AFFECTED POPULATIONS

Integrating the efforts of CBOs and affected populations can expand service availability.

This document focuses on the role of CBOs and affected populations in the community-level response to viral hepatitis. For various reasons, CBOs and affected populations are key components of the response to viral hepatitis at the local level.

Most significantly, given that the lack of resources is, for most communities, the greatest challenge to service delivery, integrating the efforts of CBOs and affected populations can expand service availability. Expanding existing services through integration can be less expensive than establishing new services. In addition, CBOs and affected communities can play an important advocacy role. In increasing awareness about the impact of viral hepatitis and the unmet service needs, CBOs and affected populations can be instrumental in securing the resources needed to address the epidemic.

CBOs are known for providing cost-effective services. They are experienced in doing more with less and often have tapped into nonfinancial resources within the community, such as the use of volunteers and other types of in-kind donations. They also may have ties to the local philanthropic community that can be beneficial to future endeavors. However, as CBOs integrate new activities, they may need additional

Benefits of Involving CBOs

- Tie to affected populations
- Recognized and trusted providers of services
- Culturally sensitive/competent
- Knowledgeable of community resources (funding, volunteers, other CBOs, etc.)
- Have an existing service infrastructure

Benefits of Involving Affected Populations

- Can provide insight on how to effectively reach affected populations
- Have first-hand knowledge of the needs of affected populations
- Can “put a face on the issue” and serve as effective advocates
- Can serve as “peer” workers in both outreach and support efforts

support in training for staff and management, handling new administrative responsibilities, and identifying resources specific to hepatitis.

Involving affected populations in the community-level response to viral hepatitis may present some challenges. For various reasons, to be discussed later, the viral hepatitis epidemic has not spawned the rise of patient advocacy organizations that has resulted with other health-related conditions (although this is changing). Also, because it may take 10 to 20 years before people who are infected with hepatitis B or C become symptomatic, people with hepatitis may not feel compelled to take on an advocacy role.

However, to ensure that services reflect the needs of the community and are sensitive to affected populations, both CBOs and affected populations should be involved in the community-level response. For example, CBOs are often better able to reach targeted populations because they are indigenous to the community, have a history of serving local residents, and are viewed as a resource.

Health care providers have not always recognized the value of involving affected communities in the local response. However, as we have learned from the HIV epidemic, listening to those who are confronting the illness can greatly enhance awareness efforts and the delivery of health care services. Affected populations have the knowledge and experience about reaching people at risk and the service needs of those who are infected, which health care providers and public health professionals cannot match. They are the best spokespersons to express their needs and to raise awareness of the disease. In addition, some subpopulations affected by hepatitis, such as IDUs and minorities, are distrustful of mainstream service providers. Involving these populations in the community's response can help build their trust.

With so much that needs to be done to address hepatitis in the United States and so few organizations to do it, hepatitis-related community-based organizations can find themselves serving in a wide range of capacities. That is the story of Hep-C ALERT. Founded in South Florida in July 1997, this CBO has since carried out various successful services addressing hepatitis at the local, state, and national levels.

Hep-C ALERT started as an Internet-based organization. It expanded to provide local support groups and resources, such as newsletters, targeting people living with HCV. In 1999, the organization received its first major grant and partnered with the Florida Association of Health Maintenance Organizations (HMOs) to provide a statewide, toll-free English/Spanish hepatitis C education, counseling, and referral hotline. Soon fielding calls nationwide, 877-HELP-4-HEP continues today as one of the country's top health education and support hotlines.

Also in 1999, Hep-C ALERT embarked on a direction that would take it to a truly national level, working with the fire and rescue industry. Work began at the local level with presentations to fire and rescue personnel in South Florida. Based on the overwhelmingly positive response from both personnel and management, a fully integrated hepatitis C education and screening program was created, and a research protocol was designed. The study methods included education, informed consent, confidential hepatitis C testing, and post-test notification. The program was piloted at the Coral Gables Fire and Rescue Department in November 1999 and expanded to the Miami-Dade Fire Rescue Department in March 2000. A total of 3,362 personnel from 11 different Florida Fire and Police Departments participated in the study. In June 2000, Oregon Health Sciences University used the same protocol for a similar study commissioned by the Oregon Legislature, with Hep-C ALERT performing the field services. Hep-C ALERT has worked with the International Association of Fire Fighters to conduct a screening program at their annual conference and by fire rescue and police departments in nine other states. After September 11, 2001, the priorities of fire and rescue workers changed dramatically, and the demand for Hep-C ALERT's services declined. However, a grant was awarded in 2003 for Hep-C ALERT to educate and provide baseline hepatitis C testing for all Broward County firefighters and paramedics over the next year.

Currently, in addition to continuing to focus on health education and testing activities in South Florida, Hep-C ALERT is conducting the following two programs.

- **Addiction Recovery Hepatitis Intervention Project**

Hep-C ALERT is collaborating with six drug treatment programs and the state health department to provide staff training, patient education, hepatitis C counseling and testing, and hepatitis A and B vaccination. In nine months of the project, over 750 patients were served, with 84 percent being tested for HCV, 82 percent receiving the first dose of the HBV vaccine, and 91 percent of those who remained in the drug treatment program completing the second dose of the HBV vaccine.

- **Co-Infection Connection**

In 2002, Hep-C ALERT became a registered HIV testing provider. Hep-C ALERT is collaborating with an HIV organization to provide integrated HIV/HCV outreach, counseling, testing, and referral services to their clients.

Collaboration with other organizations was key in all these activities. Through collaboration, Hep-C ALERT has identified a variety of facilitators and challenges, profiled on the next page.

Facilitators

- **Reaching out to other organizations, especially those without hepatitis expertise.**

Nonhepatitis service providers, such as HIV and substance abuse treatment organizations, are becoming aware of viral hepatitis because it is affecting their clients. They do not have the capacity to address the issue, but they recognize that it is necessary to do so. Hep-C ALERT made itself known in the community by networking, attending meetings, and letting people know the organization was willing to work with them.

- **Recognizing the importance of a mentor.**

Hep-C ALERT found a “mentor” who facilitated their collaboration with HIV service providers by vouching for their credibility as a provider. A mentor is key, because provider communities can be insular and distrustful of outsiders.

- **Providing what no one else can.**

By being able to provide hepatitis C health education, counseling, and testing, which are highly sought-after services, Hep-C ALERT became a highly attractive collaborative partner. They also offered several train-the-trainer programs to other agencies to encourage and increase communitywide capacity for viral hepatitis services.

Challenges

- **Funding is an ongoing challenge.**

However, funders recognize the advantages of collaboration and appear to favor funding collaborative activities.

- **Collaboration should be truly collaborative.**

For example, serving as a subcontractor, with no say in the project, is not collaboration. Collaborators need to act as equals and determine common goals, objectives, strategies, and outcomes. Partners must trust each other, and all partners must contribute to the delivery of a quality service.

- **Sharing organizational resources is beneficial.**

Any community usually has one logical provider of a service and many others who would provide that service, with varying degrees of success, if paid to do so. Hep-C ALERT has made it a point not to provide services outside of its goals as an organization and has aided other organizations in securing funds to provide these services. In one instance, Hep-C ALERT wrote a grant for another organization because the funded services would benefit Hep-C ALERT clients.

- **Collaboration, like any relationship, is work.**

At some point, an organization needs to assess what it is gaining from a collaborative arrangement. Doing so is not always an indictment of one’s collaborators. With today’s funding realities, organizations are often squeezed by their major funder and have little leeway to add auxiliary services. However, if an organization finds that their collaborator cannot deliver, they should not hesitate to look for another provider that is more responsive.

In the face of overwhelming demand for diverse services in an environment where funding is difficult to identify, and transitory once it has been secured, Hep-C ALERT has pulled together a core of services to meet the needs of people living with hepatitis in South Florida. As Hep-C ALERT President Andi Thomas acknowledges, however, the real need is to educate policymakers, other service providers, and the general public on the significance of hepatitis-related services, given the impact that hepatitis will have on society in the coming years.

For more information on Hep-C ALERT go to: <http://www.hep-C-alert.org>.

RESPONDING TO VIRAL HEPATITIS AT THE LOCAL LEVEL

Because of the overlap between HIV and hepatitis (the diseases have similar transmission modes), many have wondered why the public health response to viral hepatitis has been less robust than with HIV. Reasons include the following:

- Many people infected with viral hepatitis are asymptomatic and consequently unaware of their infection. This is particularly true of HCV infection, which has been characterized as a “hidden” or “silent” epidemic. Many people only begin to experience symptoms 10 to 20 years after infection, when complications of liver disease begin to occur.
- Hepatitis does not carry the same stigma as HIV did in the early days of the epidemic. Because there is less fear of discrimination, people living with hepatitis may not have the same impetus to bond together and advocate on their own behalf.
- Because most people with hepatitis do not get seriously ill immediately, if at all, there has not been the need to develop the wide range of support services that were required with HIV (housing, meal programs, etc.).
- Many of the populations affected by viral hepatitis, such as IDUs, MSM, immigrants, and people of color, are traditionally disenfranchised and underserved populations. They may distrust mainstream service providers and be skeptical that any advocacy efforts will result in change.
- People who were infected years ago may not feel a need to advocate. Many are now “baby boomers” with jobs that provide health coverage. Their focus may be living a “normal” life, and they may not be compelled to advocate for greater awareness and additional services. Also, some

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stigma is still attached to hepatitis. Given that they do not see any direct benefits resulting from their advocacy effort, they may not want to risk becoming involved in the issue.

Because of these reasons, in most areas, there are no existing networks of affected populations working together to advocate for and provide hepatitis-related services. This trend is changing, however. Awareness of hepatitis is growing, and as more people become aware of the risk and their serostatus, the demand for services is increasing. The services required to meet demand are diverse, and can include harm reduction services for people who continue to inject drugs, drug treatment, screening, vaccination, support groups, clinical treatment, case management, and mental health services. Given that it is unlikely that significant increases in funding and other resources will be available from the federal government, how will your community address this demand? The following section provides an overview of how to respond to viral hepatitis in your community.

What's Happening in Your Community?

The first step in drawing upon and integrating existing services is to be aware of them. Since every community is different, it is impossible to provide a precise process for integration. However, some general guidelines are provided here.

1. Build Interest in the Issue

To build interest in viral hepatitis at the local level, you must first be able to demonstrate that it is an issue relevant to your community. Building interest is essential to:

- Lay a groundwork for advocacy efforts with policymakers at the local, state, and national level.
- Create buy-in with potential collaborative partners.

- Lay the foundation for awareness activities targeting both the general public and at-risk communities.
- Tap into other efforts addressing viral hepatitis of which you might not be aware.

At this point...

1. Develop a list of why viral hepatitis is an important issue for your community. Topics to cover might include:
 - Epidemiologic data on viral hepatitis and surrogate markers such as drug use, STD rates, and HIV rates.
 - Current services and service providers.
 - Special concerns such as a high level of injection drug use, lack of syringe exchange programs, increasing rates of syphilis, or high incarceration rates.
2. Develop a fact sheet on viral hepatitis that incorporates local data and reflects the issues identified in your list of important issues.
3. Develop a preliminary Action Plan for your community. Consider this a living document that will change as more stakeholders become involved in the process. The plan should be a logical progression of activities designed to engage stakeholders, educate policymakers, create awareness in the general population, reach at-risk individuals, and implement needed services.

Potential Stakeholders

Consumers/Clients

- Affected populations, including current and former drug users, MSM, incarcerated and formerly incarcerated individuals, health care providers, hemophiliacs, transfusion and blood product recipients, and people of color.
- Organizations representing affected populations, such as professional organizations for health care providers and emergency response professionals, and organizations representing specific, at-risk subpopulations (hemophiliacs, people of color).

Policymakers

- State legislators and staff
- Governors and staff
- State health directors
- Local elected officials (city and county)

Service Providers

- Drug treatment providers
- Drug prevention organizations
- AIDS service organizations
- STD service providers
- Gay/Lesbian/Bisexual/Transgender organizations
- Corrections
- Health education and outreach organizations
- Veterans Administration (VA) hospitals
- Managed care organizations
- Community health centers
- Public hospitals (or other indigent care providers)

Others

- Foundations with an interest in health care
- Representatives of the health insurance industry
- Pharmaceutical company representatives
- Blood bank industry
- Transplantation organization
- Liver-related organizations
- Church leaders

2. Identify Stakeholders

“Stakeholders” is a catchall term for anyone or any organization that has an interest in the issue. When casting the stakeholders net, make it as wide as possible. Think long and hard about organizations with an interest in the issue.

Stakeholders are a diverse group. They present various perspectives and offer an array of skills and expertise. **Consumers/affected populations** can provide insight into reaching populations at risk, as well as service needs. **Policymakers** can be instrumental in securing more funding or can help to enact policies favorable to integrating or expanding services. **Service providers**, such as drug treatment providers and STD service providers, can help expand available services through integration or provide access to at-risk populations that they may be serving.

At this point...

1. Consider having a community forum on viral hepatitis. This may be a good way to reach out to people who have been overlooked.
2. Ask stakeholders to identify additional stakeholders. To do this, consider conducting a survey or interviewing key informants.

Reaching Those Affected by Hepatitis

Even with the understanding of the importance of including affected populations in your efforts, it is sometimes difficult to identify which individuals to include. One strategy for identifying potential participants is through organizations providing services to populations affected by hepatitis, such as harm reduction services and drug treatment programs. Also, numerous patient support groups have been formed across the country. The following organizations include listings of patient support groups that may help you identify one in your community.

- **American Liver Foundation**
<http://www.liverfoundation.org/db-list/chapter/2/ascend/ChapterName/Validated>
- **Hepatitis B Information and Support List**
A list-serve that provides resources information and support to persons living with hepatitis B and/or their family and friends. <http://www.geocities.com/Heartland/Estates/9350/hblist.html>
- **Hepatitis B Foundation**
<http://www.hepb.org/02-0072.hepb>
- **Hepatitis C Education and Support Network**
<http://www.hepcesn.org/contact2.htm>
- **Hepatitis C Support Project**
<http://www.hcvadvocate.org/community/community.asp>
- **Hepatitis Foundation International**
http://www.hepfi.org/pages/support_start.html
- **Hepatitis Magazine**
<http://www.hepatitismag.com/supportgroups/default.asp>
- **National Hepatitis C Advocacy Council**
The National Hepatitis C Advocacy Council also includes information on how to start a support group on their Web site. <http://www.hepcnetwork.org/>

3. Identify the skills of your stakeholders. In addition to having an interest in viral hepatitis, individual stakeholders may have ties to policy-makers, experience in conducting social marketing campaigns, ties to foundations, or connections with the local media, that may be valuable in your efforts.

3. Promote Meaningful Community Involvement

While the end goal may be integrating hepatitis services across organizations within a community, the community can be involved in a variety of ways in the planning and delivery of hepatitis services:

- **Advocacy.** Educate key audiences, such as policymakers, about viral hepatitis and its impact on the community. Methods include face-to-face meetings, briefings, and the development of documents such as fact sheets and white papers (also called position papers or issue briefs) that include recommendations.
- **Community Education.** In addition to reaching policymakers and at-risk populations, it is important to educate the general public about viral hepatitis, focusing both on the risk factors and the need to address the virus as a public health concern.
- **Advisory Committee.** An advisory committee provides stakeholders with a forum for expressing their

Stakeholders can provide a wealth of information in key informant interviews or as focus group participants.

concerns and voicing their expertise. These committees can take on a leadership role and become champions of the issue. In addition to a free-standing advisory committee, consider integrating stakeholders into other health-related groups in the community, such as the HIV prevention community planning group (CPG) or CARE Act planning groups.

- **Needs Assessment.** A needs assessment is the process used to determine the current status and needs related to a specific condition or issue, for a defined population or geographic area. The process involves collecting and analyzing primary and secondary data related to a particular topic. Stakeholders, with their knowledge of viral hepatitis and the community, can play a key role in the needs assessment process. For example, stakeholders can provide a wealth of information in key informant interviews or as focus group participants.
- **Strategic Plan.** A strategic plan is a written document that details a problem and defines how to best address the problem within a certain timeframe. A strategic plan should address:
 - What needs to be done
 - What resources can be drawn upon
 - Who will do the work
 - How the work will be done
 - How it will be evaluatedStakeholders can play an important role in developing and implementing a community's strategic plan.

Strategic plans can provide a clear vision that helps focus the work and avoid duplication of effort. Planning does not stop with the development of a strategic plan. Planning activities must continue after the plan is implemented to ensure that specific activities are carried out and that they have the intended impact. Consider the plan a "living" document that can be adjusted as needs change.

4. “Grow” Community Involvement

Community involvement is not an organic process that grows of its own accord. It must be nurtured.

Many pitfalls can occur along the way. The benefits of involving CBOs and affected populations in a community’s efforts to address hepatitis cannot be underestimated. However, as with any effort that involves multiple parties, care must be taken to ensure that the process and the outcomes benefit those involved. Listed below are common pitfalls that can occur in efforts to involve the community in your activities.

- **Tokenism.** Involving CBOs and affected populations for the sake of appearance serves no one’s purpose. Unless they can contribute to the process in a valid way, participating in your activities can be a frustrating waste of time. The input of affected populations and CBOs in the process should carry the same weight as other players, including your own.
- **Infighting.** Rivalries among various organizations or individuals are common. After all, these entities often compete for limited community resources. However, infighting can derail efforts to integrate services. Con-

Needs Assessment and Strategic Planning Resources

HRSA/HAB Needs Assessment Guide

Although tailored for CARE Act grantees, this document discusses the components of a needs assessment, the process, and how to use results.

<http://hab.hrsa.gov/tools/needs/>

Starting Up: First Steps Towards the Integration of Viral Hepatitis Into HIV/AIDS/STD Programs

A NASTAD publication providing information on needs assessments and strategic planning.

http://www.nastad.org/pro_viral_hepatitis.asp?menu=pro

Examples of Needs Assessments and Strategic Plans

Needs Assessment: *Maine*

<http://www.state.me.us/dhs/boh/ddc/hepcfull.doc>

Strategic Plan: *California*

<http://www.dhs.ca.gov/ps/dcdc/pdf/Hepatitis%20C%20Strategic%20Plan%20-%202001.pdf>

Strategic Plan: *Colorado*

http://www.cdphe.state.co.us/dc/hepatitis/hep_home.asp

Strategic Plan: *Wisconsin*

http://www.dhfs.state.wi.us/dph_bcd/hepatitis/index.htm

Failure to act on input constitutes a significant breach of trust and can eliminate the possibility of future collaboration.

sider having a facilitator at stakeholder or advisory committee meetings and designing meetings so that everyone has an opportunity to express their opinion. Such processes as conducting a needs assessment and developing a strategic plan can also help to limit infighting. A cooperative effort to identify the community's needs and develop a plan to address the needs, complete with specific tasks assigned to community players, can help avoid the likelihood of some organizations or individuals feeling that they did not receive the recognition they deserved and their fair share of the resources.

- **Conflicts of Interest.** As the term "stakeholders" implies, people are involved in the issue because they have a stake in it. This stake can sometimes lead to real or perceived conflicts of interest. For example, if the advisory committee is making recommendations about resource allocation, some members of the advisory committee will likely represent organizations that will receive resources as a result of their decisions. This can appear to be a conflict of interest that may reflect on the legitimacy of the process. Consider setting up a process for disclosing conflicts of interest and making sure that all members are aware of areas where conflicts of interest could occur.
- **No Follow Through on Community Input.** Perhaps the most significant threat to ongoing community involvement is a failure to act on suggestions provided by CBOs and affected populations. No one likes to waste time. However, that is exactly how people who participate in the process will feel if they do not see any results from their input. Of course, circumstances beyond control can affect a community's response, such as changes in funding levels, an increase in cases, and availability of new, more expensive treatments. If so, and the community's input is not acted upon, be prepared to explain why and to involve the community in developing an alternative plan. Failure to act on input constitutes a significant breach of trust and can eliminate the possibility of future collaboration.

Growing a Collaboration: The Colorado Experience

Most grassroots movements grow from the efforts of one person or a small group who identify a need and work to address it. In 1995, a group of hepatitis-C-infected individuals and their families and friends in Denver, Colorado, joined together to serve as a resource for people affected by the disease. They formed Hep C Connection and initially focused on developing a plan for telephone information and referral and a support group model to be implemented in Colorado.



While serving as a resource for infected individuals and the general public, the organization also worked to educate state legislators about the problem and the lack of resources to address it. They networked with various stakeholders in the community, including the University of Colorado Health Sciences Center, Departments of Hepatology and Microbiology; the Veterans Affairs Medical Center in Denver; the Colorado Department of Public Health and Environment; and other health-related CBOs. Along with pushing for the passage of a law mandating Workers' Compensation benefits to public safety workers contracting hepatitis C on the job, Hep C Connection played a key role in securing state funding for hepatitis C services from the General Assembly in 1999. The funding went to the Colorado Department of Public Health and Environment, which in turn released an RFP soliciting proposals from service providers. Hep C Connection was awarded the funds.

With the funding, which is now \$127,000 a year, Hep C Connection provides a range of services including public information and referral (through a hotline), train-the-trainer activities, and outreach to high-risk individuals. Hep C Connection subcontracts with other CBOs to carry out some of the services.

According to Mauricio Palacio, the Hepatitis C Coordinator for the Department of Public Health and Environment, working with CBOs has been beneficial for several reasons:

1. Through their advocacy efforts, Hep C Connection was instrumental in securing state funds to carry out activities.
2. Hep C Connection had networked with many other stakeholders in the community and could draw on these contacts. They also had an existing infrastructure that could be expanded to provide more hepatitis C services, which the Health Department did not have.
3. The agency was well-positioned to provide sensitive and personalized services to clients, since many of the people involved with Hep C Connection are also infected.

Hep C Connection did require some capacity-building assistance from the health department. Since the founders of the organization had, for the most part, been infected as a result of blood transfusions, much of their outreach efforts were focused on this population. They did not have experience in working with other high-risk populations, especially IDUs. Hep C Connection hired a social worker who networked extensively with organizations serving other high-risk populations, especially HIV and STD agencies. Also, before the grant from the health department, Hep C Connection had received funding primarily from foundations and private donations. The agency did not have experience in meeting the reporting requirements associated with public funding. The health department worked with the organization in this area.

“Working with the health department provided access to a broader range of talents,” says Kathy Jensen, Director of Information and Community Outreach for Hep C Connection. “The health department has expertise in evaluation and developing outcomes and measures, which helps us to document our accomplishments. This allows us to show our other funders and legislators our successes.”

Jensen cites several factors that have facilitated working with the health department. Hep C Connection worked very hard to develop the trust of the health department from the very beginning. Since the organization was carrying out education and outreach activities, it was essential that the information provided be accurate and credible. The agency worked with the health department to identify the most appropriate information to provide. Also, the agency regularly communicates with the health department through required reports and other methods. Finally, the agency coordinates “Team Hep C,” a network of service

providers addressing the issues, and holds regular monthly meetings, which keep the health department and the broader community informed.

“The networking involved in these efforts can be time consuming,” admits Jensen. “You have to work with more people and make sure that everyone is in the loop. There will also be times when you have to give up some control.”

Palacio also identified actions on the part of Hep C Connection that increased the confidence of the health department. “They engaged in a strategic planning process that really made the priorities and goals of the organization clear,” he says. “We knew that they were going in a direction that was consistent with our goals.”

The collaboration has led to benefits beyond the scope of the health department’s and Hep C Connection’s activities. An AIDS Education and Training Centers (AETC) Center of Excellence focusing on hepatitis and HIV co-infection was recently funded in the state. The health department and Hep C Connection serve on the advisory committee. The Center for Excellence will focus on providing training to infectious disease specialists on how to treat hepatitis so that co-infected individuals can receive better, more coordinated care.

While both the health department and Hep C Connection place a great deal of value on the collaboration, and the benefits of the services to affected individuals are evident, Palacio emphasizes that the funds the health department provide to the organization are a critical part of the relationship. The funding that Hep C Connection’s advocacy efforts secured from the General Assembly serves as the glue in the relationship.

“We have a really good relationship, but money plays a key role. If the state money disappeared, it would impact the relationship and the services that are provided,” says Palacio.

The critical role funding plays was recently reinforced when Hep C Connection, as with many hepatitis service providers around the country, lost some of their private funding. As a result, the organization had to reduce staff and hours of operation.

“The bottom line is that collaboration can only go so far,” says Palacio. “If we lose the state funding, we won’t be able to provide the services. That is why the advocacy work that these CBOs do is so critical.”

For more information, contact: Mauricio Palacio, Hepatitis C Coordinator, Colorado Department of Public Health and Environment, at 303/692-2674 or Mauricio.palacio@state.co.us and Kathy Jensen, Director, Information and Community Outreach, Hep C Connection, 720/917-3960 or kjensen@hepc-connection.org.

Lessons Learned

- Build a large network of stakeholders and work with them on an ongoing basis.
- Realize that advocacy efforts focusing on policymakers can result in availability of additional resources.
- Include partners in the program design process. Successful collaborations begin at the planning stage.
- Be open to suggestions and advice from collaborative partners.
- Recognize that your collaborative partners may have additional priorities outside the scope of your collaboration and, if possible, support these priorities.
- Leverage partners’ expertise that your organization may not have.
- Be willing to give up some control when participating in collaborative projects.
- Be a partner who instills confidence. Strive to carry out high-quality work and take steps, such as strategic planning, that make the goals and priorities of your organization clear.
- Recognize that collaborative activities may require a time investment and some organizational resources.
- Remember, networking and collaboration can only go so far in the absence of new resources. Once new resources are obtained, work to ensure that the funds continue to be available.

5. Look to the Long Term

Once you have a healthy process of community involvement, consider these steps for sustaining community support for the process.

- **Identify New Stakeholders.** As you work to integrate hepatitis services, in all likelihood you will encounter more individuals and organizations with an interest in the issue. Be sure to have a strategy for incorporating new stakeholders into the process on an ongoing basis.
- **Train Stakeholders.** The quality of a process depends greatly on participants' expertise. While each of the participants will have expertise in a specific area, they can always enhance their knowledge in other areas. Training does not have to be highly structured or intensive. Consider putting aside time at advisory council meetings where participants can learn more about hepatitis in their community. For example, various service providers can make presentations about their services, outreach workers can speak about their work in the field reaching at-risk populations, the health department epidemiologist can present surveillance data, and people with hepatitis can talk about what it is like to live with the disease. Another idea is to ask participants who attend national conferences to give summaries of workshops they found valuable.
- **Communicate With Stakeholders.** Keep people informed of the process and efforts to integrate services. People are more likely to remain engaged in a process if they have ongoing information about it. Consider using various communication tools such as list-serves, chatrooms, Web sites, and newsletters to keep participants up to date.
- **Avoid Burn Out.** Those participating in the process over time are in danger of experiencing burn out. While asking people to attend occasional

People are more likely to remain engaged in a process if they have ongoing information about it.

meetings may not seem like a huge demand, on top of all the other responsibilities they have, it can become a burden. Consider the following steps to minimize the possibility of burn out.

- *Show appreciation.* Never underestimate the value of thanking people for their efforts. A little gratitude goes a long way. Consider holding an annual appreciation luncheon and recognizing ongoing participation in some way (certificates, etc.).
- *Rotate responsibilities.* Are the same people always chairing meetings and volunteering for taskforces? Distributing work among participants reduces the likelihood that people will be overwhelmed by the responsibilities.
- *Provide opportunities for feedback.* Any process can be improved. Making sure that participants have opportunities to provide feedback about the process can lead to a more streamlined and efficient use of time and energy.

Capacity-Building Resources

CARE Act Technical Information and Education (CATIE) TA Library

This online, searchable library contains resources on a variety of topics including needs assessment, planning, and working with affected communities (conflict of interest, roles and expectations for advisory committee members).

<http://hab.hrsa.gov/CATIE/>

Center for Community-Based Health Strategies, AED

The Center has numerous resources, including fact sheets and reports on viral hepatitis and technical assistance documents. <http://www.healthstrategies.org/>

HIVAIDSTA.ORG

This Web site, a project of NASTAD and the Academy for Educational Development (AED), provides TA materials for HIV prevention community planning groups (CPGs). Included are resources on assessment, planning, and meeting facilitation. <http://www.hivaidsta.org>

- ***Provide Capacity-Building TA for Service Providers.*** Service providers who are asked to assume new responsibilities may need capacity-building technical assistance to facilitate the incorporation of those activities. Health department staff or other service providers in the community may be able to provide this assistance. Otherwise, look to other sources of technical assistance, such as the CDC, NASTAD, or other national organizations.
- ***Identify New Resources.*** Seeking out additional resources should be an ongoing effort. While integration of services is an effective strategy for delivering services with few resources, your community will likely always have a list of needed services that cannot be established or expanded unless new resources become available.

Advocacy in Action



Few identify IDUs as individuals who wield significant political power. While substance abuse is often on the radar screens of local policymakers, their perspective, which usually focuses on ridding neighborhoods of drugs and reducing crimes associated with drug use, rarely focuses on the needs of drug users and those in recovery. Yet the Recovery Association Project (RAP), which was formed by recovering addicts in 1999 in Portland, Oregon, has succeeded in working with elected officials and other community players. These efforts resulted in the initiation of an array of services and activities responsive to the needs of RAP's members.

RAP is dedicated to providing a vehicle for people in recovery to speak out on substance abuse-related issues. Many people in recovery participate in 12-step programs, but these programs are focused on recovery and do not have community education or advocacy components. RAP was organized to provide people in recovery with a separate platform to publicly speak about recovery and drug-related issues. Initial efforts were funded through a Substance Abuse and Mental Health Services Administration (SAMHSA), Center for Substance Abuse Treatment (CSAT) grant for community organizing.

“We started out by talking to people. We're big on talking,” says Bruce Tyberg, one of RAP's founding members. “We found that many IDUs had hepatitis C but did not have any information about the disease. Even their doctors couldn't give them information. People were frightened of it. They thought they were going to die.”

At the same time, a very high number of deaths in Multnomah County were caused by heroin overdose. Hepatitis C and overdose prevention became two major priorities for RAP. After determining the needs of their members, RAP took these concerns to the county commission. At a public meeting, RAP asked the commission to form taskforces on these two issues, made up of RAP members and staff from the Multnomah County Health Department (MCHD).

At the direction of the county commission, the two taskforces were formed, and roles, deliverables, and timelines were established. The taskforces developed sets of recommendations addressing the issues. The taskforce structure was extremely important in the final, successful outcome of the process. RAP was an equal partner in the process and was empowered to push for the needs of their community and be a significant voice in program design. MCHD provided the public health expertise, both administrative and technical.

Once the recommendations were developed, RAP organized a public meeting that was attended by all the key players: county commissioners, MCHD, state agencies, law enforcement representatives, and RAP members. RAP leaders and members gave testimonials, and then the recommendations of the two taskforces were presented. The County Commission agreed to implement the recommendations.

MCHD was provided with funds to establish the hepatitis-C-related services identified by the taskforce, including outreach to affected communities, training for service providers (doctors), and testing of high-risk populations. Also, several activities were initiated to address heroin overdose.

These included posters warning inmates about the risk of heroin overdose (19 percent of overdose victims got out of jail less than 60 days before they died), medical authorities instructing doctors to be wary of prescribing benzodiazepine to patients with a history of drug abuse (mixing heroin with this drug increases the risk of overdose), and instructing outreach workers at detox centers and needle exchange sites to reassure IDUs that they would not be arrested if they call 911 in the event of an overdose. By 2000, overdose deaths dropped by 36 percent.

“By being prepared and organized,” says Gary Oxman, MD, MCHD Health Officer, “RAP arranged the interaction between elected officials, the bureaucracy, and community members. RAP was instrumental in creating awareness among elected officials, legitimizing the need for the hepatitis C and overdose prevention services, and, ultimately increasing services.”

From RAP’s perspective, the health department was the only entity that could address the problem. “We can see the problems,” Tyberg says, “but they have the expertise and the procedures for addressing them.”

The process that RAP used to gain support for their priorities resulted in what many of those involved saw as an “everyone wins” outcome. The county commissioners could respond to community needs with concrete services, specific needs that RAP members had expressed to the organization’s leadership were addressed, and MCHD received new resources to implement appropriate public health approaches.

While the end results of the process were positive for all involved, RAP’s initial activities did result in some concerns for MCHD. Some health department staff were nervous about RAP’s advocacy efforts, fearing a loss of their professional power and control. They were also concerned about criticism of their programs, feeling the community was “beating them up.” Fortunately, the taskforce process that RAP established ensured that all parties had a voice in developing proposed programs.

“Some staff were concerned that we could not control the process,” says Oxman. “We were very happy with the end product and learned that CBOs may appear intimidating, but they really are essential partners.”

Oxman also stressed the importance of recognizing the priorities of community advocates. Heroin overdose issues were very important to RAP. If MCHD had refused to work with the organization on this issue, RAP may have backed off, and there may not have been a hepatitis C program.

Oxman also stresses that all the benefits resulting from the efforts of community advocates may not be immediately evident. As a result of the hepatitis-C-related services in place, funded by the County, MCHD has been well-positioned to seek out additional funding to expand their hepatitis C-related activities.

For more information, contact Gary Oxman, MD, Multnomah County Health Officer, at 503/988-3674 or gary.l.oxman@co.multnomah.or.us.

The Benefits of the Internet

The Internet has played an important role in the activities of many health departments and CBOs as they develop viral-hepatitis-related services. Using the Internet can be an effective way to reach diverse audiences with targeted information. While developing and maintaining a Web site does require resources and technical expertise, it can be highly cost effective in the long run. Agencies have used Web sites to:

- Post documents, such as strategic plans, for download, which saves printing, handling, and postage costs;
- Maintain and update calendars of events, support group schedules, and other time-sensitive materials; and
- Provide links to other Web sites that connect viewers with a broad range of information on treatment, support services, and other topics.

The Hep C Advocate Network (HEPCAN), a nonprofit, national organization based in Texas, has developed an extensive Web site to educate people across the country about viral-hepatitis-related issues. Advocacy activities are a major focus of the site. Included is information on what legislation is pending at the national and state levels, how the legislative process works at the federal level, and how to contact legislators. The site also includes state-by-state information on Medicaid, discussion of funding for hepatitis services, training information, and updates related to hepatitis. The site is interactive. Viewers can submit questions and comments, provide information on advocacy activities in their state, and sign up for the organization's list-serve. To view the Web site, go to <http://www.hepcan.org>.

In addition to the use of Web sites, many CBOs and health departments rely on e-mail to communicate with collaborative partners and clients. For example, in New Mexico, the health department found that e-mail was an effective way to remind people to come back for their hepatitis A and B vaccine doses. E-mail works even with homeless individuals, since many access e-mail accounts at the public library.

E-mail is also being used to communicate with individual clients as well as groups through list-serves and chat-rooms. Newsletters and action alerts can also be distributed by e-mail.

Beyond Your Community

While the work is done at the local level, the reality is that the bulk of the resources needed to carry out the work come from the state or federal government. Integration can only go so far. This health crisis is of such a magnitude that new resources will be needed at some point to meet the demand for services.

To some degree, it is the job of health departments to educate policymakers. Policymakers naturally consult with health directors and their staff about specific health issues, as they are the local public health experts. As public employees, however, there are limits on the extent to which state and local health department staff can become involved in advocacy. Extensive advocacy activities can appear to be a conflict of interest or possibly be perceived as a misuse of public funds.

It is the role of the community, CBOs, and af-

Nothing will win support as effectively as people who are affected by viral hepatitis sharing their stories and presenting their perspective on what is needed to address the issue.

affected populations, for the most part, to take the lead in advocacy efforts—to convey to policymakers the “will of the people.” However, many of the basic activities of public health, such as surveillance, planning, and community organizing, are very important to advocacy efforts. Surveillance data can help advocates tell the story of who is affected and how the problem is growing in the community. Planning activities that identify service gaps allow advocates to communicate what is needed to address the problem. Community organizing can bring together those with an interest in the issue.

Another way state and local health departments can communicate with policymakers is through national member organizations, like NASTAD, that represent state and local health departments and advocate on issues important to their constituents. These organizations include the Association of State and Territorial Health Officials (ASTHO) and the National Association of County and City Health Officials (NACCHO). Consider becoming involved with these national organizations if you are not already working with them.

How Advocates Can Convey Their Message

While it is up to the community to communicate their needs to policymakers, a little coaching may be in order to help them be more effective. The following are some general rules for effective advocacy by community organizations and affected populations.

- **Let Affected Populations Tell Their Stories**
At the most basic level, politics is about people. Making a case with data and reports is important, but nothing will win support as effectively as people who are affected by viral hepatitis sharing their stories and presenting their perspective on what is needed to address the

issue. Making a personal connection with policymakers may result in their taking an interest in the issue.

- **Develop a Broad Base of Support**

Policymakers are concerned about keeping their constituents happy. When making decisions, they often carefully weigh how many people will be in support of their actions and how many will be disappointed since, come election time, these sentiments may translate into votes. A diverse group of stakeholders advocating on an issue can demonstrate that the issue has broad support within a community—making it more appealing for policymakers to support it.

- **Know What Is Needed**

To generate interest, advocates need to be able to present the issue in a compelling way. However, this is just half the story. Advocates also need to be able to articulate, clearly and simply, what actions policymakers need to take to address the issue. For example, when asking for more funds, advocates need to tell what services are needed, how much money is required, and how the funded services will address the need within the community.

- **Coordinate the Message**

Everyone involved in the advocacy efforts must ask for the same thing. Efforts should be coordinated among stakeholders. For example, in an effort to increase Congressional funding for state-level hepatitis programs, advocates should come to agreement on appropriation numbers so that congressional staff are not inundated with different groups asking for different things.

- **Ask for Something That is Deliverable**
Before you embark on advocacy efforts, do your research. Advocates must ask for something that policymakers can actually deliver. You don't want to ask a member of Congress to act on something over which Congress has no jurisdiction.
- **Follow Up With Policymakers**
Once you have made contact with a policymaker, follow up regularly. Let them know the impact of their actions and what remains to be done. Cultivating support among policymakers can pay off over the years, especially if they take a leadership role on the issue.

How to Communicate With Policymakers

It's not only high-powered lobbyists who get their messages heard. In fact, most policymakers make a special point of providing access and responding to their constituents. Various ways of communicating with policymakers include:

- Writing letters;
- Making telephone calls or using e-mail and fax;
- Having meetings face-to-face (either at the local office or in the state capitol or Washington, DC); and
- Attending a community forum with the policymaker.

Also, building support among the general public can help to raise the issue with elected officials. Consider developing a media strategy that will make people more aware of hepatitis. This could include public service announcements as well as news stories that explore the impact of hepatitis in your community. Various resources on how to work with the media are listed in the resource section.

National Hepatitis C Advocacy Council



The National Hepatitis C Advocacy Council (the Council) is a coalition of patient advocacy organizations. The Council's goal is to develop a cohesive hepatitis-related strategy on such issues as research, education, legislation, diagnostics, clinical trials, and fundraising. Currently, the Council has 21 members.

According to Council President Andi Thomas, a unified advocacy effort is critical because little has been done to increase the capacity of the existing service infrastructure to provide hepatitis services. It wasn't until 2003 that the first hepatitis-specific legislation was introduced in Congress, Senate Bill 1143, "Hepatitis C Epidemic Control and Prevention Act." Given the number of people infected with hepatitis in the United States and the substantial costs that will result in providing medical care to these individuals, it is imperative that more federal resources be made available. Advocacy efforts will likely be instrumental in bringing this about.

The Council works to coordinate the advocacy efforts of its members and to promote advocacy on the part of individuals. The Council's Web site provides information on pending legislation, and a list-serve periodically distributes "Action Alerts" and updates to the hepatitis community and concerned individuals. Also, Council members individually take on legislative issues within their own states and local communities. The Council supports these activities by providing technical assistance and by serving as a forum for sharing ideas and strategies. Andi Thomas credits Council members' efforts with an increase in awareness at the state and local level, leading to the rise of advisory councils, strategic planning processes, and other activities that give the hepatitis community and affected individuals a voice.

An important part of the Council's work is bringing together various elements of the hepatitis community so that it can "speak with one voice." However, Thomas also acknowledges that more outreach is needed to broaden the constituent base. Community members may also need to be educated on effective strategies for enhancing and increasing hepatitis services. For example, some are resistant to integrating hepatitis services with HIV/STD services. Given the limited resources available for hepatitis, integration with HIV/STD services is viewed by many as one of the only viable approaches. By educating those within the hepatitis community and working to expand the community, the Council can further strengthen the message.

An additional goal of the Council is to provide technical assistance to build the capacity of local patient advocacy organizations. However, resources are not available to support activities in this area. In the future, the Council would like to be able to provide capacity-building support. For example, it could assist in developing resources for organizations, to eliminate the need for each to reinvent the wheel, and also take the lead in developing standard outcomes for various services to facilitate evaluation across organizations. Information on how to start a patient support group is available from the Council.

For more information on the [National Hepatitis C Advocacy Council](http://www.hepcnetwork.org), go to:
<http://www.hepcnetwork.org>.

Advocacy Resources

Pending Legislation

American Liver Foundation

Posted on their Web site is information on pending legislation at the national and state levels and reprints of testimony.

<http://www.liverfoundation.org>

National Hepatitis C Advocacy Council

This Web site includes the text of pending legislation, along with a list-serve for action alerts and updates.

<http://www.hepcnetwork.org>

Sample Letters and Other Advocacy Aids

HepatitisActivist.Org

HepatitisActivist.org hosts a Web site that includes sample letters on various topics (increased funding, research, organ transplant) and has an Automated Congressional E-mailer (ACE) System that allows people visiting the site to send an e-mail directly to their members of Congress.

<http://www.hepatitisactivist.org>

General Resources

Changing Times, Continuing Needs: An Overview of HIV/AIDS Policymaking and Programs at the Federal Level

A NASTAD legislative primer on HIV/AIDS

<http://www.nastad.org/publicpolicyresources/legprimer.pdf>

Library of Congress: Thomas

A searchable Web site with legislative information, such as the status of bills, committee information, and *The Congressional Record*. It also provides information on Congress, including how laws are made.

<http://thomas.loc.gov/>