

**State of Illinois**

Rod R. Blagojevich, Governor

**Department of Public Health**

Damon T. Arnold, M.D., M.P.H., Director



---

# Viral Hepatitis Strategic Plan

October 2007

Page Intentionally Left Blank

**Table of Contents**

**Acknowledgements.....2**

**Viral Hepatitis Strategic Planning Participants.....2**

**Executive Summary.....3**

**How to Use the Document.....5**

**Mission and Vision Statements, Strategic Priorities and Long-Term Goals.....6**

**Progress Towards Reducing the Impact of Viral Hepatitis.....7**

**Voids in Services That Impact Viral Hepatitis in Illinois.....9**

**The Prevention Plan.....10**

**Prevention and Education.....10**

**Medical Management.....11**

**Surveillance.....12**

**Advocacy.....13**

**Programmatic Infrastructure.....13**

**Appendices.....14**

**Hepatitis Background.....14**

**Cost of Viral Hepatitis.....15**

**Hepatitis A.....16**

**Hepatitis B.....17**

**Hepatitis C.....18**

**Burden of Chronic HCV Disease.....20**

**Hepatitis Provider Survey.....21**

**Consumer Survey.....23**

**Key Findings from Community Forums.....25**

## **Acknowledgements**

In 2003, the Illinois Department of Public Health (IDPH), Division of Infectious Diseases, applied for funding from the Council of State and Territorial Epidemiologists (CSTE) in response to a request for proposals on “Hepatitis Program Building at the State Level.” IDPH was granted funding to conduct a needs assessment and to develop a strategic plan for the prevention of viral hepatitis in the state, modeled on an earlier planning process for Sexually Transmitted Diseases (STD) prevention and control in the state. Representatives from the STD and Immunization Programs developed a steering committee that oversaw the hepatitis strategic planning process. This report reflects the culmination of this process. The IDPH Division of Infectious Diseases would like to express special appreciation and credit to the members of the steering committee who devoted countless hours to develop the ideas and recommendations that make up the plan. The entire steering committee brought vision, energy and commitment to the planning process.

Appreciation also is given to all the individuals and organizations that participated in the development and planning of this statewide viral hepatitis strategic plan. In addition, the steering committee would like to acknowledge the Council of State and Territorial Epidemiologists for their support of this project.

## **Viral Hepatitis Strategic Planning Participants**

Mark Dworkin, IDPH Epidemiologist  
Charlie Rabins, IDPH STD Section  
Richard Zimmerman, IDPH STD Section  
Carol Finley, IDPH Immunization Section  
Corinna Dan, Hepatitis Foundation International  
Dee Dunnett, Winnebago County Health Department  
Dr. Willard Elyea, Illinois Department of Corrections  
Hong Liu, Asian Health Coalition  
Basmatte Boodram, University of Illinois at Chicago, School of Public Health  
Rick Alonzo, Illinois Department of Human Services (IDHS), Office of Alcohol and Substance Abuse  
Jacqueline Dominquez, American Liver Foundation  
Don Doty, Georgia Doty Health Education Fund  
Ron Hershow, UIC, School of Public Health  
Don Hunt, Sangamon County Health Department  
George Martinez, HIV Empowerment and Living Together with Hepatitis  
Cynthia Noa, IDPH, Division of Infectious Diseases  
Patrick Piercy, IDPH Communicable Diseases Section  
Andre Rawls, IDPH HIV/AIDS Section  
Nikunj Shah, Loyola University Medical Center, Hines Veterans Affairs  
Virginia Warren, Asian Health Coalition  
Jonathan Yoder, IDPH Division of Infectious Diseases

## Executive Summary

Viral hepatitis is a major public health problem in the United States, with an estimated 113,000 new infections in 2005. Centers for Disease Control and Prevention (CDC) estimates that the economic impact of hepatitis A, B and C is \$1.8 billion based on 1999 dollars, which includes direct medical cost and lost productivity. CDC projects that each 1 million high-risk adults vaccinated would save up to \$100 million in future direct medical costs by preventing 50,000 new hepatitis B infections, 1,000 to 3,000 chronic hepatitis B infections, and 150 to 450 deaths from cirrhosis and liver cancer.

Representatives from the IDPH STD and Immunization Programs developed a steering committee that oversaw the hepatitis (the planning was not for hepatitis but for developing a hepatitis prevention plan) strategic planning process. The planning process stresses five major areas of interest:

- **Prevention and Education** – Reduce/eliminate new cases by increasing awareness of viral hepatitis and effective prevention and risk reduction strategies. Promote and provide information to health care workers, patients, at-risk persons, and the general public.
- **Medical** - Increase the medical community's capacity to identify, counsel, vaccinate and care for patients with viral hepatitis to limit the progression of liver damage and complications associated with chronic disease.
- **Surveillance** - Develop a surveillance system that will monitor disease trends, detect outbreaks of acute hepatitis and measure the overall burden of disease to evaluate the effectiveness of prevention and risk reduction strategies.
- **Advocacy** - Advocate and establish alliances with industry and lobbyists to promote progressive legislation to support care of persons with chronic viral hepatitis, improve donor standards and increase donor populations, and effect strategies with national organizations to ensure that Illinois needs are addressed.
- **Programmatic Infrastructure** - Develop an infrastructure at the state level to coordinate hepatitis prevention and care funding, planning and services.

The overall purpose of this plan is to provide a road map for the Illinois Department of Public Health and its partners for the development and delivery of viral hepatitis prevention services in the state of Illinois to reduce the impact of viral hepatitis and related liver disease among Illinois residents.

During the summer of 2004, surveys of consumers and providers were completed to identify existing and needed hepatitis services in Illinois. Key needs identified included limited:

- Community awareness and knowledge about viral hepatitis and its prevention
- Prevention services, and services for hepatitis-related care and treatment
- Social support systems for those living with hepatitis

Community-based forums conducted in 2005 identified key needs as:

- Educational awareness campaign for health care providers and community members
- Medical services for vaccination, testing and treatment
- Increased federal and state funds to support hepatitis prevention efforts and address voids in care

Of particular concern since the hepatitis C virus (HCV) was identified in 1989, is evidence of an emerging epidemic of HIV/HCV co-infected individuals. According to CDC, approximately 25 percent of persons living with HIV/AIDS also are infected with HCV. In co-infected persons, HCV infection progresses faster, leading to serious liver disease. HCV also is exacerbated by the continued use of alcohol or drugs (including injection drugs and medications used in retro-viral therapy for HIV-positive persons), which may cause further toxicity and damage to the liver. Persons dually infected with HIV/HCV have twice the risk of cirrhosis as does a person only infected with HCV. In addition,

persons with previous history of STDs are at increased risk of infection with viral hepatitis. Raising the awareness and ensuring the integration of hepatitis services in HIV, STD, correctional and drug treatment settings is essential for successful strategic hepatitis prevention planning.

There are no state or federal grant programs which provide consistent, sustainable funding to state and local public health agencies to support hepatitis prevention, surveillance, detection and medical care.

## **How to Use This Document**

This report summarizes the needs assessment data collected and outlines a strategic plan for preventing and eliminating viral hepatitis in Illinois. Information in this report was generated by hepatitis surveillance, gathered via written documentation, research and primary data collection. Many stakeholders already involved in hepatitis work were interviewed or included in the formation of this plan. This report can be used by a broad array of agencies and individuals responsible for and impacted by viral hepatitis to plan, fund, advocate and deliver viral hepatitis prevention, testing, treatment, research, training and policy. Copies of this and other states' hepatitis plans can be found at: [http://www.cdc.gov/ncidod/diseases/hepatitis/partners/state\\_plans.htm](http://www.cdc.gov/ncidod/diseases/hepatitis/partners/state_plans.htm).

The appendices contain a national and state overview on viral hepatitis A, B and C and summarized survey results from providers, consumers and community forums.

## Mission and Vision Statements, Strategic Priorities and Long Term Goals

### Mission Statement

To provide a comprehensive, collaborative strategic plan to reduce the impact of viral hepatitis in Illinois and to limit the progression and complications from viral hepatitis related liver disease among those living in Illinois.

### Vision Statement

The vision for viral hepatitis prevention in Illinois is to reduce and/or eliminate new hepatitis A, B and C infections through coordinated local and state efforts supported by public and private partnerships.

### Strategic Priorities

- **Prevention and Education** – Reduce/eliminate new cases by increasing awareness of viral hepatitis and effective prevention and risk reduction strategies. Promote and provide information to health care workers, patients, at-risk persons, and the general public.
- **Medical** - Increase the medical community's capacity to identify, counsel, vaccinate and care for patients with viral hepatitis to limit the progression of liver damage and complications associated with chronic disease.
- **Surveillance** - Develop a surveillance system that will monitor disease trends, detect outbreaks of acute hepatitis and measure the overall burden of disease to evaluate the effectiveness of prevention and risk reduction strategies.
- **Advocacy** - Advocate and establish alliances with industry and lobbyists to promote progressive legislation to support care of persons with chronic viral hepatitis, improve donor standards and increase donor populations, and effect strategies with national organizations to ensure that Illinois needs are addressed.
- **Programmatic Infrastructure** - Develop an infrastructure at the state level to coordinate hepatitis prevention and care funding, planning and services.

### Long-Term Goal:

The long-term goal for the Viral Hepatitis Strategic Prevention Plan is to reduce and/or eliminate the incidence and reduce the prevalence of viral hepatitis in Illinois.

## Progress Towards Reducing the Impact of Viral Hepatitis

Prevention - in the forms of risk reduction counseling and vaccination - can help reduce the number of new cases of viral hepatitis. Hepatitis B virus (HBV) has been vaccine preventable since 1982; hepatitis A since 1995. CDC projects that \$100 million in future direct medical costs could be saved by vaccinating 1 million high-risk adults against HBV; vaccinating these adults could prevent an additional 50,000 new hepatitis B infections, 1,000 to 3,000 chronic hepatitis B infections, and 150 to 450 deaths from cirrhosis and liver cancer. Early identification among HBV and HCV infected persons is critical to allow medical evaluation of disease, monitor liver functions, identify possible treatments, teach patients how they can prevent transmission to others and reduce further harm to their livers by reducing alcohol intake and getting vaccinated against hepatitis A and/or hepatitis B. Effective treatment of HBV and HCV can reduce the number of liver transplants needed and reduce the current severe shortage of donor organs.

Currently, in Illinois:

- Over 90 percent of all infants and school aged children up through 19 years of age are age-appropriately vaccinated against hepatitis B; over 85 percent of all juveniles housed in the state's juvenile detention facilities complete hepatitis B vaccination prior to release.
- Physicians and hospitals providing care to pregnant and birthing women routinely screen for hepatitis B and provide aggressive preventive vaccination to the newborns.
- Local health departments routinely case manage infants born to women with hepatitis B infections to ensure timely completion of the three dose hepatitis B vaccination and conduct blood tests to ensure that hepatitis B infection was prevented among their infants.
- Local health departments facilitate the reporting of viral hepatitis, provide childhood vaccinations against hepatitis A and B, vaccinate household and sexual partners of persons with hepatitis B and routinely provide vaccination against hepatitis A and B to economically disadvantaged residents with hepatitis C and/or HIV.
- A few local health departments have collaborated with area physicians to streamline access to medical care for under-insured patients.
- Hepatitis-specific risk reduction counseling, vaccination and limited HCV testing has been integrated into public STD counseling and testing programs since 2000.
- Several Chicago-based, minority health service programs have conducted outreach to at-risk populations (primarily to Asian Americans and Asian immigrants, and more recently to African Americans) to facilitate education and screening for hepatitis B and C and to provide vaccination against hepatitis A and B.
- The Secretary of State's Organ Donor program has been very successful in collaborating with regional organ and tissue donor networks to champion support to improve donor standards and increase the donor population.
  - Promoted legislation creating the first-person consent law, which discontinues the previous practice of requiring additional family member consent to carry out an individual's documented wishes to become an organ and tissue donor.
  - Produced an African-American Community Guidebook and multi-lingual materials to educate the specific sub-populations on the importance of organ donation and the increasing need for more Illinoisans to register as donors.
  - Sponsors a semi-annual conference on organ donation to increase awareness among representatives of the medical community, funeral directors, coroners and any interested persons.
  - Developed effective donor recruitment initiative through driver's licensure and via online enrollment in the Illinois Organ/Tissue Donor Registry.
- In July 2004, Illinois became the first state with a law specifically allowing HIV-infected people to donate organs to other persons infected with the virus. However, before the law can be implemented, federal rules barring these donations will need to change.

- Illinois families have benefited from the services of COTA, the Children's Organ Transplant Association, which provides fundraising assistance for children and young adults needing life-saving transplants and promotes organ, marrow and tissue donation
- Illinois has two active organ procurement organizations: Mid-America Transplant Services serving southern Illinois and the metro-East St. Louis area and Gift of Hope Organ and Tissue Donor Network serving central and northern Illinois. Each of these organizations also promotes living donor programs for liver recipients.
- Illinois has eight transplant centers (three in downstate Illinois and five in the Chicago metropolitan area.)

## **Voids in Services That Impact Viral Hepatitis in Illinois**

Despite the grave health and economic consequences that Hepatitis A, B and C cause for thousands of Illinoisans and millions of Americans, there is very limited support and funding to address many hepatitis-related health interventions. There are no state or federal grant programs which provide consistent, sustainable funding to state and local public health agencies to support prevention, surveillance, detection and care.

Access to anti-viral treatment(s) for persons with chronic hepatitis B and/or C is very expensive; a course of anti-viral treatment can cost \$10,000-\$15,000 for 6 to 12 months, and many insurance companies do not cover these costs. Other service voids and disparities identified by the steering committee include:

- Many persons throughout Illinois are at increased risk of viral hepatitis - yet services to educate and counsel them about viral hepatitis risk reduction practices are very limited.
- Routine vaccination against hepatitis A and B is not routinely available for high-risk adults.
- Many persons served in public or private health facilities are at-risk of viral hepatitis - yet services to screen for hepatitis A, B or C are not routinely available.
- Access to medical providers capable of monitoring liver-related health care and providing antiviral treatment against hepatitis B and C is limited. Finding a knowledgeable physician to provide hepatitis-related care remains one of the most elusive components of surviving chronic infection with viral hepatitis.
- Access to medical services to monitor liver health for persons with hepatitis B and C is a critical gateway or a barrier to treatment, depending on the availability of health care coverage. Most physicians require patients with chronic hepatitis B or C to have their liver enzymes routinely tested and/or ultrasounds to assess degree of disease progression. Many clients that access services at local health departments or community based clinics do not have health insurance or lack coverage for testing to determine liver health.
- Access to medical specialists for transplantation, when applicable, remain very costly and availability is usually limited to metropolitan areas. Chronic hepatitis C is the most common cause of liver damage requiring liver transplantation for survival.
- Support groups can offer information, resources and hope for persons impacted by chronic hepatitis. Although the American Liver Foundation facilitates some weekly meetings in the Chicago area and three local health departments (Springfield, Champaign, and Macon) offer monthly meetings in central Illinois, many areas of the state do not have support group services.
- Supplemental services, such as mental health, transportation, respite care, etc. are often nonexistent for persons needing medical treatment for hepatitis. Patients are frequently faced with long distances to travel, and an uncoordinated system of complex medical care.
- Income assistance programs generally do not acknowledge or cover the needs of persons with chronic hepatitis. Even though persons with chronic hepatitis can become too disabled to work for intermittent periods, this condition is not covered by current Medicare services.
- Although HCV prevalence among prison inmates is three to five times greater than that in the general population, access to viral hepatitis screening and prevention services are not routinely available in Illinois prisons.
- Services to clients that injected illegal drugs, who are at high risk of acquiring or transmitting HIV, hepatitis B and C, are difficult to deliver or non-existent.
- Infection control practices at long-term care facilities are poor or lacking which can place individuals at increased risk of acquiring hepatitis B and C. Medical literature suggests there are significant issues with infection control in assisted living and long-term care facilities, placing individuals at risk for hepatitis B and C.

# The Prevention Plan

## Prevention and Education

**Goal #1: Reduce/eliminate new cases of viral hepatitis by increasing awareness of effective viral hepatitis prevention and risk reduction strategies.**

**Strategies: Increase Awareness of General Population**

### **Short term (within one or two years)**

- Develop or purchase educational materials (videos, pamphlets, wallet cards, etc.) and distribute widely to effectively promote evidence-based risk reduction strategies.
- Provide information on viral hepatitis risk reduction practices to persons accessing HIV, STD, family planning, drug treatment and needle-exchange services.
- Increase community-based involvement in awareness campaigns to address viral hepatitis prevention and risk reduction practices by developing partnerships with agencies serving at-risk individuals, such as the American Liver Foundation-Illinois Chapter.
- Provide training on the epidemiology of hepatitis and prevention-based counseling.
- Fund minority based organizations that provide HIV or STD prevention services for African-Americans, Asian/Pacific Islanders or Hispanic residents to include information on prevention, testing, and treatment.

### **Long term (within three or four years)**

- Develop public service announcements so that the general public can identify risk behaviors that lead to infection.
- Develop public service announcements to increase awareness of the chronic nature of hepatitis B and C infections.
- Incorporate information on risk behaviors for viral hepatitis into primary and secondary school curricula in conjunction with information utilized with sexually transmitted diseases and substance abuse curricula.
- Integrate hepatitis prevention messages into programs dealing with women's and men's health issues.

**Goal #2: Promote and provide information to health care workers to increase prevention services to patients/persons at increased risk for acquiring viral hepatitis infections.**

**Strategy: Increase Awareness of Health Care Providers Serving At-Risk Populations**

### **Short term (within one or two years)**

- Integrate hepatitis prevention and risk reduction education into the client centered counseling curricula used for HIV, STD and substance abuse counselors.
- Increase the number of local health departments (LHDs), community-based organizations (CBOs) and substance abuse treatment programs integrating hepatitis prevention messages into counseling sessions for HIV/STD risk reduction counseling.
- Develop and provide an annual hepatitis prevention training designed specifically for substance abuse counselors and provide CEUs for substance abuse counselors who attend.
- Develop a formal hepatitis training presentation for use by IDPH staff with various community and state agencies.
- Educate healthcare staff on specimen collection and result interpretation practices for clients testing for hepatitis A, B and C.

### **Long term (within three or four years)**

- Increase availability of hepatitis A and B vaccination and testing services in STD, HIV, drug treatment and syringe exchange sites.
- Revise Illinois Administrative Rules to require substance abuse counselors to discuss hepatitis prevention messages with clients.
- Educate public and private providers on the chronic nature of hepatitis B and C infections and the possibility of chronically infected persons spreading the diseases.
- Ensure that health care providers delivering hepatitis-related care and case management acquire patient behavioral history, choose appropriate hepatitis B and C screening tests, administer vaccinations, and report hepatitis B and C cases to IDPH.
- Establish and disseminate a provider resource directory, identifying private and public providers who can manage needs of patients with hepatitis B and C.

## **Medical Management**

**Goal # 3: Increase the medical community's capacity to identify, counsel and care for patients with viral hepatitis to limit the progression of liver damage and complications associated with chronic disease.**

### **Strategies**

#### **Short term (within one or two years)**

- Facilitate the availability of support groups for persons impacted by viral hepatitis that are geographically accessible.
- Establish dedicated funds to support HCV testing for high-risk populations.
- Continue to educate donors on hepatitis-related risks and continue to screen all blood, plasma, and tissue donors for the presence of blood borne pathogens.

#### **Long term (within three or four years)**

- Develop and fund a case management service structure for patients with chronic hepatitis B and C.
- Continue to educate providers on the guidelines to screen all pregnant women for HBsAg so that babies born in Illinois hospitals have maternal hepatitis B surface antigen test results on file.
- Distribute guideline-based standards for the care and management of chronic hepatitis B and C.
- Support the American Liver Foundation's effort to make available a hepatitis resource guide of private and public health clinician's that provide hepatitis related medical services for Illinois residents.
- Acquire resources to increase availability of screening for HBV and HCV for persons at risk including persons seeking services at:
  - State and county correctional centers
  - Drug and substance abuse treatment facilities, including methadone clinics
  - HIV counseling and testing clinics
  - STD clinics
- Acquire resources to support PCR testing for HBV and HCV.
- Educate all birthing hospitals in Illinois about the need to adopt policies and implement standing orders to require establishing HBsAg serostatus of all women prior to delivery and delivering birth dose vaccination to all infants.
- Fund comprehensive care for persons with chronic viral hepatitis so those underinsured, veterans, correctional inmates, substance abusers, etc. have access to primary and specialty care services, e.g., liver enzyme and HCV RNA testing, ultrasound of the liver, liver biopsies and genotyping of HCV, antiviral therapy, mental health, social and substance abuse services and peer support.

- Identify funds to provide hepatitis prevention education and hepatitis treatment services to inmates at county and state correctional facilities.
- Collaborate with local and regional medical centers to identify and establish medical resources to augment treatment-related services at strategically located health departments.
- Provide HIV and hepatitis prevention/risk reduction messages at the orientation and pre-start sessions at all IDOC facilities and at monthly prevention sessions at Adult Transition Centers and the Illinois Youth Centers.
- Ensure HCV testing to Illinois Department of Corrections (IDOC) inmates with elevated liver enzymes or signs/symptoms of hepatitis.
- Monitor HCV infected inmates and provide treatment for HCV when appropriate.

## Surveillance

**Goal #4: Develop a surveillance system that will monitor disease trends to evaluate the effectiveness of prevention and risk reduction strategies.**

### Strategies

#### Short term (within one or two years)

- Establish perinatal hepatitis B surveillance system to ensure that policies and procedures are in force with staff from birthing hospitals and obstetrics offices to routinely establish hepatitis B serostatus for all pregnant women and to ensure that all infants born to infected women receive Hepatitis B Immune globulin and their first dose of hepatitis B vaccine within 12 hours of birth.
- Ensure that all infants born to hepatitis B infected women complete their hepatitis B vaccination series and are tested to identify infants who become carriers following birth.
- Ensure that all birthing hospitals participate in the Adverse Pregnancy Outcome Reporting System (APORS) to identify children at-risk of hepatitis B infection at birth.
- Ensure that laboratory and healthcare providers utilize the Illinois National Electronic Data Surveillance System (INEDSS) to report cases of viral hepatitis.
- Ensure that reporting rules for viral hepatitis cases adhere to state and/or federal guidelines
- Ensure data accuracy and completeness of reporting within INEDSS.
- Produce standardized reports within INEDSS for LHDs to identify trends in morbidity, associated risk behaviors, health disparities, etc.

#### Long term (within three or four years)

- Investigate all reports of viral hepatitis to determine classification (acute or chronic), provide prevention and risk reduction counseling, vaccination and referrals for additional services as indicated and appropriate, and provide prevention services to identified contacts.
- Routinely screen for viral hepatitis among persons known to be at risk.
- Determine the rate of HIV/HBV and HIV/HCV coinfection among persons reported with HIV to identify additional health needs.
- Utilize an electronic registry system to record, track and create reminder notices for persons being vaccinated against hepatitis A and B, and document provision of risk reduction counseling and community-based referrals for care.
- Identify health disparities evidenced by higher prevalence of viral hepatitis in some populations and target resources and methods to reduce disease in those communities
- Evaluate “lessons learned” from reported data and disseminate.

# Advocacy

**Goal #5: Increase support from the general public, policy makers and local, state and federal elected officials for adequate funding of viral hepatitis prevention and care programs and services.**

## Strategies

### Short term (within one or two years)

- Collaborate with the national organizations, such as, the American Liver Foundation (ALF) and Hepatitis Foundation International on advocating for state and federal funding for hepatitis prevention and treatment services.
- Collaborate with the Illinois Secretary of State to increase the number of Illinois residents that are willing to donate organs.
- Establish an advocacy network to rapidly respond to issues and legislation impacting hepatitis care and prevention.
- Collaborate with ALF and local agencies to conduct an annual hepatitis advocacy event during May, Hepatitis Awareness month, when the Illinois General Assembly is in session.

### Long term (within three or four years)

- Collaborate with partners to help gain support for funding the activities delineated in 20 ILCS 2310, Hepatitis Education and Outreach Act, which includes forming a Hepatitis Council and conducting a hepatitis education and outreach campaign.
- Advocate for revision of Social Security Administration disability criteria to include disability encountered by persons with chronic viral hepatitis.

# Programmatic Infrastructure

**Goal #6: Develop an infrastructure at the state level to coordinate hepatitis prevention and care funding, planning and services.**

## Strategies

### Short term (within one or two years)

- Designate an IDPH organizational structure to respond to the 2007-08 CDC viral hepatitis grant application and transfer federal funding from the ELC grant to the new structure.
- Develop an internal IDPH Workgroup to coordinate hepatitis activities conducted by IDPH Offices and Divisions which may include Infectious Diseases, Long-Term Care, and Minority Health.
- Develop an internal IDPH Division of Infectious Diseases Hepatitis Workgroup to coordinate hepatitis activities conducted by IDPH Division of Infectious Diseases programs including surveillance, immunization, integration and perinatal.
- 

### Long term (within three or four years)

- Establish an Adult Viral Hepatitis Prevention Coordinator (AVHPC) to coordinate the IDPH, Division of Infectious Diseases Viral Hepatitis Collaboration and Services Integration Workgroup comprised of key staff in the Communicable Diseases, HIV/AIDS, Immunization (perinatal hepatitis B), STD and Tuberculosis Programs. The workgroup will integrate viral hepatitis prevention services into trainings and clinics.

# Appendices

## Hepatitis Background

### Overview of Hepatitis

Hepatitis is an inflammation of the liver, which can cause acute or chronic disease, compromise quality of life or be life threatening. Hepatitis is caused by many factors, including excessive alcohol consumption, drug use (including some prescription or treatment-related drugs which damage the liver), poisons and many viruses, including hepatitis A, B, C, D and E. Approximately 11,000-15,000 persons die from chronic liver disease annually nationwide.

Viral hepatitis is a major public health problem in the United States, with an estimated 113,000 new infections in 2005.

### Number of Cases of Reported Acute Hepatitis A, Acute Hepatitis B, and Acute Hepatitis C in the U.S. 2004-2005

	U.S. (2005)	U.S. (2004)
	Number	Number
<b>Hepatitis A</b>	4,488	5,683
<b>Hepatitis B</b>	5,494	6,212
<b>Hepatitis C*</b>	3,200	4,200

\* Estimated

Cases of hepatitis A, B, and C must be reported to the local authority under Illinois Administrative Code part 690. Surveillance for viral hepatitis is undertaken by staff from the Communicable Disease and Immunization Sections of the Division of Infectious Diseases of the Illinois Department of Public Health.

Chronic infection from hepatitis B and C can lead to serious medical conditions such as cirrhosis of the liver, hepatic fibrosis and liver cancer and can result in death. Like many other diseases, viral hepatitis often goes undiagnosed for years; reports of chronic hepatitis greatly underestimate the true disease burden.

- An estimated 1.25 million persons (6-10 percent of those infected or at least 500 per year) progress to chronic hepatitis B disease.
- An estimated 3.2 million persons (75-85 percent of those infected or at least 23,000 per year) progress to chronic hepatitis C disease.
- Ninety percent of infants infected with hepatitis B at birth develop chronic disease.
- Nationally, hepatitis B causes 3,000-5,000 deaths each year while hepatitis C causes 8,000 to 10,000 deaths annually.
- CDC projects that between 36,246 and 60,410 Illinois residents have chronic hepatitis B disease.

The complications of viral hepatitis disease are expected to increase over the next 20 years with an 81 percent increase in liver cancer and up to 180 percent increase in liver-related deaths attributed to viral hepatitis.

## The Cost of Viral Hepatitis

CDC has estimated, based on 1999 dollars, that the annual economic impact of hepatitis A, B and C was \$1.8 billion, which included direct medical costs, lost wages and decreased productivity. CDC projects that each one million high-risk adults vaccinated would save up to \$100 million in future direct medical costs by preventing 50,000 new hepatitis B infections, 1,000 to 3,000 chronic hepatitis B infections, and 150 to 450 deaths from cirrhosis and liver cancer.

Viral hepatitis contributes to multiple burdens on the United States economy including direct medical expenditures, lost wages, and decreased productivity.

- Hepatitis A infections result in an estimated \$489 million in medical costs and lost wages annually (1).
- Costs associated with hepatitis B infections exceed \$658 million each year (2).
- Estimates for the direct medical costs of hepatitis C infection exceed \$750 million annually (3), with employers estimating loss from absenteeism at \$4 billion to 5 billion annually (4). Societal costs for premature disability and death caused by hepatitis C between 2010 and 2019 are expected to be \$75.5 billion with 3.1 million years of life lost due to hepatitis C over that period (5).

Additional costs for which reliable monetary value estimates are not available include decreased employee productivity, compensation for occupational exposure, malpractice and liability, and family care.

1. Berge, J.J.; Drennan, D.P.; Jacobs, R.J. Jakins, A.; Stubblefield, W.; Weinberg, M. The cost of hepatitis A infections in American adolescents and adults in 1997. *Hepatology* 2000; 31: 469-473.
2. Alter, M. J. Epidemiology and disease burden of hepatitis B and C. *Antiviral Therapy* 1996; 1:9-14.
3. American Gastroenterological Association. *The Burden of Gastrointestinal Diseases*. American Gastroenterological Association. Bethesda, Maryland. 2005. pp 43-45.
4. Dulworth, S.; Patel, S.; Pyenson, B.S. *The hepatitis C epidemic: looking at the tip of the iceberg*. Milliman & Robertson, Inc. Washington, D.C. 2000.
5. Wong, J.B.; McQuillan, G.M.; McHutchison, J.G.; Poynard, T. Estimating future hepatitis C morbidity, mortality, and costs in the United States. *Am J Public Health*. 2000;90:1562-9.

## Hepatitis A

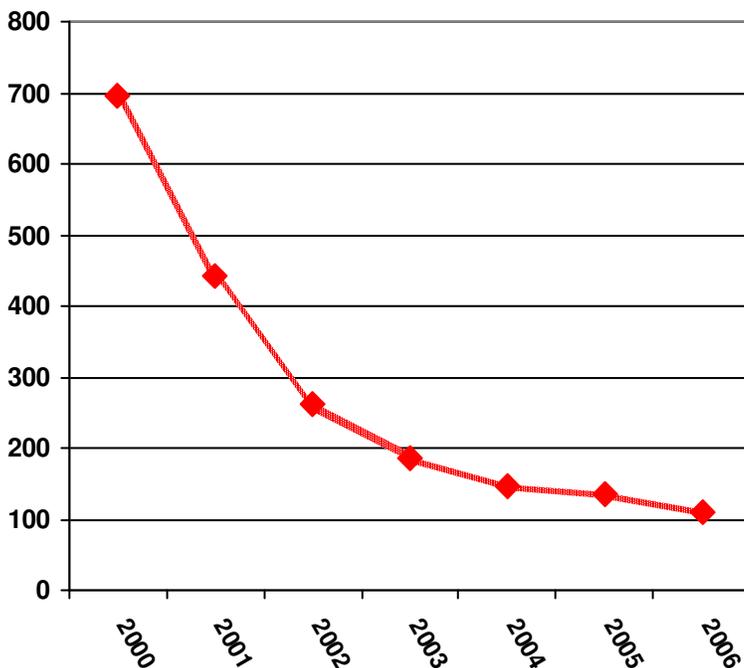
Approximately one-third of the United States population has been infected with the hepatitis A virus (HAV), a self-limiting disease with no chronic state which may be either asymptomatic or symptomatic. Those who become ill suffer with fever, decreased energy, and jaundice, and about 15 percent of persons are hospitalized. Although rare, hepatitis A can cause death from acute liver failure, especially in those who have a chronic liver disease.

HAV infection occurs via fecal to oral transmission and usually involves close personal contact or eating food or drinking water contaminated with HAV. The incubation period, during which the disease can be transmitted, averages 28 days. Some people, particularly young children, experience no symptoms. If symptoms are present they usually occur abruptly in the form of fever, fatigue, anorexia, nausea, abdominal pain, dark urine and jaundice. Symptoms among older children and adults usually last less than two months, although some patients (10% -15%) will experience prolonged or relapsing disease lasting up to six months. There is no chronic infection and HAV infection confers life-long immunity against HAV.

HAV has been vaccine preventable for people older than age two since 1995. Two doses of the vaccine, given at least six months apart, are needed for lasting protection. Vaccination is recommended for the following persons 1 year of age and older:

- Travelers to countries with high rates of Hepatitis A;
- Children living in regions of the United States with consistently high rates of HAV;
- Men who have sex with men;
- Injecting or non-injecting drug users;
- Persons with chronic liver disease;
- Persons with clotting factor disorders; and
- Anyone who wants to be protected from contracting HAV.

In Illinois, the number of reported cases of hepatitis A during the years 2000-2006 ranged from 696 in 2000 to 109 in 2006 with an average annual rate for the last five years of 179 cases reported.



### Hepatitis A causes sporadic outbreak-related infections

#### Transmission: Fecal-oral

#### Known Risk Factors:

- Contact with an infected person
- Travel to areas with high rates of hepatitis A
- Men who have sex with men
- Drug use
- Consumption of hepatitis A contaminated food and/or water

#### Prevention:

- Vaccination
- Hand hygiene

#### Vaccination in communities with outbreaks offers continued protection

#### No current childhood vaccination requirements or initiatives in Illinois

In Illinois, vaccination is offered to those at higher risk (e.g. injection drug users, those with hepatitis C, STD clients with multiple sex partners)

## **Hepatitis B**

The hepatitis B virus (HBV) causes a bloodborne viral infection that is 100 times more infectious than HIV/AIDS. Infected persons may be asymptomatic or may experience “flu-like” symptoms and jaundice. Among adults infected by hepatitis B, 90 percent to 94 percent recover completely and have no long-term effects. An estimated 15 percent to 25 percent of persons with chronic hepatitis B infection eventually die of chronic liver disease. Chronic carriers have the virus in their bodies and can continue to transmit the virus to others.

Hepatitis B remains one of the most common vaccine preventable diseases in the United States. School-aged children are recommended to be vaccinated upon entry to the fifth grade. Populations at risk include:

- Men who have sex with men;
- Sexual contacts of infected persons;
- Injection drug users;
- Household contacts of chronically infected persons;
- Infants born to infected mothers;
- Infants/children of immigrants from areas with high rates of HBV infection;
- Health care and public safety workers; and
- Hemo-dialysis patients.

At present, injection drug use, men who have sex with men and heterosexually active persons are the three primary risk groups, but the relative contributions of these risk groups have changed dramatically over time. It is evident from surveillance data that high-risk heterosexual activity has emerged as the predominant source of HBV infection among U.S. adults and therefore, HBV is a vaccine preventable STD.

HBV infection occurs via blood or body fluid exchange, which can include having sex with an infected person without a condom, sharing “works” when “shooting” drugs and suffering an occupational injury. HBV is vaccine preventable (since 1982) and chronic infection occurs in less than 10 percent of persons infected over 5 years of age. However, 90 percent of infants infected at birth suffer chronic infection.

## **Burden of Chronic Disease**

An estimated 1.25 million persons in the United States have chronic hepatitis B infection. It is believed that the reports of chronic hepatitis B greatly underestimate the true disease burden. According to the CDC, 4.9 percent of the U.S. population has been infected with the hepatitis B virus (1) and 6 percent to 10 percent of those persons progress to chronic disease. According to that formula, the true disease burden of chronic hepatitis B in Illinois is between 36,246 persons and 60,410 persons. While 0.3 percent of the U.S. population has chronic hepatitis B infection, Asian and Pacific Islander Americans (API) make up more than half of the 1.3 to 1.5 million known hepatitis B carriers in the United States.

- 10 percent to 20 percent of Asian-Americans have chronic hepatitis B infections
- The CDC has recognized that the greatest health disparity between Asian Americans and Caucasian Americans is liver cancer, 80 percent of which is caused by chronic hepatitis B virus infection

## Hepatitis C

The hepatitis C virus (HCV) is a blood-borne virus that can lead to cirrhosis, liver failure and liver cancer. It is considered a public health threat because an estimated 3 million to 5 million Americans have been infected with HCV. Hepatitis C virus infects approximately 36,000 persons each year and is the leading cause of liver transplantation in the United States.

While the hepatitis C virus has existed for at least the past 50 years, it is only recently that its real impact has been recognized. During the 1970s and 1980s, epidemic transmission of this virus was occurring in the United States, but most of these infections were “silent”- asymptomatic and undiagnosed. Since the causative agent of hepatitis C was only first identified during the early 1990s, it has become clear that a significant proportion of Americans are chronically infected, and that many of them are at risk of developing life threatening disease complications during the next several decades.

Hepatitis C is the most common chronic bloodborne infection in the United States. CDC estimates that 1.6 percent of the U.S. population has been infected with the hepatitis C virus at some point in their lifetime. It infects individuals of all ages, ethnic groups, and socioeconomic classes in urban and rural areas of Illinois. The two major risk factors for hepatitis C among infected Illinois residents are: a history of receiving a transfusion of blood or blood products prior to 1992 (when more effective blood screening tests became available) or a history of sharing needles for injection drug use (even once, even many years ago). Other risk factors for hepatitis C include: a history of accidental needle-stick or other blood exposures among health care workers, a history of long-term kidney dialysis, the receipt of clotting factors for hemophilia (before 1987), transmission from infected women to their newborn children (uncommon), or a history of sexual contact with an infected partner (also uncommon).

Populations at risk include:

- Injection drug users (highly efficient mechanism for transmitting HCV);
- People who had a blood transfusion or invasive surgery prior to 1992;
- Hemodialysis patients and recipients of clotting factors made before 1987;
- Persons who are exposed to blood in health care or emergency service;
- People who have had unprotected sex with multiple partners, repeated sex with an infected partner, or a history of sexually transmitted diseases;
- Persons receiving or administering tattoos or another skin penetration; and
- Infants born to infected mothers.

Although the acute phase of hepatitis C generally has a mild presentation and many people have no symptoms, hepatitis C is much more likely than hepatitis B to lead to chronic liver disease. When symptoms do occur, they may be mild and indistinguishable from HAV or HBV. It is estimated that there are approximately 3.2 million HCV chronic carriers in the United States. Seventy-five percent of these infected persons have no symptoms and are unaware of their infection. Although the acute case fatality rate is low, 75 percent to 85 percent of infected persons develop chronic infection. As with Hepatitis B, chronic HCV carriers have the virus in their bodies and can continue to transmit the virus to others.

Still, most HCV infected persons have not been tested, and opportunities for preventive and therapeutic care are being lost. CDC estimates there are about 15,000 persons infected with hepatitis C in Illinois; about 5,000 chronic carriers are identified annually in Illinois.

No vaccine currently exists for HCV. Treatment is costly, causes difficult side effects and has limited effectiveness (less than 50 percent) in eliminating the virus and reducing liver injury. Some hepatitis C issues are particularly challenging: Prisons and jails throughout the United States have exceptionally high rates of infection and need to develop policies concerning diagnostic screening practices and the

availability of antiviral treatment for prisoners with hepatitis C. Insurance programs (including Medicaid systems and HMOs) are becoming increasingly burdened by the costs of HCV treatment and will be further challenged in the next 10-20 years by the costs of care for end-stage HCV-related liver disease.

Between 25 percent and 40 percent of persons diagnosed with HIV infection also suffer from hepatitis C. This combination of diseases poses very difficult problems for medical management.

Hepatitis C infects approximately 36,000 persons each year and is the leading cause for liver transplantation in the United States. Chronic hepatitis C is the cause of 8,000 to 10,000 deaths in the United States. each year.

- Chronic liver infection from hepatitis C occurs in 75 percent to 85 percent of persons infected; the remainder resolve their acute infections without further problems.
- Chronic hepatitis C infection is much more common in males than females.
- CDC estimates that there are about 15,000 Illinoisans infected with HCV annually.
- About 5,000 new chronic carriers between the ages of 30 and 59 are identified each year in Illinois, with between 99,863 and 150,903 persons known to be suffering from chronic hepatitis C infection.
- An estimated 20 percent to 40 percent of persons living with HIV also have hepatitis C. HIV/HCV infected persons have twice the risk of developing cirrhosis and a six-fold increased risk of liver failure as compared to those with HCV alone. Chronic liver infection with hepatitis C can complicate treatment with antiretroviral medication, anti-tuberculosis treatment, and other medications. HIV infection also can accelerate the progression of hepatitis C. Deaths from chronic hepatitis among patients co-infected with HIV are expected to increase as antiretroviral therapy is needed to extend their life span.
- Almost one of every three HIV-infected Illinoisans are also infected with the hepatitis C virus (HCV) and almost 45 percent of deaths occurring in this co-infected population are caused by liver damage from chronic hepatitis C infection.

Non-Hispanic blacks, American Indians and Alaskan Natives continue to have higher incidence rates of chronic hepatitis C infection than other groups.

- HCV infection is highest among African-American males aged 40-49 years (9.8 percent), while other prevalence rates include: non-hispanic blacks (3.2 percent), Mexican Americans (2.1 percent), and non-hispanic whites (1.5 percent).
- The percentage of African Americans (19.5 percent) reported in Illinois with chronic hepatitis C was higher in 2004 than the percentage of African Americans (14.7 percent) within Illinois' population.
- Although progression to cirrhosis appears to be lower among African Americans than non-African Americans, incidence of hepatocellular carcinoma is higher with African-American men, who have the highest age-adjusted incidence rate of hepatocellular carcinoma.
- Overall, African Americans have a two to three times greater incidence of mortality from hepatocellular carcinoma than Caucasians.

## **Burden of Chronic HCV Disease**

An estimated 3.2 million persons in the United States have chronic hepatitis C infection according to the CDC. In Illinois, reports of chronic hepatitis C have been collected since April 2001. The number of annual reports ranged from 3,896 in 2002 to 6,835 in 2006. It is believed that the reports of chronic hepatitis C greatly underestimate the true disease burden. According to the CDC, 1.6 percent of the U.S. population has been infected with the hepatitis C virus at some point in their lifetime (2); 15 percent to 25 percent of these persons resolve their acute infections without further problems. The remainder develops chronic hepatitis. According to that formula, the true disease burden of chronic hepatitis C in Illinois is between 99,863 persons and 150,903 persons. Hepatitis C is the leading indication for liver transplants and is the cause of 8,000 to 10,000 deaths in the United States each year.

**HCV-associated chronic liver disease is the most frequent indication for liver transplantation among adults.** Chronic hepatitis C infection is much more common in males than females. The percentage of African Americans (19.5 percent) reported with chronic hepatitis C during 2004 is higher than the proportion of African Americans (14.7 percent) within Illinois.

Other persons who have a higher burden of hepatitis C are those living with HIV. An estimated 20 percent to 40 percent of HIV infected persons also have hepatitis C. HIV/HCV infected persons have twice the risk of developing cirrhosis and a six-fold increased risk of liver failure as compared to those with HCV alone. Chronic liver infection with hepatitis C can complicate treatment with antiretroviral medication, anti-tuberculosis treatment, and other medications. HIV infection also can accelerate the progression of hepatitis C. **Deaths from chronic hepatitis among patients co-infected with HIV are expected to increase as antiretroviral therapy extends their life spans.**

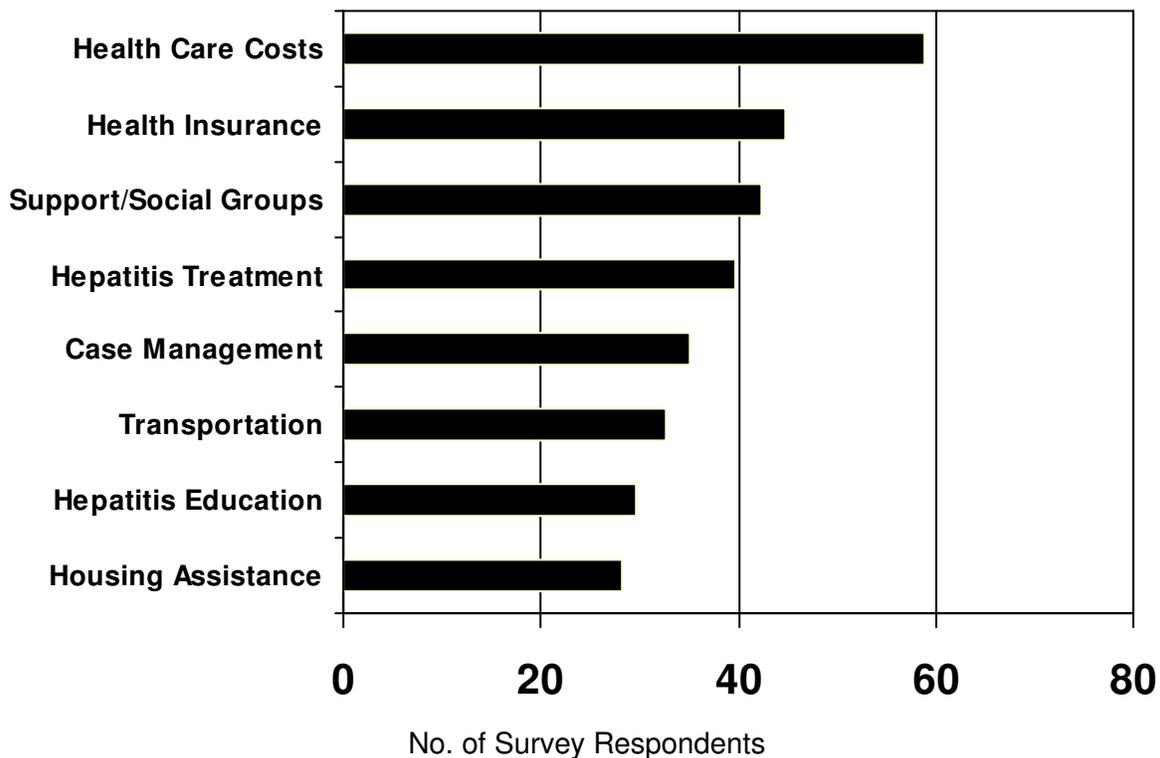
### The Strategic Planning Process

During the past three years, the Hepatitis Prevention Steering Committee met to initiate the development of a Statewide Strategic Plan for the prevention, control and medical management of hepatitis A, B and C. A viral hepatitis prevention needs assessment survey was developed and disseminated to service providers. A consumer survey was disseminated to hepatitis support groups across the state and three community forums to gather community input on gaps and barriers to hepatitis services was performed. The findings from the provider and consumer surveys and community forums follow.

### Hepatitis Provider Survey

In 2004, a survey was conducted among providers who were identified as providing care to individuals affected by, or at risk from, viral hepatitis. This survey was mailed to 529 providers across the state; 204 (39 percent) responded. These responses were from providers throughout Illinois and included providers from settings such as HIV, STD and immunization clinics, substance abuse treatment and correctional facilities, as well as medical providers. The survey provided information on the types of services available in the community, types of clients served, barriers to provision of services, and training needs.

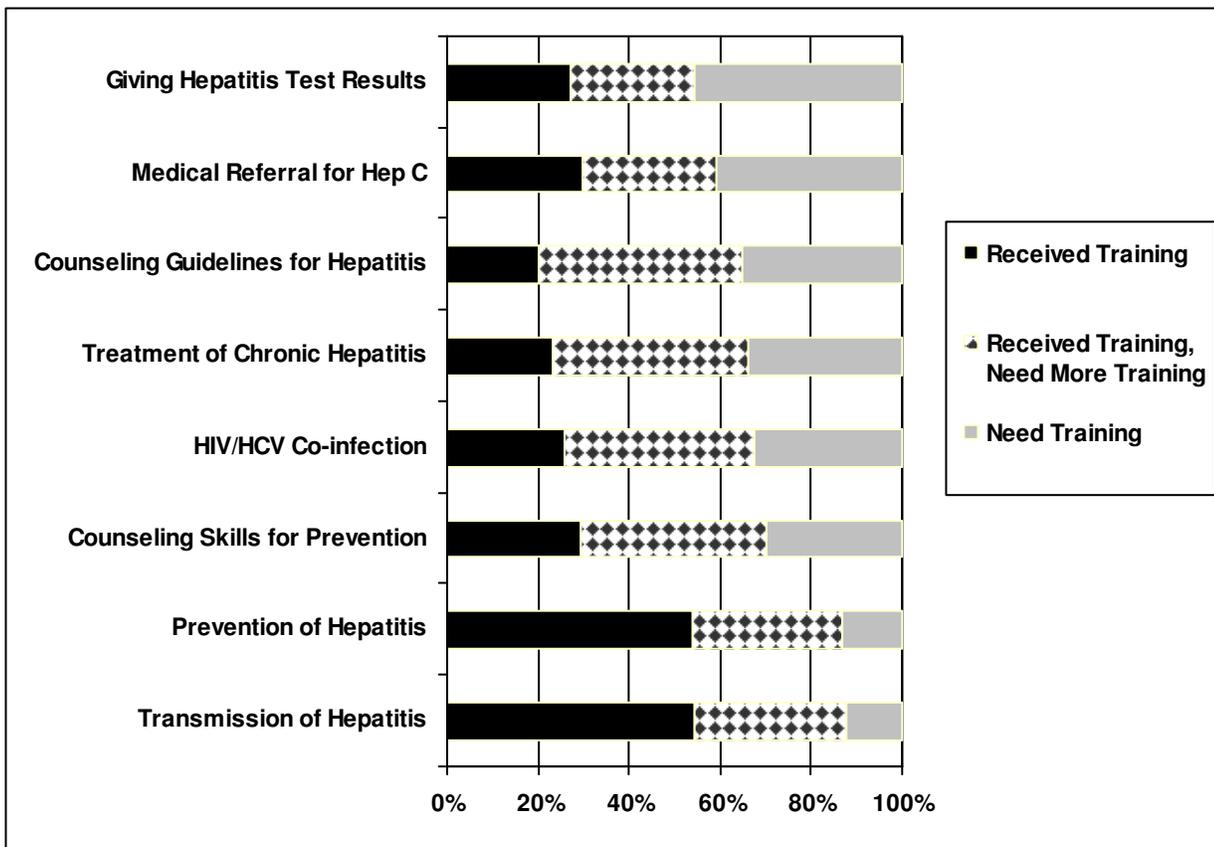
### Gaps in Services for People Living with Hepatitis C, Provider Survey—Illinois, 2004 (N=204)



In listing the service gaps for viral hepatitis in Illinois, survey respondents consistently mentioned:

- Inadequate access to care
  - Assistance with health care costs
  - Access to health insurance
- Lack of support for those living with hepatitis
  - Support/Social groups
  - Transportation
- Inadequate treatment or coordination of care
  - Hepatitis treatment
  - Case management

**Reported Training Needs for Hepatitis Providers, Providers Survey—Illinois, 2004 (N=204)**



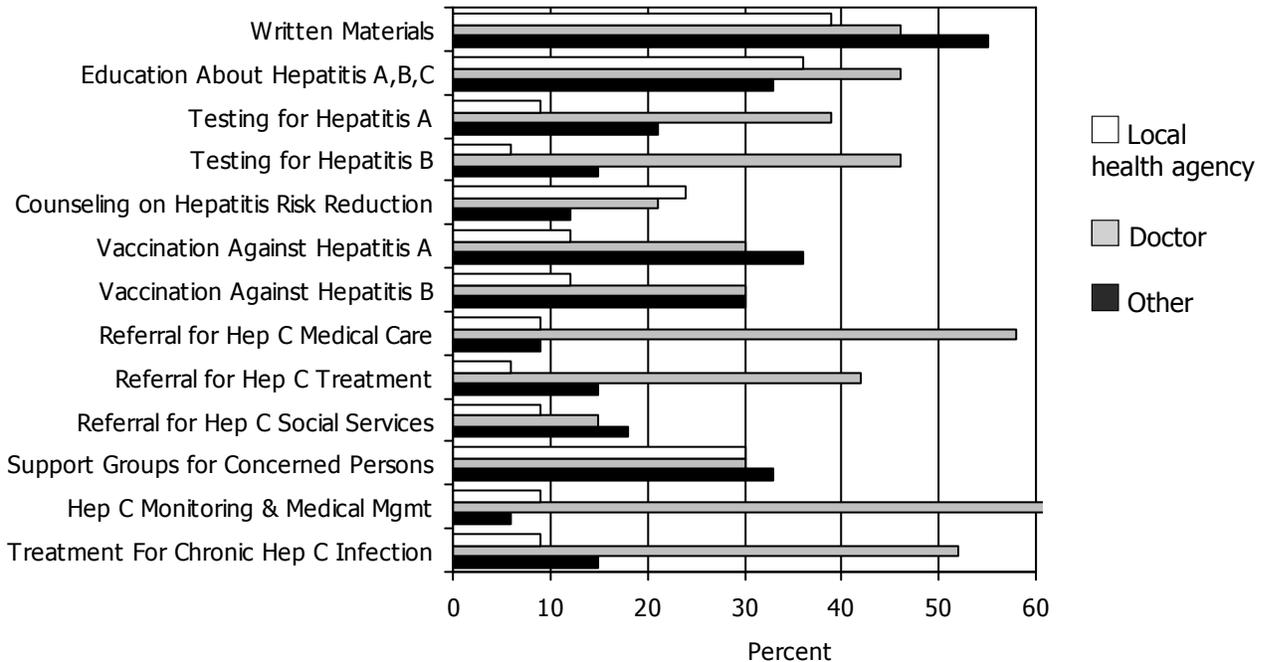
In detailing the barriers to integrating hepatitis prevention into their current program, survey respondents listed:

- Lack of agency resources
  - Categorical funding
  - Time spent with client
  - Hepatitis A/B vaccine
- Lack of knowledge
  - Client understanding of the risk of hepatitis
  - Provider knowledge of hepatitis
- Lack of community resources
  - Availability of testing or treatment in the community

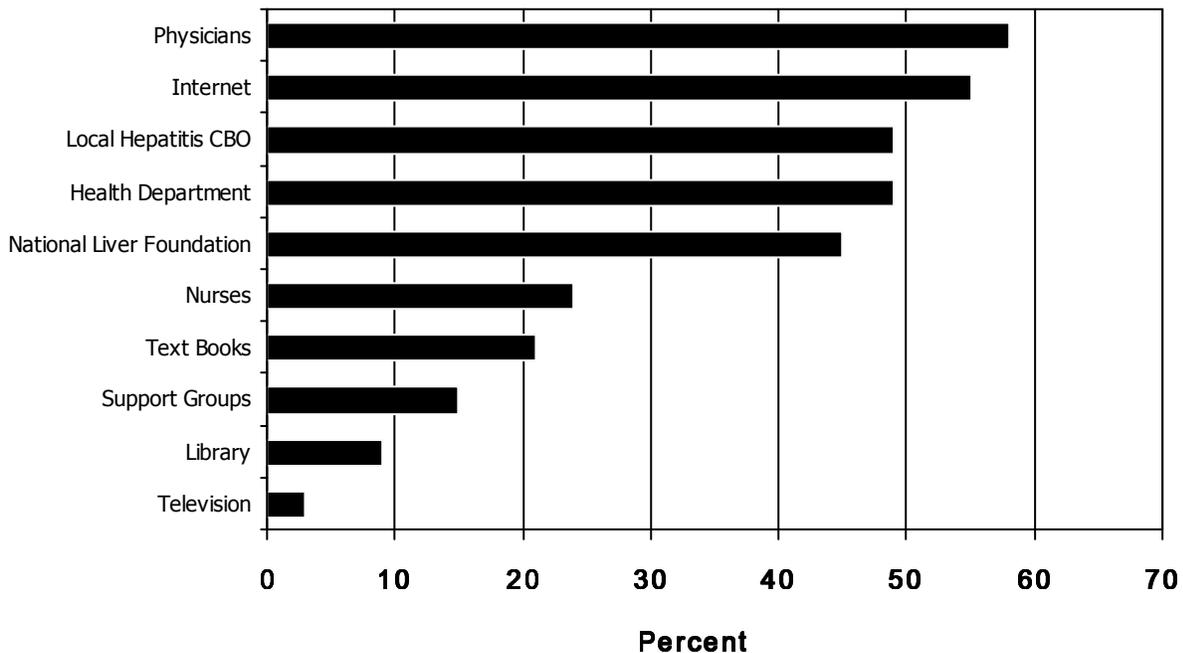
### Consumer Surveys

In 2004, a survey of community members impacted by hepatitis and participants of Illinois-based Hepatitis support groups was conducted. The following graphs summarize the survey results.

#### Where can you find hepatitis-related services - at a local health agency, health care provider, or some other source?

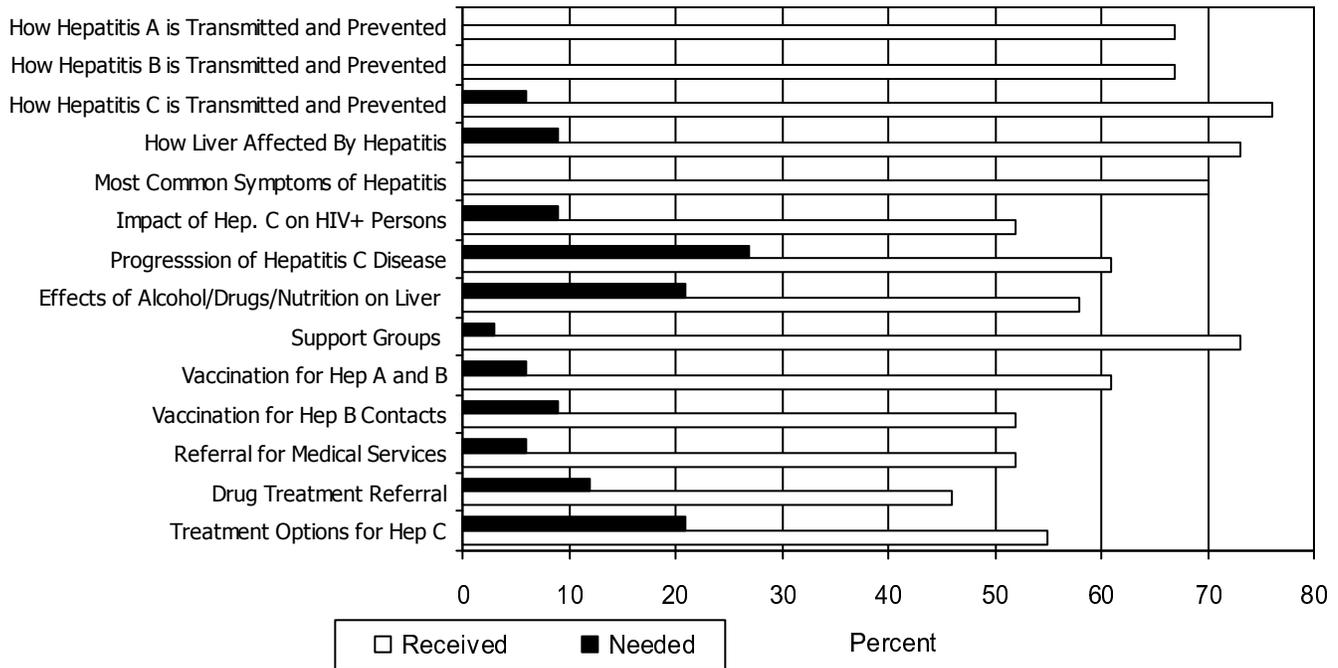


#### Where do you get your information on hepatitis?

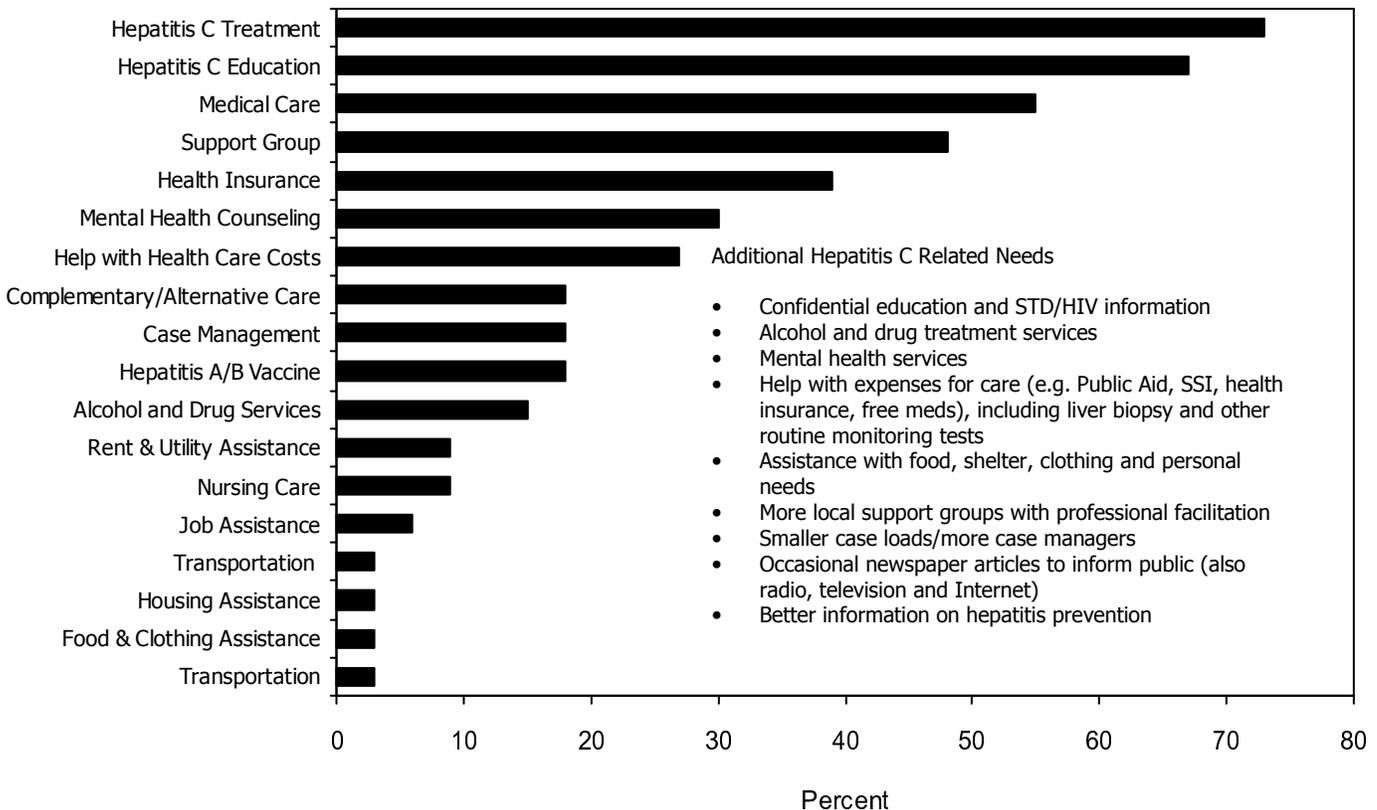


## Consumer Survey Results (continued)

### What information have you received/is still needed about viral hepatitis?



### What are the most important services for people living with Hepatitis C?



## Key Findings from Community Forums

Between December 2004 and June 2005, members of the Hepatitis Prevention Planning Committee held several community-based forums on hepatitis. These forums were advertised in local newspapers and held in public, handicapped accessible sites. The primary focus of the forums was to identify existing hepatitis-related awareness and medical services available within the community and to confirm unmet service needs identified in consumer and provider surveys completed during the summer of 2004. Forums were held in Springfield, Carterville/Carbondale, Aurora, Rockford and Chicago.

### The Top Three Unmet Needs, Which were Identified Within Each of the Forums, were:

Access to medical services for laboratory testing, vaccination and treatment  
 Educational programming for doctors and awareness campaigns for the community  
 Federal and state funds to support hepatitis prevention efforts

### Key Issues Identified at the Springfield Forum were:

Services Available	Services Needed
Support group held monthly in Springfield	Educational programming for doctors on medical management of chronic hepatitis infection
Vaccinations	Local doctors willing to accept referrals
Limited materials at health departments for hepatitis prevention and education	Support groups throughout central Illinois
	Funds to support increased access to treatment
	Community awareness campaign
	Transportation to medical care

### Factors Impacting Services Identified at the Springfield Forum:

- No community awareness about HCV
- Cost of treatment
- No doctor accepting uninsured patients or no doctor who can manage HCV infected clients
- Stigma experienced by persons impacted by hepatitis
- Poor surveillance and reporting of hepatitis C infections

### Top Three Priorities Identified at the Springfield Forum:

1. Educational awareness campaign for doctors and public
2. Increased availability of testing and prevention services
3. Funds to cover treatment

### Key Issues Identified at the Carterville/Carbondale Forum were:

Services Available	Services Needed
2 GI doctors in area, all other patients must drive to St. Louis	Access to treatment locally
	Access to testing locally
Health care workers vaccinated against hepatitis B	Educational programming for doctors on medical management of chronic hepatitis infection
Vaccinations available at local health departments	Support group(s)
	Local doctors willing to accept referrals
	Community awareness campaign
	Transportation to medical care

**Factors Impacting Services Identified at the Carterville/Carbondale Forum:**

- Cost of treatment
- More HCV infected clients than doctors can handle
- No educational programming for health care professionals and clients
- Local Medicaid provider (Harmony Card-HMO) does not provide hepatitis management/treatment
- Stigma experienced by persons impacted by hepatitis
- Lack all services in southern Illinois
- No community awareness about HCV
- VA medical services are hard to access/medical providers cannot refer unestablished veterans to VA system
- Compliance issue with drug users, providers unwilling to work with “unrecovered” patients

**Top Three Priorities Identified at the Carterville/Carbondale Forum:**

1. Access to free treatment services and routine monitoring and management
2. Access to free vaccinations services outside the health department
3. Access to testing services

**Key Issues Identified at the Aurora Forum Were:**

<b>Services Available</b>	<b>Services Needed</b>
Several local support groups hosted by the American Liver Foundation	Educational programming for doctors on medical management of chronic hepatitis infection
Vaccinations	More doctors willing to accept referrals
Limited materials at health departments for hepatitis prevention and education	Support groups throughout central Illinois
	Funds to support increased access to treatment
	Community awareness campaign
	Transportation to medical care
Some skilled doctors but unable to meet demands of increasing number of clients needing services	Education resource center
	Treatment for hepatitis
	Legislation to mandate and fund medical services to hepatitis-infected residents and education awareness of general public
	Hepatitis clinic or center
	Reimbursement for liver biopsy
	Free legal advice and assistance for filing work or disability
	Need guidelines for hepatitis management for doctors

**Factors Impacting Services Identified at the Aurora Forum:**

- Cost of treatment
- More HCV infected clients than doctors can handle
- Need more educational programming for health care professionals and clients
- Transportation
- Stigma experienced by persons impacted by hepatitis
- No community awareness about HCV
- Hospitals do not want Medicaid HMO (Harmony card)
- Little or no state or federal funding for services

**Top Three Priorities Identified at the Aurora Forum:**

1. Access to treatment, vaccination, and testing services
2. Increase public awareness of hepatitis through public service announcements
3. Increase availability of federal and state financial support for primary care for persons with chronic hepatitis infection

**In addition, there were forums hosted for sub-populations (persons attending Liver Foundation support groups, harm reduction groups, and from Chicago-based groups, which focused on health issues with the Asian, African, Hispanic and immigrant populations.)**

**Key Issues Identified at These Forums Were:**

<b>Services Available</b>	<b>Services Needed</b>
Support groups	Free testing for hepatitis B and C
Compassionate care programs offered by pharmaceutical companies providing access to expensive treatment(s)	More doctors, gastroenterologists, hepatologists, infectious disease specialists willing to treat patients
Needle exchange programs	Transportation to medical care
Liver Foundation	Social services skilled in addressing need of people with chronic hepatitis
Local health departments	
Hepatitis Foundation International	More support groups
Information on Internet	Treatment for under and uninsured
Limited access to vaccinations	Monitoring testing for under and uninsured
	More access to harm reduction services
	More access to vaccination(s)

**Factors Impacting Services Identified at these Forums:**

- No community awareness about HCV
- Cost of treatment
- No doctor accepting uninsured patients or no doctor who can manage HCV + clients
- No treatment options for people with no insurance
- Access to medical specialists within a reasonable time frame
- Stigma experienced by persons impacted by hepatitis
- Language barriers
- Limited access to vaccination services
- Lack of advocacy

**Top Three Priorities Identified at These Forums:**

1. Educational awareness campaign for doctors and public
2. Increased availability funds to defray costs of routine lab tests, liver biopsy, and additional procedures (scans) to monitor liver function
3. Funds to cover treatment