AAPCHO

Understanding and Combating Stigma

A Toolkit for Improving Care and Support for People Affected by HBV

Association of Asian Pacific Community Health Organizations
July 2017

About AAPCHO

Established in 1987, the Association of Asian Pacific Community Health Organizations (AAPCHO) is a national association of community health organizations dedicated to promoting advocacy, collaboration and leadership that improves the health status and access of Asian Americans, Native Hawaiians and Pacific Islanders in the United States and its territories.

Acknowledgements

We offer our sincere thanks to staff and volunteers at our partner organizations for contributing their time, expertise and insight to assemble this toolkit.

CONTRIBUTING REVIEWERS

Cathy Phan
Health Initiatives Project Manager, HOPE Clinic

Chari Cohen, DrPH, MPH
Director of Public Health Research, Hepatitis B Foundation

Grace M. Wang, MD, MPH, FAAFP
Family Physician, International Community Health Services

Janice Lyu, MS
Senior Hepatitis B Program Associate, Charles B. Wang Community Health Center

Karen Jiobu, DLM(ASCP)
Health Care Consultant, Asian American Community Services

Kate Moraras, MPH
Senior Program Director, Hepatitis B Foundation and Director, Hep B United

Paula Wong
Director of Educational Outreach, Project H+EAL, Hep Free NYC

Thaddeus Pham
Viral Hepatitis Prevention Coordinator, Harm Reduction Services Branch, Hawaii Department of Health

AAPCHO STAFF

Beverly Quintana
Communications Manager

Isha Weerasinghe, MSc
Director of Policy and Advocacy

Table of Contents

Introduction

About HBV

The hepatitis B virus (HBV) attacks and injures the liver causing hepatitis B, which is the most common serious liver infection in the world and is a global public health problem. Two billion people worldwide have been infected with HBV and more than 240 million people are living with a chronic hepatitis B infection. While preventable and treatable, hepatitis B has been dubbed a "silent epidemic" because most people do not have symptoms when they are newly infected or chronically infected. These statistics reflect the challenges health care providers and community health advocates face in combating this disease.

In addition to increasing the medical awareness about HBV, it is important to understand and address the socioeconomic factors that can impact the prevention or spread of the disease. Social determinants of health (SDOH) or the "conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life,"[1] such as stigma and discrimination, influence the health and well-being of individuals and communities.

Understanding the role of SDOH and that HBV not only impacts the lives of individuals but also of their families and communities is an important step in combating this disease. HBV affects everyone. We can all get HBV and stigmatizing those affected does not help or benefit anyone.

We all play a part in preventing stigma and discrimination associated with HBV, and can better work to improve the care and support for people affected by HBV.

HEPATITIS B IS PREVENTABLE AND TREATABLE.

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[1] World Health Organization: Social determinants of health. Available at: http://www.who.int/social_determinants/en. Accessed July 28, 2017.

HBV, Stigma and At-Risk Groups

Stigma and discrimination are SDOH that negatively affect the health and well-being of people living with or most vulnerable to HBV. HBV-related stigma refers to the devaluation of people living with or affected by HBV, or risk factors associated with acquiring the virus (e.g., race/ethnicity, sexual orientation). Negative attitudes (prejudice) and negative behavior (discrimination) follow stigma and often result in unfair and unjust treatment of people at risk for or living with HBV. HBV-related stigma contributes to keeping people from accessing prevention, care and treatment for the disease, and helps fuel the global hepatitis B epidemic.

In the United States, 1 in 20 people (12 million) has been infected with HBV. Nationally, Asian Americans and Pacific Islanders (AAPIs) account for more than 50 percent (1 in 12)[2] of roughly 2 million chronic HBV cases, and consequently have the highest rate of liver cancer among all ethnic groups. AAPIs from China, Vietnam and the Philippines are at particularly high risk for hepatitis B due to low infant immunization rates against the disease in those countries, and account for nearly 40 percent of all foreign-born persons living with hepatitis B in the United States.[3] Most AAPIs who have hepatitis B contracted it during childbirth from their mothers.

Also at high risk are immigrants from other countries with increased burdens of HBV, including other countries in Asia, Oceania (including Polynesia, Micronesia, Melanesia, and other Pacific Island regions), the Caribbean and sub-Saharan Africa. Other at-risk groups include HIV-positive persons, injection drug users (IDUs), household contacts or sex partners of persons with HBV infection, and men who have sex with men (MSM).[4]

Five Steps to Stop HBV Stigma

KNOW THE FACTS

Even if you know about HBV, make sure you understand how HBV is transmitted, who is at risk, and how effective care and support is implemented for people affected by HBV. ***Learn the facts and address the myths (Appendix 4).***

BE MINDFUL OF YOUR ATTITUDES AND BEHAVIOR

Prejudices and judgmental thinking about how those affected by HBV should not speak about their illness are learned and often commonplace. Family, friends, society and the media reinforce these attitudes and behaviors. ***We can change our thinking and recognize people not as labels but as unique individuals.***

CHOOSE YOUR WORDS WISELY

The way we speak can affect how other people think and speak. ***Use accurate and sensitive words when talking about people at risk for or living with HBV. Understand that they might not want to disclose their status, and try to understand why.***

EDUCATE OTHERS

Take opportunities to share facts and positive attitudes about people affected by HBV. ***If people present information that is not true, share correct information. Let them know that their negative words and misinformation affect people at risk for or living with HBV, and contribute to false notions.***

TAKE ACTION

Increase awareness about HBV-related stigma and how stopping it could benefit public health overall. ***If you witness a person living with or affected by HBV experiencing discrimination, speak up. We can help make sure that those affected by HBV are treated equally and with respect.***

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2. Hepatitis B Foundation: Facts and Figures. Available at: http://www.hepb.org/what-is-hepatitis-b/what-is-hepb/facts-and-figures. Accessed December 26, 2016.

3. Kowdley KV, Wang CD, Welch S, Roberts H, Brosgard CL. Prevalence of chronic hepatitis B among foreign-born persons living in the United States by country of origin. HEPATOLOGY 2012;56:422-433.

4. U.S. Preventative Services Task Force: Final Recommendation Statement, Hepatitis B Virus Infection: Screening 2014. Available at: https://www.uspreventiveservicestaskforce.org/Page/Document/RecommendationStatementFinal/hepatitis-b-virus-infection-screening-2014. Accessed December 26, 2016.

Combating HBV Stigma in a Health Care Setting

As trusted members of society, health care providers can play a key role in combating HBV-related stigma. In addressing stigma, providers can help improve care and support for people affected by HBV, and help reduce the global impact of hepatitis B beginning with the patients and communities they serve.

Stigma around HBV is often due to lack of awareness and misinformation (myths), fear, and association of hepatitis B with improper behavior. To combat HBV-related stigma in a health care setting, interventions must work both at the individual and institutional levels. Addressing HBV-related stigma at multiple levels will benefit both health care workers and HBV-positive patients.

There is increasing evidence of the benefits of supportive and integrative health care settings. Through the support and enabling services, or non-clinical services such as housing, transportation and translation support, they receive at health care settings, people at risk for or living with HBV can be empowered to get involved in their broader community and to challenge stigma elsewhere where it may occur. In confronting stigma and ensuring that people affected by HBV can participate and contribute equally in society, health care providers can help bring an end to hepatitis B. Module E includes exercises for understanding and combating HBV stigma in a health care setting.

How to Use this Toolkit

This toolkit is written for health care providers and community health advocates who want to improve the care and support for people affected by HBV. The aim of this toolkit is to support you and anyone you are working with to confront and reduce the stigma associated with HBV, and to promote increased prevention, care and treatment of hepatitis B. Anyone can get HBV. We need to work together to promote understanding and action to combat HBV-related stigma and discrimination to combat this disease.

While this toolkit is primarily designed to help you plan and organize exercises for other individuals and organizations working with people affected by HBV, it also includes exercises to help you understand your individual relationship with HBV-related stigma. Before educating the community, we need to look at our own attitudes, language and relationships, and get a better understanding of stigma. These exercises are designed to help us check our own behavior and attitudes first, particularly as we work with individuals, families and communities affected by HBV.

We hope that this toolkit will be helpful in your efforts to promote understanding and action to combat HBV stigma and discrimination. HBV is a significant problem within many communities. With increased awareness and in working together, we can promote better care and support for people living with or affected by HBV, and more effectively work towards eliminating hepatitis B for future generations.

PARTICIPATORY LEARNING

Changing attitudes around HBV stigma requires more than giving people information through lectures and reports. This form of change happens best when people figure things out for themselves.

The exercises in this toolkit are designed to get participants learning through doing, including: sharing feelings, concerns and experiences; discussing and analyzing issues; solving problems; planning and taking action.

The process of helping health care providers, other individuals, and organizations working with people affected by HBV understand and challenge stigma needs to be participatory. Engaging people in the process of creating a safe space where they can express their fears and concerns, freely discuss sensitive and taboo issues, and clear up misconceptions, helps to foster understanding and attitude change to better challenge HBV stigma.

PICK AND CHOOSE

This toolkit includes modules with participatory learning exercises. Choose the exercises you need for your purposes and your target groups. Select and adapt the materials in this toolkit to suit the individuals and organizations you are working with. We know that not all of these modules may be applicable to your clinic, practice or experience.

START WITH YOURSELF

Use this toolkit to first reflect on your own attitudes, values, language and behavior towards people living with or affected by HBV before you try to educate others.

WHAT IS THIS TOOLKIT?

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- This toolkit is a collection of participatory educational exercises for use in raising awareness and promoting action to challenge HBV stigma. Health care providers, and other individuals and organizations working with people affected by HBV can select modules and exercises to plan their own curriculum for different target groups.

- The exercises in this toolkit use a learner-centered, participatory approach, built around discussion and small group activities. The aim of these exercises is to facilitate open discussion on HBV-related stigma and what we can do to promote a change in attitude and practice.

WHY WAS THIS TOOLKIT DEVELOPED?

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- This toolkit was developed to provide people working with patients and others affected by hepatitis B with a set of modular, easy-to-use educational materials to raise awareness about HBV-related stigma and discrimination. The aim is to help people at all levels and across all sectors to understand HBV-related stigma—what it is, why it is important, what its root causes are—and to develop strategies to challenge it.

- We hope that this toolkit will help you promote a safe space where people at-risk for or living with HBV can: talk about their fears and concerns about hepatitis B; look at the roots of stigma and how it affects them, their families, children and communities; examine attitudes and judgmental habits; and develop strategies and skills to confront stigma and discrimination in different settings.

WHO CAN USE THIS TOOLKIT?

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Anyone can use this toolkit. You might be a:

- HBV health care provider or educator – Someone who provides health care services or conducts health educational sessions for community groups/other practitioners, or provide individual or group counseling on HBV issues.

- Community member or part of a community group that HBV providers and educators work with – Someone who is part of a community-based organization such as youth groups, churches, family support groups, etc.

- Someone living with or who knows someone who is affected by HBV (partner, child, parent or friend).

- Someone who can use the materials in this toolkit to adapt them for use to train other groups (media, policymakers, other community based organizations, etc.).

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Source: *Exercises included this toolkit are in the process of being pilot-tested. Exercises have been adapted from 1) Ross Kidd and Sue Clay, "Understanding and Challenging HIV Stigma: Toolkit for Action," International Center for Research on Women, September 2003 and 2) Beri Hull, Amy Kay, Shetal Datta, Rita Wahab and Eman Said, "HIV Principles and Stigma Reduction Training Curriculum: Addressing HIV and Stigma in the Healthcare Setting in the Middle East and North Africa Region," U.S. Agency for International Development, July 2010.*

MODULE A

Understanding and Confronting Stigma

This module takes people through their own experience of being stigmatized and stigmatizing others. The aim is to get people to understand and confront stigma not only on a theoretical level (through a definition) but also personally and emotionally. In helping participants connect directly with how stigma affects people through their own experience, they can more fully understand and empathize with how stigma can isolate or exclude—and how it can be harmful to mental health and public health overall.

Exercises in this module aim to get participants learning through doing to understand what stigma means for people:

- What are the forms of stigma? What does it look like (our attitudes, language, and behavior)?
- What are the effects of stigma—on people living with HBV, families, communities, and people's access to health services, etc.?
- What are the root causes of stigma? Exercises explore the forms, effects and root causes of stigma.

Causes, Forms and Effects of Stigma

MAIN CAUSES OF STIGMA INCLUDE:

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- Lack of knowledge, misbeliefs and fears about what HBV is and how HBV is transmitted
- Fears about death and disease
- Judgments about improper behavior of people living with HBV (prejudice and assumptions of sexual promiscuity, drug use, etc.)
- Not recognizing the presence and impact of stigma on affected individuals

DIFFERENT FORMS OF STIGMA INCLUDE:

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Social and perceived/self-stigma. Both forms can exhibit themselves in the following ways -

- Discrimination and loss of rights and decision-making power
- Physical and social isolation from family, friends and community
- Gossip, name calling and condemnation
- Perceived/Self-stigma—people living with HBV blaming and isolating themselves
- Stigma by association—family or friends of person living with HBV affected by stigma
- Stigma by looks/appearance/type of occupation

THE EFFECTS OF STIGMA INCLUDE:

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- Lacking self-worth and despair (can lead to depression, suicide, alcoholism, etc.)
- Being kicked out of family, house, job, rented accommodation, organization, etc.
- Dropping out from school due to bullying
- Creating climate of fear that contributes to keeping people from seeking prevention, care and treatment, which leads to poor health outcomes, miseducation, lack of awareness, and continued spread of HBV

WE ALL STIGMATIZE

We stigmatize when:

- We say things like "she was promiscuous" and "he deserves it;"
- We do things such as isolating people living with and affected by HBV, and by excluding them from decision-making, etc.; and
- We don't speak up when we witness a person living with or affected by HBV experiencing discrimination.

Exercise A1 - Stigma Through Pictures

OBJECTIVES :

Participants will be able to:

- Identify types stigma, different forms and in different context
- Identify how stigma affects people living with HBV

TIME :

1 hour

MATERIALS :

- Selection from stigma pictures (Appendix 1)
- Notepads
- Flipchart sheets
- Pens and markers

ACTIVITIES

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Breakout Groups:

- Divide participants into groups of 2-3 people.
- Ask each group to select one of the pictures.
- Ask the group to write down notes to answer and discuss, “What do you see in the picture? How does this picture show stigma?”

Report Back:

- Put up one picture at a time and ask respective groups to present their highlights from their breakout group discussions.
- Record major points on flipchart sheets and have one other recorder take notes of common points that will be summarized and shared with all participants at the end.

Summary:

Forms of stigma:

- Isolation, insults, judging and blaming
- Perceived/Self-stigma—people living with HBV blaming and isolating themselves
- Stigma by association—family or friends of person living with HBV affected by stigma
- Stigma by looks/appearance/type of occupation

Exercise A2 – Stigma Tree: Forms, Effects and Causes

OBJECTIVES :

Participants will be able to:

- Identify different forms of stigma and how stigma affects people
- Identify some of the root causes of stigma

TIME :

1-2 hours

MATERIALS :

- Tree wall diagram/cutout
- Post-it notes
- Pens and markers

ACTIVITIES

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- Ask participants to divide into pairs.
- Hand out post-it notes and markers, and ask participants to record forms, effects and causes of stigma.
- Ask participants to place post-it notes on the tree wall diagram/cutouts as follows::
  - Forms – on the tree trunk
  - Effects – on the tree branches
  - Causes – on the tree roots

Debrief:

- Review one level at a time.
- Cluster common points and combine duplicates.
- Spend some extra time talking participants through the different levels of effects—direct impact (e.g., isolation) and indirect impact (e.g., job loss) on people living with HBV..
  - If there is extra time, ask participants, “What are the effects on the family/friends/community?”

HBV STIGMA EXAMPLES

FORMS

Name calling; scapegoating; finger pointing; teasing; social media/ cyber bullying; labeling; blaming; shaming; judging; gossiping; making assumptions; suspecting; neglecting; rejecting; isolating; not sharing utensils; staying at a distance; harassment; physical violence; abuse. Self-stigma: blaming and isolating oneself; stigma associated with cultural practices (for example how the disease is perceived in country of origin compared to how it is perceived in the United States). Stigma by association: whole family or friends also affected by stigma. Stigma by looks/appearance.

EFFECTS

Shame; denial; self-isolation; loneliness; neglect; loss of hope; depression; alcoholism; isolation. Self-rejection; self-blame; self-pity; self-hatred; anger; violence; withdrawal from public activities (e.g., church membership); become very quiet; commit suicide or start thinking about suicide; feel unproductive/useless/not contributing; forced to leave family, community or job; loss of promotion, scholarship opportunities, rented accommodation; decline in school performance or dropout from school; abuse or poor treatment by relatives; deprived of medical care; reluctance to take medication, no treatment; spread of infection.

CAUSES

Morality: View that people living with HBV are sinners, promiscuous, unfaithful. Fear: fear of infection, the unknown or death. Lack of knowledge and misconceptions makes people fear physical contact with people living with HBV. Inferiority and superiority complex. Marginalized and underserved populations are often more stigmatized (e.g., people of color, women, people living in poverty).

Exercise A3 – Our Experience as Stigmatizer and Stigmatized

OBJECTIVES :

Participants will be able to:

- Describe their personal experiences with stigma
- Identify some of the feelings involved in being stigmatized or stigmatizing others

TIME :

1-2 hours

MATERIALS :

- Notepads
- Pens and markers

ACTIVITIES

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I. OUR EXPERIENCE OF BEING STIGMATIZED

- Ask participants to sit on their own.
- Then ask participants to, “Think about a time in your life when you felt isolated or excluded for being seen as different—or when you saw other people treated this way.”
    - Explain that, “This does not need to be examples of HBV stigma and it could be any form of isolation or rejection for being seen as different.”
    - Ask them to think about, “What happened? How did it feel? What impact did it have on you?”

Share in Pairs:

- Ask participants to, “Share your experience with someone who you feel comfortable.”

Report Back:

- Invite participants to share their stories with the large group. Make sure that they know sharing is not mandatory and that they can share only if they feel comfortable.

Role Play:

- Invite some participants to act out their stories with other participants playing the other roles.
- At the end of each scene, ask the role players, “How did you feel to be stigmatized?”

II. OUR EXPERIENCE OF STIGMATIZING OTHERS

- Ask participants to sit on their own.
- Then ask participants to, “Think about a time in your life when you isolated or excluded other people for being different.”
    - Ask them to think about, “What happened? How did you feel? What was your attitude? How did you behave?”
- Then ask participants to write down any thoughts, feelings or words that they associate with stigma.

Report Back:

- Ask each participant to read their list out loud and record the points.
- Then discuss, “What feelings are associated with stigma?”

Summary:

- Everybody has felt isolated, treated like a minority at some point in their lives.
- This is ok to feel like that because you are not alone—we have all experienced this sense of exclusion.

MODULE B

More Empathy and Less Fear

HBV KNOWLEDGE GAPS INCLUDE:

- How HBV is transmitted and not transmitted;
- Who is at risk; and
- That people living with or affected by HBV can and have a right to contribute and take equal part in society.

Stigma around HBV is often due to lack of awareness, fear, and association of hepatitis B with improper behavior. Most people have some information about hepatitis B but fewer have enough knowledge to counter myths and misconceptions. For example, most people know that HBV can be transmitted through unprotected sex, but less know that it can't be transmitted through casual (non-sexual) contact like touching doorknobs or sharing food.

Lack of accurate information often leads to a climate of fear that contributes to the cycle of stigma, which then serves to fuel the global hepatitis public health problem. Discrimination follows fear and stigma, resulting in the unfair and unjust exclusion of people living with HBV. For example, people living with HBV may be unnecessarily isolated from others in a separate room or even denied health services.

However, knowing the facts is only part of the process of increasing empathy and understanding to improve care and support for people affected by HBV. People may know the basic facts about HBV but may still not believe them. Prejudices and judgmental thinking are learned and often commonplace, and family, friends and the media often reinforce these attitudes and behaviors.

People need more than facts to truly own or internalize accurate knowledge of HBV and overcome their misconceptions and fears. To gain genuine understanding, people need to learn by doing—to compare, test and question the information they have heard with their own experience, beliefs and common sense.

Educational Process: From Fear to Understanding

- Create a safe environment for participants to raise all of their fears, concerns, and questions about HBV
- Assess knowledge: Find out what participants know and don't know about HBV
- Provide accurate information to address fears and challenge popular misconceptions (Appendix 4)
- Emphasize common sense around safety and hygiene (e.g., we don't share needles with other people, we don't eat from a plate that has blood on it)
- Provide information in a participatory learning process to allow people to internalize the information—to discuss it with their peers, and connect it to their own ideas and experiences.

FROM FEAR TO UNDERSTANDING

- Not internalized and rote knowledge
- Popular misbeliefs
- One way communication

- Internalized and applied knowledge
- Accurate beliefs
- Interactive and experience-based learning

Exercise B1 – Assessing Our Knowledge Levels

OBJECTIVES :

Participants will be able to:

- Identify what they know and don’t know about HBV

TIME :

1 hour

MATERIALS :

- HBV Quiz (Appendix 3)
- Flipchart sheets
- Pens and markers
- Tape

ACTIVITIES

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I. TAKE ONE STEP FORWARD

- Ask participants to stand against one side of the room.
- Then ask, “True or false, HBV can be transmitted through hugging? Take one step forward if true, or stay in place if false.”
- Continue this process, asking new true or false statements each time. For each topic, ask one person to explain what they know about the topic.
- After several rounds, stop and discuss with participants what they know and don’t know about HBV.

II. RISK CONTINUUM

- Put up four flipchart paper on the wall and write down a risk level at the top of each sheet:
    - Higher Risk
    - Lower Risk
    - No Risk
- Hand out 2-3 HBV Transmission Risk Cards to each participant and ask them to tape their cards under a chosen risk level (the cards and risk levels are listed in the table below).
- When all participants are finished, come back together as a group and discuss their choices, moving incorrectly placed cards to their correct risk level.

RISK CONTINUUM EXAMPLES

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Risk Level	Ways HBV Can Be Transmitted
HIGER RISK	Having sex without a condom; having a baby when infected with HBV without treatment and prophylaxis; tattooing with an unsterile needle; sharing a razor, nail-clipper, earrings or toothbrush with an infected person (through direct contact with blood or open sores of an infected person)
LOWER RISK	Having sex with a condoms; some instances of babies receiving pre-chewed food from someone with HBV[5]
NO RISK	Kissing; hand holding; coughing; hugging; shaking hands; sneezing; sharing water, food or eating utensils; eating food prepared by someone with HBV; sharing sheets, towels or clothing; using toilets; sleeping in room with a person living with HBV; bites from mosquitoes or fleas; using the same pool or hot tub; touching doorknobs; sharing pens/pencils; using the same washer/dryer; sharing a computer or using the same phone

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5. Centers for Disease Control and Prevention, Can Hepatitis B be spread through food?, https://www.cdc.gov/hepatitis/hbv/bfaq.htm#bFAQ12a (accessed July 28, 2017).

Exercise B2 – Talking About and Addressing Our Fears

OBJECTIVES :

Participants will be able to:

- Articulate their fears about HBV
- Explain how these fears affect how they respond to people living with HBV

TIME :

1-2 hours

MATERIALS :

- Post-it notes
- Pens and markers

ACTIVITIES

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- Hand out post-it notes and ask participants to write down their three greatest fears about HBV and put them up on the wall. Cluster common points.
- Divide into pairs and ask participants to discuss, “How do my fears affect the way I feel and treat people living with HBV?”

Examples of Our Fears About HBV	Examples of How Fears Affect Our Behavior and Attitudes Toward People Living with HBV
Getting infected; dying; blame, shame and isolation; the unknown; infecting my partner; divorce or separation; losing friends; losing my job; a friend getting sick and dying; no chance to have children; getting HBV from taking care of someone else; leaving my children as orphans; being a burden to my parents/family if I get sick.	I separate the dishes used by my mother who is sick; I avoid using the same toilet as someone who might be infected; I don’t let my son play with our neighbor’s daughter; I avoid hugging my friend who is sick; we serve my brother’s meal in a separate pot from the rest of the family; I tell the student/patient to sit in a separate room from the other students/patients; I refuse to have sex with my partner.

Summary:
Thank participants about being open about their fears and how they affect their behavior and attitudes toward people living with HBV. Explain that these fears are natural and we all have them (they are rooted in basic fears of “contagion”), but that fear is a major part of stigma and causes us to instinctively—and often unfairly and unjustly—isolate and exclude people living with HBV.

Fear leads to stigma, and stigma leads to the discrimination of people living with HBV. Fear can stop us from being rational and finding or believing accurate facts, or it can lead us to accept incorrect information and believe in myths and misconceptions. It is important for us to talk about and address our fears about HBV so that we can all combat stigma, and help improve the care and support for people affected by HBV.

Exercise B3 – Fears About Casual Contact

OBJECTIVES :

Participants will be able to:
- Name their fears in relation to forms of casual contact with people living with HBV
- Identify why they think that HBV can be transmitted through those activities

TIME :

1 hour

MATERIALS :

- Hepatitis B – General Information Fact Sheet (Appendix 2a)
- Post-it notes
- Pens and markers

ACTIVITIES

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- Divide into pairs and ask participants to discuss, “What fears do you think people have about casual contact with people living with HBV at home or at work?”
- Ask participants to write down their answers on post-it notes and put them up on the wall.

Role Play:
- Ask pairs to choose one example of the fears on and make a role play about how people stigmatize because of this fear of casual contact with people living with HBV.
- Ask pairs to present their role plays to the full group and after each ask:
  - “What happened?”
  - “Why do people think that form of contact will lead to HBV infection?”

Discussion:
- Take each example and why people think HBV can be transmitted that way.
- Review the fact sheet and discuss why HBV can’t be transmitted through casual contact.

Examples of common fears about casual contact with people living with HBV:

- Eating a communal meal in a common pot with a family member who is living with HBV
- Contact with blood when I am helping to wash a family member who is living with HBV
- When a friend or family member who is living with HBV cuts themselves by accident and blood gets on food
- People living with HBV holding or playing with children
- Sharing toilets with people living with HBV (virus/germs in toilet)
- Shaking hands with people living with HBV (HBV in sweat)

MODULE C

“Us” vs. “Them”

Diseases are often associated with shame and blame, leading to stigma and discrimination of people living with the disease, and creating a dynamic of “us” vs. “them” where “them” or the “other” are people living with HBV. Because HBV can be transmitted sexually or through contaminated needles, it can be associated with “bad behavior” by the affected individuals. Another common misconception about HBV is that it is passed on genetically and so families with a member living with hepatitis is considered to have “weak genes” and may be seen inferior within their community.

Exploring the real and perceived links between sex, drugs, morality and disease is critical in understanding and challenging stigma associated with HBV. This module aims to tackle these difficult and often taboo subjects, and explore ways to disentangle them from the disease to improve care and support for people at-risk for and living with HBV.

Exercise C1 – We Are All in the Same Boat

OBJECTIVES :

Participants will be able to:

- Warm-up and get comfortable with each other, while recognizing that we can all get HBV and
- That stigmatizing those who are at-risk or living with HBV doesn't help or benefit anyone.

TIME :

15 minutes

ACTIVITIES

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- Ask participants to stand in a line facing the same direction.
- Then explain the game: "We are all standing on a riverbank. When I say,
  - "In the river" – take one step forward,
  - "On the river" – don't move,
  - "On the bank" – take on step back, and
  - "In the bank" – don't move.
  - If anyone makes a mistake, they will be out of the game.
- Start the game. Give the commands quickly and ask anyone who makes a mistake to leave the game.
- After a few rounds, stop and debrief with the group.

Debrief:

- Note that everyone laughed when someone made a mistake and was out of the game.
- Ask the people who made the mistakes and had to leave the game, "How did that make you feel?" Examples: I felt embarrassed/frustrated/angry/stigmatized. The laughter made me fell self-conscious or bad.
- Explain that this game illustrates how "we are all in the same boat."
  - We are all facing and living with the HBV epidemic together, and there is no "us" vs. "them."
  - We are all affected and we have all taken risks or made mistakes at some point in our lives.
  - We all have a friend, family member or know someone who is at-risk for, living with or have died of HBV.
  - People often like to judge people affected by HBV, but one day you may "fall into the river" and experience the same shame and blame..
- <u>HBV affects everyone.</u> We can all get HBV and stigmatizing those affected doesn't help or benefit anyone.

Exercise C2 – Things People Say

OBJECTIVES :

Participants will be able to:

- Identify labels used by people to stigmatize people living with HBV and other stigmatized groups
- See that these words and labels hurt

TIME :

1-2 hours

MATERIALS :

- Role cards and container (e.g., hat, small box) to pull cards out of
- Flipchart sheets
- Pens and markers

ACTIVITIES

-

I. CALLED OUT CHAIRS GAME

- Set up chairs in a circle around the room. Ask participants to draw a role card from the container: "Person living with HBV, gay man, immigrant or refugee, sex worker, drug user."
- Ask participants to sit in a chair and explain the game:
  - I am the *caller*. I don't have a chair.
  - When I call out two roles, for example "Person living with HBV" and "sex workers", all "people living with HBV" and "sex workers" stand up and run to a new chair.
  - I will grab a chair and the person without a chair becomes the new caller.
  - The new caller calls out two more roles and we continue the game.
- Play a few rounds of the game and then stop to debrief.

Debrief:

- Ask the group, "How did it feel to be called 'person living with HBV,' 'sex worker,' etc.?"

II. THINGS PEOPLE SAY

- Put up five flipchart papers on the wall and write down a role at the top of each sheet.
- Divide into five groups based on the roles assigned from the game ("Person living with HBV, gay man, immigrant or refugee, sex worker, drug user") and ask each group to go to their flipchart station.
- Ask each group to write on their flipchart, all the things people say about those in the group.
- After two minutes, say "change" and ask groups to rotate to another station.
- Continue until all groups have contributed to all five flipcharts and come back to their original station.

Report Back:

- Walk as a group around the room looking at the flipcharts. At each flipchart ask,
  - "How do you, the [group role], feel if you are called these names?
  - In what situations do these comments hurt the most?
  - What are the judgments or assumptions behind some of these labels?

Breakout Groups:

- Review the lists of characteristics (see examples above) and ask groups to discuss:
  - What is the impact on people affected by HBV if these are the commonly believed labels and images of people at-risk for or living with HBV? If the effects are negative, what can we do to help change these effects?

THINGS PEOPLE SAY EXAMPLES
-

Labels/Images:	Effects:	How to Change:
Promiscuous; sinners; careless/reckless.	Shamed and blamed, and condemned by society.	Remind others that we are "all in the same boat" and we all put ourselves at risk or at some time point in our lives.
Burden; useless; lazy or no longer productive; waiting to die.	Treated as no longer being able to contribute.	Educate that people at risk for or living with HBV can contribute. Empower and promote opportunities for people affected by HBV to participate equally in society.
Dangerous; disease carriers; they can infect other people through touch.	Prejudice and discrimination, isolated and excluded.	Educate people with accurate information about why some groups are at a higher risk for HBV, and about how HBV is transmitted and not transmitted.

Exercise C3 – Sex: Breaking the Ice

OBJECTIVES :

Participants will be able to:

- Talk more openly about sex and their feelings about sex
- Recognize that the view that “SEX = SIN” is one of the roots of stigma

TIME :

1-2 hours

MATERIALS :

- Flipchart sheets
- Post-it notes
- Pens and markers

ACTIVITIES

-

I. SEX: BREAKING THE ICE – OUR IMAGES OF SEX

- Put up a flipchart on the wall and write “SEX” at the top of the sheet.
- Hand out post-it notes and pens/markers to participants and ask them to write the first thing they think about when they hear the word “sex.”

Debrief:

- Ask the group, “What does this tell us about how people think about sex?”

EXAMPLE

Sin **Love**

Forbidden **SEX** **Immoral**

Intimacy **Disease** **Fun**

ACTIVITIES CONT'D

-

II. GOOD (SINLESS) SEX VS. BAD (SINFUL) SEX

- Break out in pairs. Hand out post-it notes and ask pairs to write examples of “good” sex and “bad” sex.
- Put the post-it notes on the wall in two columns next to each other (see examples below).

Good (Sinless) Sex	Bad (Sinful) Sex
• Sex with spouse • Sex for procreation • Sex after you get married • Sex at night • Sex without a condom • Sex with the opposite sex	• Sex with sex worker • Sex for pleasure • Sex before you get married • Sex any time of the day • Sex with a condom • Sex with the same sex (gay sex)

Summary:
Although we are aware of these judgments, many of us do have “sinful” sex, even though we may keep it hidden. Sometimes we feel ashamed and are not able to discuss sex more openly, leading people to take more risks. These judgments about sex and sin can fuel stigma against people living with HBV and is harmful to public health overall.

MODULE D

Understanding Stigma in Your Family and Community

Family relationships and ties within the broader community can be closely linked to sources of HBV stigma. Family members, friends, neighbors and community members may cause some forms of stigma, not knowing how to care or how best to support those living with HBV. This, coupled with misinformation or fear can lead to stigma, leading to individuals living with HBV being blamed, targeted and otherwise discriminated against.

Caring for and supporting family members, friends, neighbors and community members living with HBV is an area that needs much more awareness and education. To better manage and address HBV in the household and broader community, people need skills, understanding, and external support (access to quality, affordable, and culturally and linguistically appropriate health care services).

We hope this module will be helpful in starting conversations between those who are living with HBV and their family, friends, neighbors and community, and in leading to more knowledge and information sharing that will help reduce stigma.

Exercise D1 – Stigma in the Household

OBJECTIVES :

Participants will be able to:

- Understand forms of stigma in a household with a person living with HBV
- Identify ways to address stigma and create a healthier and more supportive household environment

TIME :

1 hour

MATERIALS :

- Selection from stigma pictures (Appendix 1)
- Notepads
- Pens and markers

ACTIVITIES

-

Breakout Groups:

- Divide participants into groups and give each group a picture.
- Ask the group to write down notes to answer and discuss:
    - “What do you see in the picture? What do you think is happening? Does this happen in your family/household?
    - How does it affect you? How does it affect the people living with HBV in your house?
    - What can you do to address this stigma and create a more supportive household?
    - As a person living with HBV, how would you want your family members to treat you and make you feel comfortable?
- Report back to the group.

Summary:

Explain how stigma in the family/household takes many forms including isolation, blaming, and judging those living with HBV. The first step to combatting stigma is to identify and acknowledge it, then work together to solve it.

Some examples of stigma in the household:

- Separation of utensils—plates, cups, spoons.
- Burn or discard clothing and other things used by person living with HBV
- Physical isolation (e.g., forced to sleep alone or in a separate room).
- Minimum physical contact. No hugging. Told not to touch/play with children.
- Treated as a burden (e.g., extra money needed for treatment, extra time for care and management).
- Judging. Blaming. Condemning. Made to feel s/he has disgraced family.
- Partners/spouses of people living with HBV are assumed to be HBV positive.
- In-laws blame spouse for HBV (HBV exaggerates tensions with in-laws).

Exercise D2 – Stigma from Neighbors

OBJECTIVES :

Participants will be able to:

- Describe how neighbors react to households or people affected by or suspected of being affected by HBV
- Develop strategies to address stigma and educate neighborss

TIME :

1 hours

MATERIALS :

- Selection from stigma pictures (Appendix 1)
- Notepads
- Pens and markers

ACTIVITIES

-

Breakout Groups:

- Divide participants into groups and give each group a picture.
- Ask the group to write down notes to answer and discusss:
  - What do you see in the picture? Does this happen in your neighborhoods? Why do neighbors treat families or households they know or think have HBV?
  - What forms of stigma is going on here? What can we do to educate your neighbors and change things?
- Report back to the group.

Examples of how neighbors can stigmatize:	**Examples of why neighbors can behave this way:**
• Don’t let the person or family affected by HBV to visit or use the bathroom/ utensils/play with children/ etc. • Stop visiting person or family affected by HBV. • Tell the landlord to kick the family out of the apartment they’re renting. • Gossip about person or family affected by HBV, or anyone who may interact with them.	• Fear of being infected through casual contact. • Fear that they will be stigmatized through association.

Exercise D3 – Building Community Support

OBJECTIVES :

Participants will be able to:

- Identify forms of stigma and discrimination in the community
- Develop strategies for building community support for people/families/households affected by HBV

TIME :

1 hour

MATERIALS :

- Selection from stigma pictures (Appendix 1)
- Notepads
- Pens and markers

ACTIVITIES

-

Group Discussion:

- Display three pictures showing how a community can stigmatize and discriminate against people/families/households affected by HBV.
- Ask the group to discuss:
  - "What do you see in the picture? Does this happen in your community?
  - How does it affect you? How does it affect the people affected by HBV?
  - What forms of stigma and discrimination is going on here? What can we do to educate the community?
- Report back to the group.

Examples of ways to build community support:

- Organize community meetings/gatherings to raise awareness and understanding about HBV.
- Join or form associations of families, neighbors and church groups to address HBV and stigma.
- Offer the most vulnerable or at-risk individuals and families support and resources (safe space to engage with community members, information about where to get care and treatment for HBV, etc.)

Summary:

Discuss the importance of educating and mobilizing the whole community, not just families who are immediately affected, to build support for those affected by HBV. Addressing the problem of HBV is the responsibility of the whole community. Emphasize that we are all at risk of getting HBV so we should all work to support those who are already affected by HBV. Explain that community education and mobilization will help to help to reduce stigma, as well as help improve HBV prevention, treatment and care.

MODULE E

Combating Stigma in a Health Care Setting

Health care providers can play a key role in combating HBV-related stigma. Stigma around HBV is often due to lack of awareness and misinformation (myths), fear, and association of hepatitis B with improper behavior. There are many ways in which stigma manifests in health care settings. Broadly, stigma in health care settings can be categorized into instances of neglect, differential treatment, denial of care, testing and disclosing of HBV-positive status without consent, and verbal abuse/gossip.[6] Stigma in health care settings is a major threat not only for individuals vulnerable to HBV but also for public health.

To combat HBV-related stigma in a health care setting, interventions must work both at the individual and institutional levels. Addressing HBV-related stigma at multiple levels will benefit both health care workers and HBV-positive patients.

At the individual level, increasing awareness among health care workers of what stigma is, the impact it has on patients, and the benefits of reducing it is essential. Ensuring that health workers have accurate information about HBV can help them better provide care and treatment to HBV-positive patients.

At the institutional level, health care providers need to ensure that workers have not only the information but also the supplies, equipment and policies or guidance related to the providing care to HBV-positive patients. Involving the whole health care team (doctors, nurses, administrative staff, etc.) in training and crafting institutional policies will ensure that the stigma-reduction processes are appropriate and effective for each health care setting.

In establishing the stigma-reduction foundation within the clinical setting, health care providers help build a broader culture of supportive and integrative health care. This supportive environment will lead to improved care and support for people affected by HBV, which can grow to include enabling services, or non-clinical services such as housing, transportation and translation support. People at risk for or living with HBV are then further empowered to get involved in their broader community and to challenge stigma elsewhere where it may occur. In confronting stigma in a health care setting and ensuring that people affected by HBV can participate and contribute equally in society, health care providers can help bring an end to hepatitis B.

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6. Laura Nyblade, Anne Stangl, Ellen Weiss, and Kim Ashburn, “Combating HIV stigma in health care settings: what works?,” International Center for Research on Women, August 2009.

Exercise E1 – Personal and Professional Impact of HBV

OBJECTIVES :

Participants will be able to:

- Explore how HBV has affected them personally and professionally
- Understand how misconceptions about HBV can affect quality of care for HBV-positive patients and develop ways to improve care for these patients

TIME :

1 hours

MATERIALS :

- Flipchart sheets
- Pens and markers

ACTIVITIES

-

- Ask participants to sit in small groups of 3-5 people; recommend that they form groups of people with mixed occupations (doctors, health care staff, HBV-positive individuals, family members, etc.).
- Provide the questions below to the facilitators and ask that each group discuss the questions for 30 minutes.
- Use the remaining 30 minutes to report back to larger group.

Questions Regarding Personal Experiences with HBV:

- When was the first time you heard about HBV/hepatitis B? What was your reaction and how did you feel about it?
- Do you know anyone who is living with HBV/who has hepatitis B? If yes, how did you react to that person when you first found out? Have your reactions or feelings changed over time? If yes, in what way?
- Has your life changed because of HBV? How? If it has not changed, why not?
- If you were infected with the HBV/had hepatitis B, would you want to know?
- How would you feel if someone conducted a HBV test without your knowledge or permission?
- If you were told you were HBV-positive/had hepatitis B, in what ways would it change your life?
- If you were told you were HBV-positive/had hepatitis B, with whom would you want to share that information? How would you want to share that information with them?
- If you were told that you were HBV positive/had hepatitis B, from whom would you want to keep that information a secret? Why would you want to keep the information secret from them? How would you feel if other people spread the information without your knowledge or permission?
- What would happen to your job if your boss or co-workers found out that you were HBV positive/had hepatitis B?
- If you were living with HBV, how would you want to be treated by others?
- If you were living with HBV, how would you want to be treated at a healthcare facility?

Questions Regarding Professional Experiences with HBV:

- If you work directly with patients, recall the first time you interacted with a patient who you knew was infected with HBV/had hepatitis B? How did you feel providing health services for that person? Did you treat him or her differently than other clients? Why or why not? Thinking back, what things would you do differently now than you did then?
- Do you think HBV-positive patients should be treated differently from patients who are not positive? Why or why not?
- What are your fears or concerns about providing health services for patients who are or might be infected with HBV?
- What led you to become a HBV health care provider?
- Do you feel stigma from others for being a HBV health care provider?
- When was the first time you heard about HBV/hepatitis B? What was your reaction and how did you feel about it?
- Do you know anyone who is living with HBV/who has hepatitis B? If yes, how did you react to that person when you first found out? Have your reactions or feelings changed over time? If yes, in what way?
- Has your life changed because of HBV? How? If it has not changed, why not?

Exercise E2 – Seeking Health Care with HBV

OBJECTIVES :

Participants will be able to:

- Better understand the perspective of people living with HBV
- To describe the impact of healthcare workers’ behaviors on HBV-positive patients’ health and well-being

TIME :

1-2 hours

MATERIALS :

- Scenario examples on cards or signs
- Flipchart sheets
- Notepads
- Pens and markers

ACTIVITIES

-

- Distribute scenario examples (see below) on cards or display case studies on signs.
- Ask participants to write one response for each case study, saying:
  - What is your reaction to these scenarios? How do they make you feel?
  - Would you change anything that happened? How?
- Report back to the group and note key points on flipchart.
- Ask participants to briefly describe a situation they have witnessed or experienced at their own health care facility where they or a patient was treated poorly because they were HBV-positive/had hepatitis B; discuss:
  - “How did you react?
  - Looking back, would you change anything that happened? How?

Scenario Examples

Example 1:
A woman came to the hospital in labor. At a certain point in her care, her doctor found out that she was HBV positive/had hepatitis B and refused to assist the delivery. He didn’t say anything to her, he just left the hospital. She was forced to seek care elsewhere.

Example 2:
A man came to the health clinic because he had a cough that would not go away. He worried all the way there about telling the nurse that he had hepatitis B. He thought they might tell him to go away. In the end he told her, and she praised him for doing so, as it was important for the staff to know this. She treated him just like she would any patient, with dignity and respect, in a caring manner.

Exercise E3 – Addressing HBV Stigma in a Health Care Setting

OBJECTIVES :

Participants will be able to:

- Explore and understand stigma and discrimination from the perspective of someone who is infected with HBV/has hepatitis B
- Recommend strategies for improving care and support for people affected by HBV in a health care setting

TIME :

1 hour

MATERIALS :

- Flipchart sheets
- Pens and markers

ACTIVITIES

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- Ask participants to form small groups of 3-5 people.

Role Play:

- Ask each group to develop a 5-minute skit/role play to demonstrate HBV-related stigma and discrimination in health care settings. Remind participants to select scenarios that most closely reflect their experiences.
  - Ask that each skit portray personal scenarios and how the situation could be addressed to reduce stigma and discrimination in the health care facility.
  - Group members should assume different roles in the skit (patient, colleague, staff person, family member, etc.). If there are not enough roles for each group member, participants who are not role-playing can provide suggestions and ideas to those who are.
- Give the groups 15 minutes to prepare. After that, all the groups will come back together and present the skits.

Discussion:

- Ask participants to observe the skits carefully and answer the following questions:.
  - Do you think these are realistic scenarios?
  - What did you observe in the behavior of the health care staff that did not reflect discrimination against the patient/colleague known or presumed to be infected with HBV?
  - What did you observe in the behavior of the health care staff that reflected discrimination against the patient/colleague known or presumed to be infected with HBV?
  - What would you do differently to ensure that people living with HBV, or those presumed to be HBV-positive/have hepatitis B, do not face discrimination?

MODULE F

Taking Action to Combat Stigma

Taking action is a critical part of the learning process. Throughout and after the learning process to understand the stigma surrounding HBV, we need to take action to combat the stigma in order to create change and improve the care and support for people affected by HBV.

This module will bring together what we've learned about HBV stigma, and what we can do to change attitudes and behaviors. We hope that by the end of this chapter, you and participants will be able to develop a tailored plan of action for combating stigma in their community.

Actions You Can Take

AS AN INDIVIDUAL:

-

- Watch your language and behavior; avoid stigmatizing words and actions
- Provide understanding and support to family members and friend affected by HBV
- Visit and support people affected by HBV and their families in your neighborhood
- Encourage people affected by HBV to seek the care and treatment that they need

WITH OTHERS:

-

- Challenge stigmatizing words and behavior—do it in a way that doesn't turn people away and instead gets them to think about how their words and actions can hurt
- Use informal conversations as opportunities to raise awareness about stigma
- Encourage people to talk openly about their fears and concerns about HBV; correct myths and misperceptions about HBV and people affected by HBV

Exercise F1 – Ten Steps to Action

OBJECTIVES :

Participants will be able to:

- Develop a strategy for taking action to combat stigma

TIME :

1-2 hours

MATERIALS :

- Notepads
- Pens and markers

ACTIVITIES

-

- Divide participants into groups of 2-4 and ask them to discuss and work together to complete the "Ten Steps to Action" as outlined in following pages.
- After each step, ask each group to give a quick report back and then move to the next step.
- Provide some time at the end to debrief and answer any questions. Ask participants if they feel confident that they can take their action plan back to their communities to combat stigma.

1 //

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Situation Analysis:

Where are you now?

-

This helps you to look at what is happening at the moment around stigma. You can ask: “What is the current situation regarding HBV stigma? What forms of stigma are common? Where is the stigma, in the household, community, workplace, etc.?”

Examples:

- High levels of fear and misinformation about HBV
- Silence around HBV and at-risk groups
- Individuals and families affected by HBV are the targets of stigma and discrimination
- Low knowledge and belief and fear of infection through casual contact
- Lack of access to quality, affordable, and culturally and linguistically appropriate health care services

2 //

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Vision:

Where do you want to be?

-

You can ask: “How would things look if you could make a difference? What is your 'vision' of the future with reduced stigma? What will it be like after [length of time] your anti-stigma actions?”

Examples:

- More knowledge about HBV transmission and less fear about casual contact
- More openness in talking about HBV and at-risk groups
- Less gossip and other discrimination towards individuals and families affected by HBV
- More access to quality, affordable, and culturally and linguistically appropriate health care services

3 //

-

Activities:

How will you get there?

-

You can ask: “What kind of activities can you do to help reduce stigma? What activities will you carry out to reach your goal and make your vision a reality?”

Examples:
- Conduct training workshops about HBV for family, friends, community, etc.
- Form support/self-help groups for people affected by HBV
- Conduct educational/advocacy campaigns on specific issues (e.g., increase HBV screening and vaccination at a local clinic; make sure HBV resources are available in multiple languages to cater to community needs; conduct visits to local elected officials to raise awareness about HBV)
- Talk more openly about hepatitis B with family, friends and community members to normalize discussion

4 //

-

Prioritize:

Where will you start?

-

You can ask: “What are the most feasible actions to start doing? What is the most important action for your target group (family, community, etc.)?”

5 //

-

Resources:

What do you need?

-

Identify any resources, skills or training that will help with you with your activities, including and any partners who can help. You can ask: “What resources do we need to do these activities?”

Examples:
- Funds and materials for the training workshops
- Elected official champions to support HBV policies and programs
- Media contacts to help raise awareness about HBV

6 //
-

Obstacles:
What challenges may get in the way?
-

Identify any challenges that might prevent you from being successful. Try to identify solutions on how to overcome these obstacles. You can ask: “What things might block your activities?”

Examples:
- Resistance and fear from family, community, etc.
- Community apathy or lack of resources
- Lack of funds

7 //
-

Indicators:
How will you know you are successful?
-

Decide how you will measure success. Identify “indicators” or signs that will show you that stigma is reducing. You can ask: “What things will show that we have been successful?”

Examples:
- More people talking openly about getting tested/vaccinated for HBV
- More HBV stories in the local newspaper
- In-language HBV brochures made freely available at the local clinic

8 //
-

Action:
-

Start your activities! Assign tasks, deadlines, etc.

9 //
-

Monitoring:
-

Monitor how you’re doing (progress toward goals, meeting deadlines, etc.)

10 //
-

Re-plan:
-

Make changes to your plan based on your progress and needs of your family, community, etc.

Exercise F2 – Different Solutions for Different Settings

OBJECTIVES :

Participants will be able to:

- Analyze the impact of stigma on their current situation
- Develop strategies for combating stigma in their own setting

TIME :

1 hour

MATERIALS :

- Flipchart sheets
- Pens and markers

ACTIVITIES

-

- Put up flipchart sheets on the wall for different groups or settings. For example: task groups. For example: family/household, youth/school, health care setting, workplace, place of worship, etc.
- Ask participants to join a group or setting of their choice by going to the relevant flipchart sheet.
- Ask groups to discuss:
  - What forms of stigma do you see in your group/setting?
  - What is the biggest stigma problem in your group/setting?
  - What is the source of this problem?
  - What are some possible solutions to this problem?
  - Identify 2-3 specific new things you would like to do to combat stigma in this setting.
- Report back to the group.

Examples of different forms of stigma in different settings:

HEALTH CARE SETTING
Forms of Stigma: Denial of care. Avoiding or isolating HBV patients. Limited physical contact or poorer quality of service with HBV patients because of fear of contracting disease. Health care provider makes assumptions about patient’s sexual history or immigration status.

Strategies to Combat Stigma: Empower health workers to talk about their own attitudes, feelings, fears and behavior about HBV. Ensure that they have the information, supplies and equipment necessary to effectively care for patients. Develop codes of practice. Continuously educate health workers about HBV and stigma through in-service training. Get feedback from clients.

WORKPLACE
Forms of Stigma: Colleagues gossip about other employees who are assumed to have HBV. Loss of opportunities (e.g., loss of job, promotion).

Strategies to Combat Stigma: Win support of leadership/management; Leadership/management create a supportive environment (employees won't lose jobs or be passed up for promotion, etc.). Encourage support groups for people affected by HBV within the workplace. Promote a code of conduct.

MEDIA
Forms of Stigma: Incorrect, fear-inducing messages and stories about HBV. Inconsistent or contradictory information leading to community confusion.

Strategies to Combat Stigma: Provide feedback to avoid fear-inducing messages and stories. Provide up-to-date and correct information. Encourage positive stories of people affected by HBV (see http://www.hepb.org/justb). Connect media contacts with people affected by HBV who are willing to share their story or be a spokesperson for HBV issues.

Exercise F3 – Changing Attitudes and Behavior

OBJECTIVES :

Participants will be able to:
- Identify negative attitudes and behavior towards people affected by HBV within a specific group/setting (see examples in Exercise E2)
- Develop a strategy for changing negative to positive and supportive attitudes and behavior towards people affected by HBV

TIME :

1-2 hours

MATERIALS :

- Flipchart sheets
- Pens and markers

ACTIVITIES

-

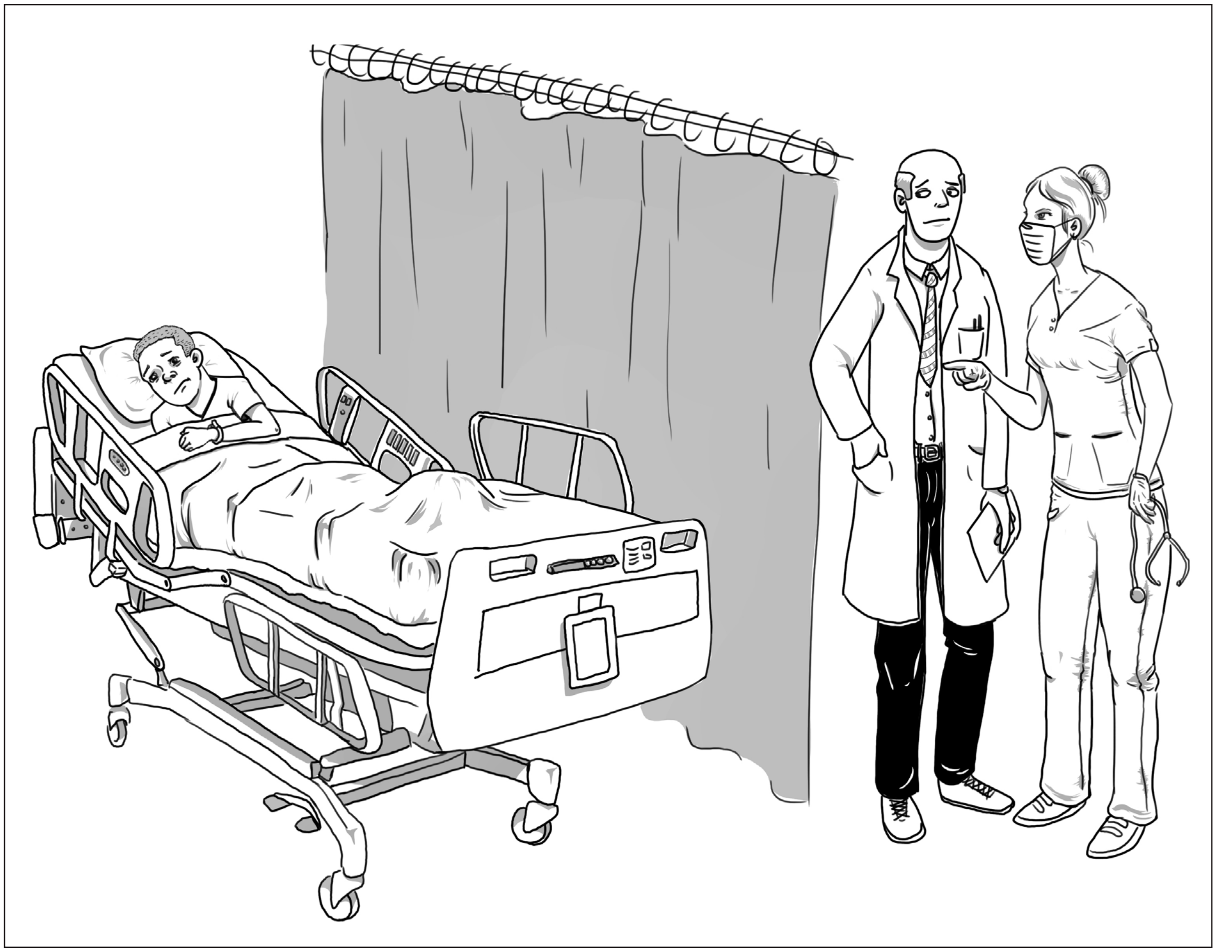
- This exercise can be done as a single large group exercise or participants can be split into groups to work on different groups/settings.
- Ask participants to discuss and work together to complete the "Behavioral Change Model" as outlined below for their specific group/setting.

Behavior Change Model			
Whose behavior needs to change?	*What is the behavior we want to encourage?*	*What are the key factors that influence this change?*	*What activities will support this change?*
Example: Faith-based leaders	Change from "stigmatizers" to ”supporters” → stop blaming and judging, and encourage education and empathy	They see their role as moral compass of the community and view people affected by HBV as “bad” or “immoral” → frame stigma as immoral and provide examples of the negative impacts of stigma, and positive impacts of education and empathy	Interactive workshops; use toolkit exercises to encourage understanding and combating of stigma

APPENDICES

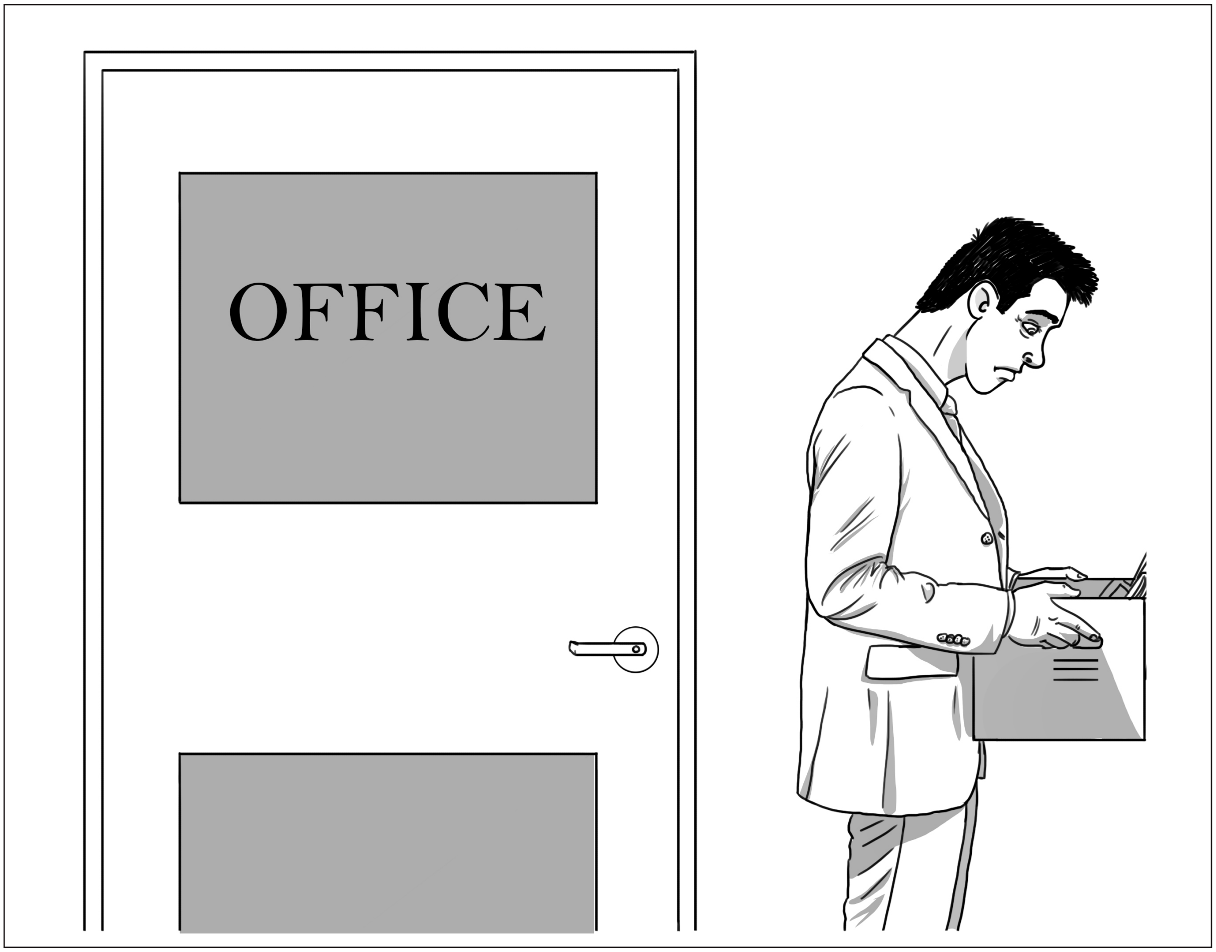
APPENDIX 1 - Pictures Showing Different Forms of Stigma

1a -



APPENDIX 1 - Pictures Showing Different Forms of Stigma CONT'D

1b -

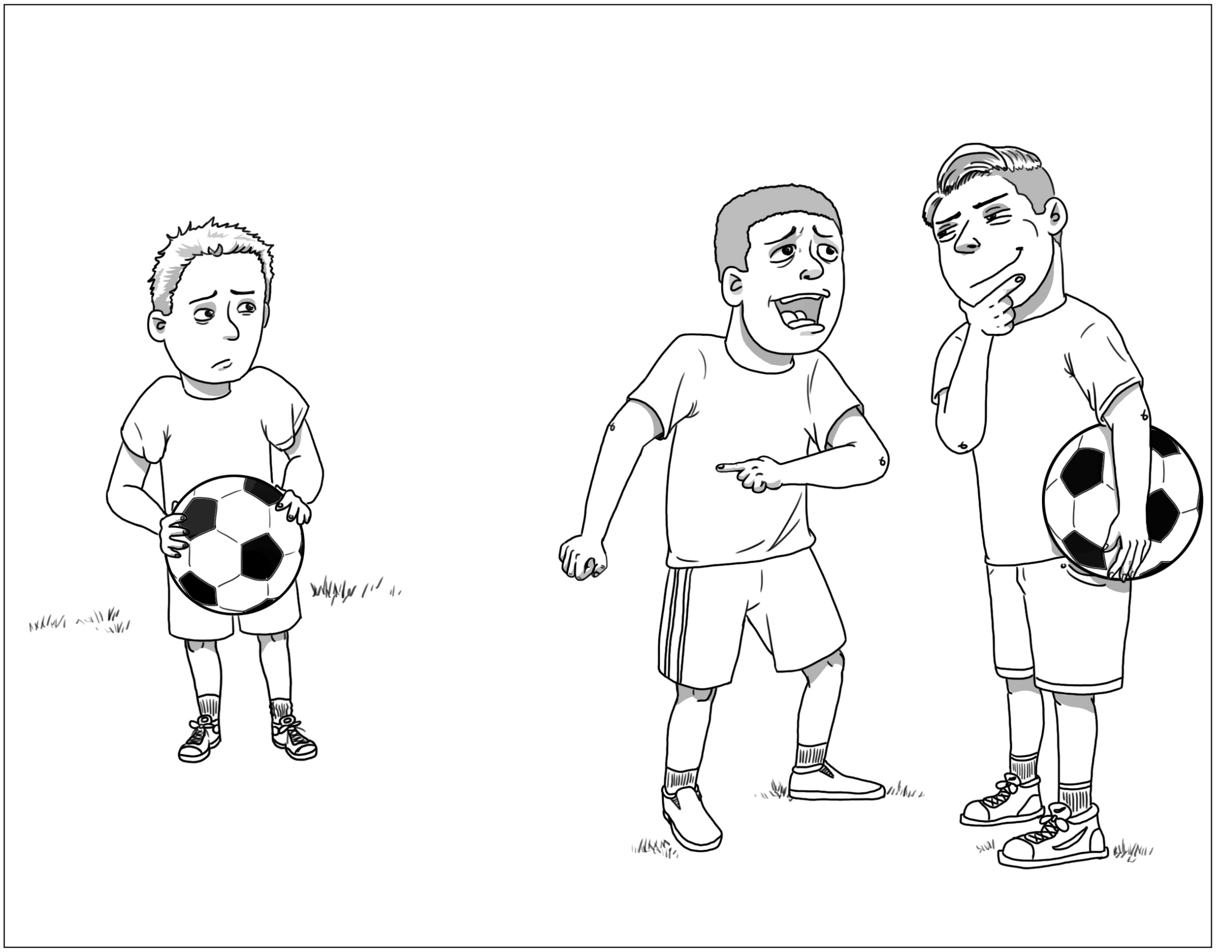


APPENDIX 1 - Pictures Showing Different Forms of Stigma CONT'D

1c -

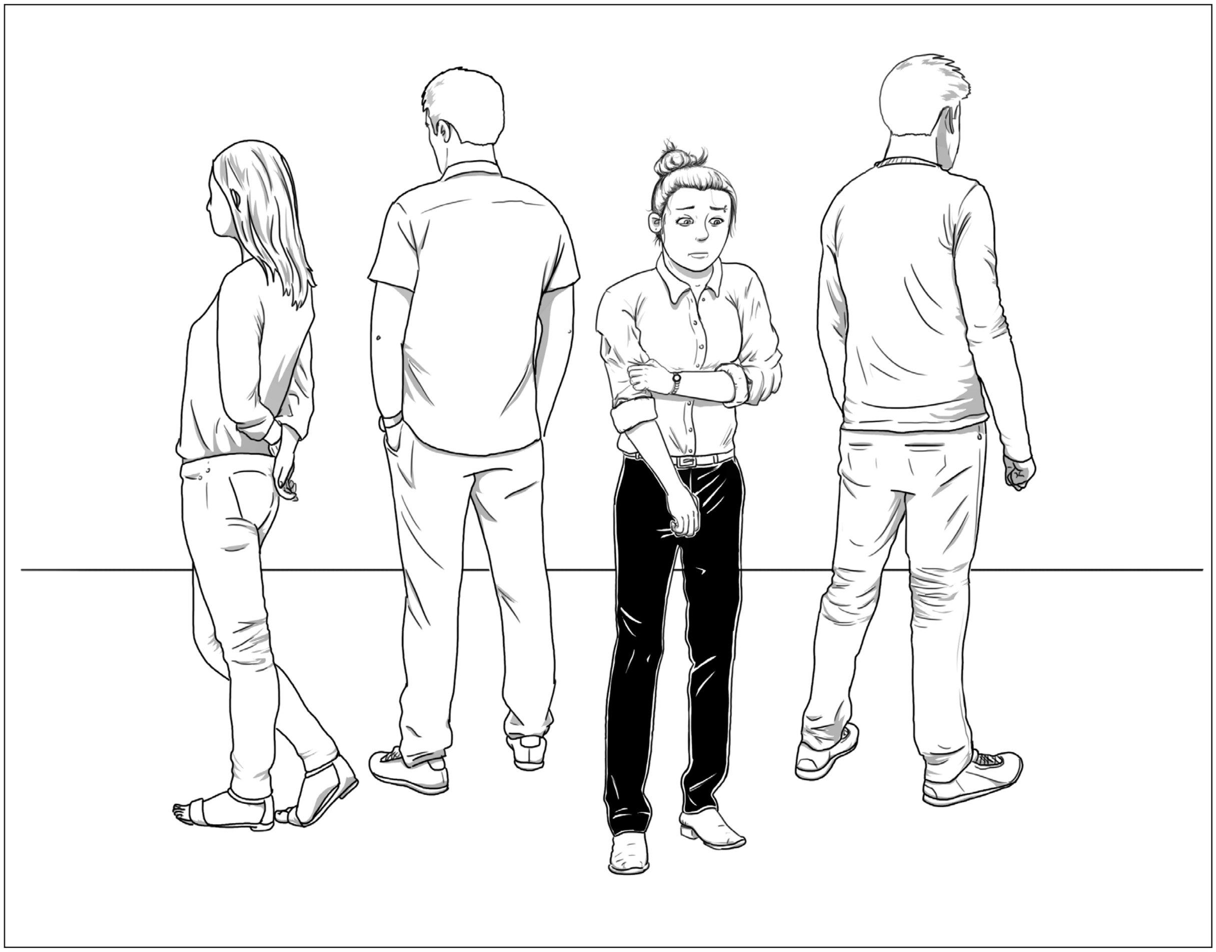
APPENDIX 1 - Pictures Showing Different Forms of Stigma CONT'D

1d -



APPENDIX 1 - Pictures Showing Different Forms of Stigma CONT'D

1e -

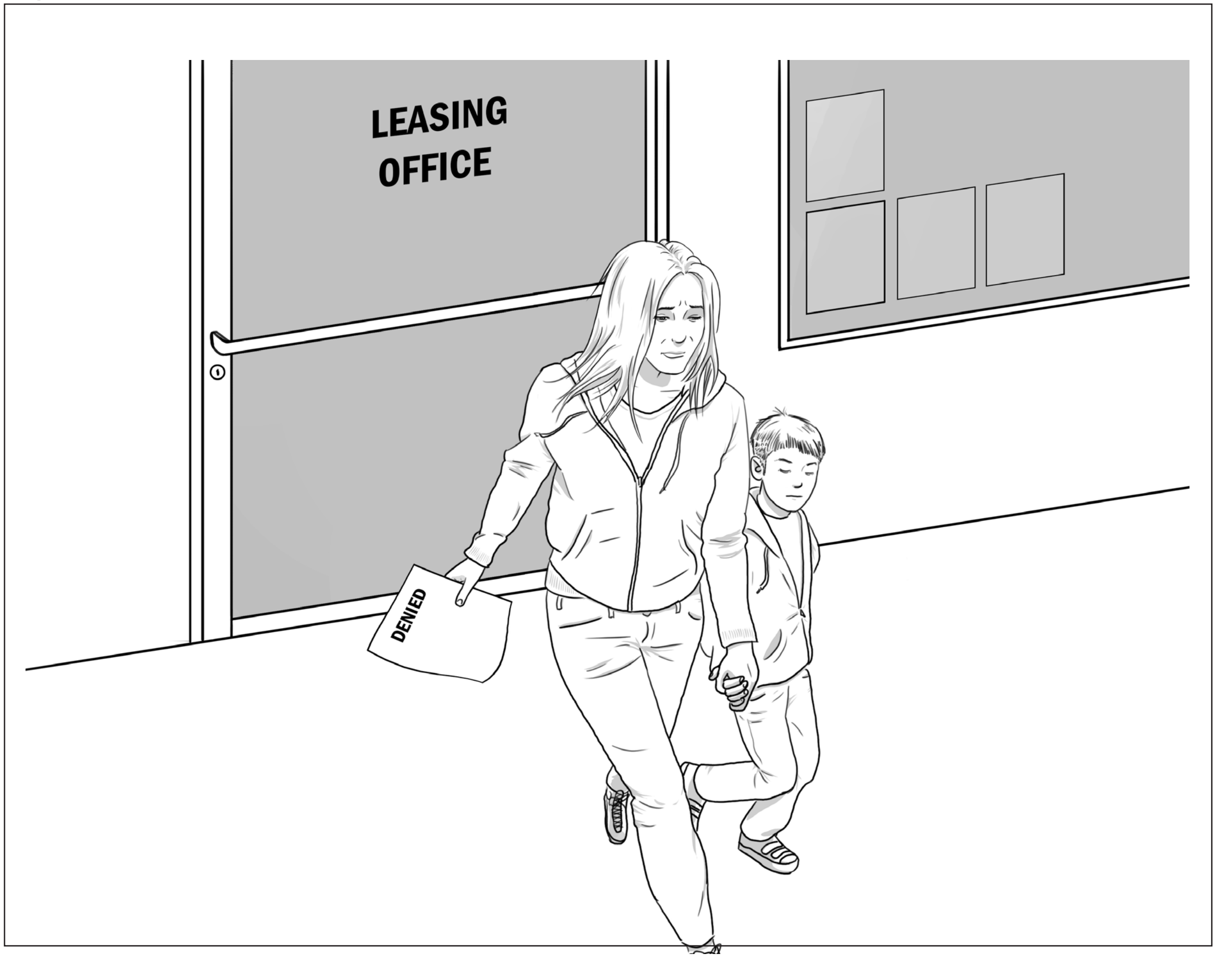


APPENDIX 1 - Pictures Showing Different Forms of Stigma CONT'D

1f -

APPENDIX 1 - Pictures Showing Different Forms of Stigma CONT'D

1g -



APPENDIX 1 - Pictures Showing Different Forms of Stigma CONT'D

1h -

APPENDIX 1 - Pictures Showing Different Forms of Stigma CONT'D

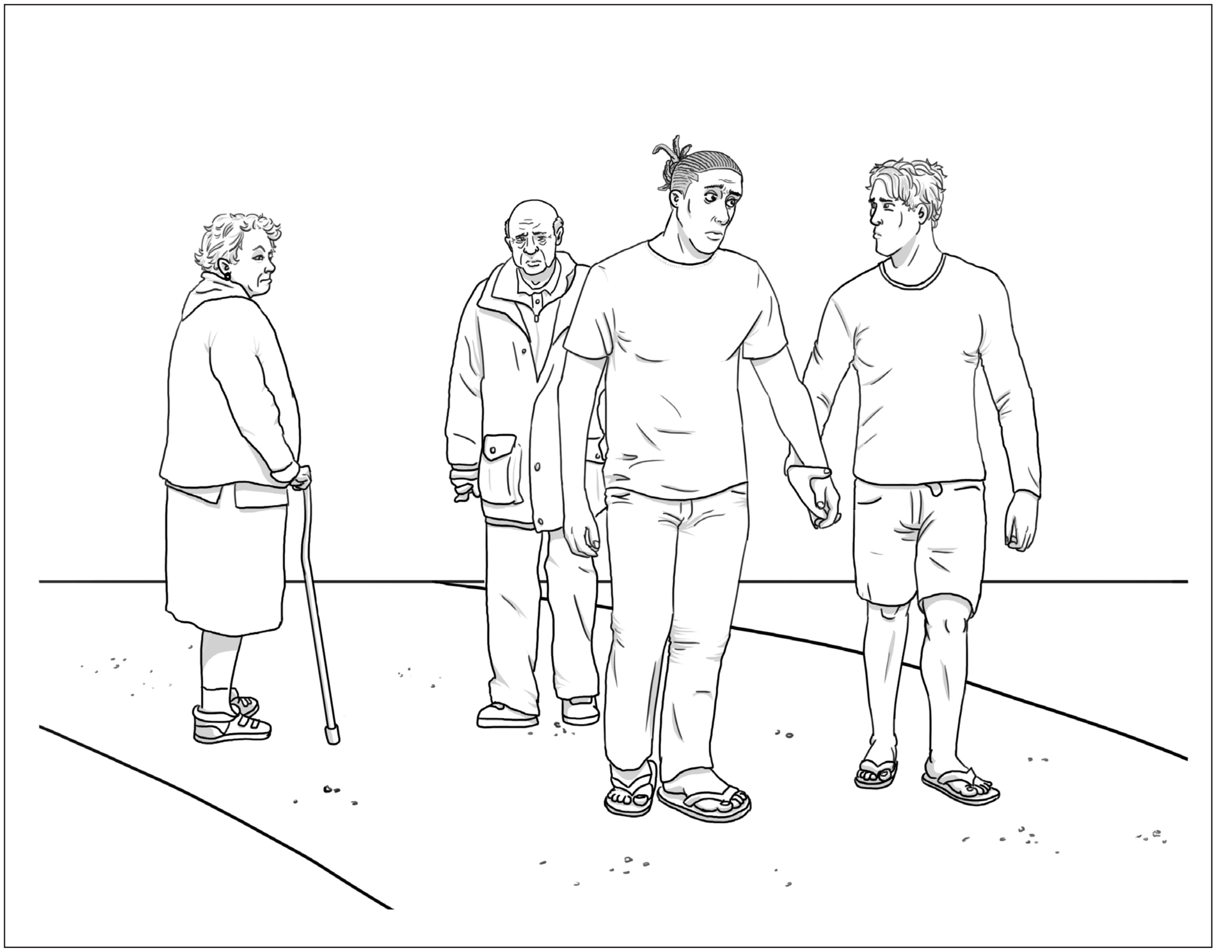
1i -

APPENDIX 1 - Pictures Showing Different Forms of Stigma CONT'D

1j -

APPENDIX 1 - Pictures Showing Different Forms of Stigma CONT'D

1k -



APPENDIX 2 – CDC Hepatitis B Resources

2a (page 1) -

HEPATITIS B

General Information

What is hepatitis?

"Hepatitis" means inflammation of the liver. The liver is a vital organ that processes nutrients, filters the blood, and fights infections. When the liver is inflamed or damaged, its function can be affected. Heavy alcohol use, toxins, some medications, and certain medical conditions can cause hepatitis. However, hepatitis is most often caused by a virus. In the United States, the most common types of viral hepatitis are Hepatitis A, Hepatitis B, and Hepatitis C.

The only way to know if you have Hepatitis B is to get tested.

What is Hepatitis B?

Hepatitis B can be a serious liver disease that results from infection with the Hepatitis B virus. **Acute Hepatitis B** refers to a short-term infection that occurs within the first 6 months after someone is infected with the virus. The infection can range in severity from a mild illness with few or no symptoms to a serious condition requiring hospitalization. Some people, especially adults, are able to clear, or get rid of, the virus without treatment. People who clear the virus become immune and cannot get infected with the Hepatitis B virus again.

Chronic Hepatitis B refers to a lifelong infection with the Hepatitis B virus. The likelihood that a person develops a chronic infection depends on the age at which someone becomes infected. Up to 90% of infants infected with the Hepatitis B virus will develop a chronic infection. In contrast, about 5% of adults will develop chronic Hepatitis B. Over time, chronic Hepatitis B can cause serious health problems, including liver damage, cirrhosis, liver cancer, and even death.

How is Hepatitis B spread?

The Hepatitis B virus is spread when blood, semen, or other body fluids from an infected person enters the body of someone who is not infected. The virus can be spread through:

- **Sex with an infected person.** Among adults, Hepatitis B is often spread through sexual contact.
- **Injection drug use.** Sharing needles, syringes, and any other equipment to inject drugs with someone infected with Hepatitis B can spread the virus.
- **Outbreaks.** While uncommon, poor infection control has resulted in outbreaks of Hepatitis B in healthcare settings.
- **Birth.** Hepatitis B can be passed from an infected mother to her baby at birth. Worldwide, most people with Hepatitis B were infected with the virus as an infant.

Hepatitis B is **not** spread through breastfeeding, sharing eating utensils, hugging, kissing, holding hands, coughing, or sneezing. Unlike some forms of hepatitis, Hepatitis B is also not spread by contaminated food or water.

What are the symptoms of Hepatitis B?

Many people with Hepatitis B do not have symptoms and do not know they are infected. If symptoms occur, they can include: fever, feeling tired, not wanting to eat, upset stomach, throwing up, dark urine, grey-colored stool, joint pain, and yellow skin and eyes.

When do symptoms occur?

If symptoms occur with an acute infection, they usually appear within 3 months of exposure and can last up to 6 months. If symptoms occur with chronic Hepatitis B, they can take years to develop and can be a sign of advanced liver disease.

Continued on next page

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APPENDIX 2 – CDC Hepatitis B Resources CONT'D

2a (page 2) -

How would you know if you have Hepatitis B?

The only way to know if you have Hepatitis B is to get tested. Blood tests can determine if a person has been infected and cleared the virus, is currently infected, or has never been infected.

Who should get tested for Hepatitis B and why?

CDC develops recommendations for testing based upon a variety of different factors. Here is a list of people who should get tested. The results will help determine the next best steps for vaccination or medical care.

All pregnant women are routinely tested for Hepatitis B. If a woman has Hepatitis B, timely vaccination can help prevent the spread of the virus to her baby.

Household and sexual contacts of people with Hepatitis B are at risk for getting Hepatitis B. Those who have never had Hepatitis B can benefit from vaccination.

People born in certain parts of the world that have increased rates of Hepatitis B. Testing helps identify those who are infected so that they can receive timely medical care.

People with certain medical conditions should be tested, and get vaccinated if needed. This includes people with HIV infection, people who receive chemotherapy and people on hemodialysis.

People who inject drugs are at increased risk for Hepatitis B but testing can tell if someone is infected or could benefit from vaccination to prevent getting infected with the virus.

Men who have sex with men have higher rates of Hepatitis B. Testing can identify unknown infections or let a person know that they can benefit from vaccination.

How is Hepatitis B treated?

For those with acute Hepatitis B, doctors usually recommend rest, adequate nutrition, fluids, and close medical monitoring. Some people may need to be hospitalized. People living with chronic Hepatitis B should be evaluated for liver problems and monitored on a regular basis. Treatments are available that can slow down or prevent the effects of liver disease.

Can Hepatitis B be prevented?

Yes. The best way to prevent Hepatitis B is by getting vaccinated. The Hepatitis B vaccine is typically given as a series of 3 shots over a period of 6 months. The entire series is needed for long-term protection.

Who should get vaccinated against Hepatitis B?

All infants are routinely vaccinated for Hepatitis B at birth, which has led to dramatic declines of new Hepatitis B cases in the US and many parts of the world. The vaccine is also recommended for people living with someone infected with Hepatitis B, travelers to certain countries, and healthcare and public safety workers exposed to blood. People with high-risk sexual behaviors, men who have sex with men, people who inject drugs, and people who have certain medical conditions, including diabetes, should talk to their doctor about getting vaccinated.

For more information

Talk to your doctor, call your health department, or visit www.cdc.gov/hepatitis.

APPENDIX 2 – CDC Hepatitis B Resources CONT'D

2b -

HEPATITIS B

KNOW HEPATITIS B™

Are You At Risk?

What is Hepatitis B?

Hepatitis B is a liver disease. It is caused by the Hepatitis B virus. For some people who get Hepatitis B, the virus stays in the body, causing a lifelong illness. Hepatitis B can cause serious health problems over time. These problems can include liver cancer and liver failure.

How is Hepatitis B spread?

Hepatitis B is spread when someone comes in contact with blood from a person who has the disease. Most people born in China and other Asian countries who have Hepatitis B were infected as infants or young children. Hepatitis B can be passed from an infected mother to her baby at birth or from a family member to young children.

Hepatitis B is not a genetic disease. People also do not get Hepatitis B from sharing meals, bowls or utensils with someone who has the disease. Hepatitis B is not spread through breastfeeding, hugging, kissing, holding hands, coughing, or sneezing.

How common is Hepatitis B?

Hepatitis B is very common in China and other Asian countries. Approximately 1 in 12 Asians are living with Hepatitis B, but most people do not know it.

What are the symptoms of Hepatitis B?

Most people who have Hepatitis B do not know they have it. The disease does not always cause symptoms. Hepatitis B can stay hidden in the body. Many people can live with Hepatitis B for 20 years without feeling sick. Still, liver damage from the disease can take place during this time.

How serious is Hepatitis B?

Hepatitis B can become very serious. For some people, this disease leads to liver damage, like liver failure or cancer.

How do people know if they have Hepatitis B?

A Hepatitis B test lets people know if they have it. This is a simple blood test that takes only a little bit of blood from a person's arm. Doctors do not always do this test, so it is important to ask to be tested.

Who should be tested for Hepatitis B?

Hepatitis B testing is recommended for:

- People born in China and other Asian countries
- People whose parents were born in China and other Asian countries
- People who live with someone who has Hepatitis B

Why should people be tested for Hepatitis B?

Getting tested lets a person know if he or she has Hepatitis B. There are treatments available for Hepatitis B that can help prevent serious liver damage. People who find out they have Hepatitis B can also keep other family members healthy. This is why women are always tested for Hepatitis B when they are pregnant. Family members who have never had Hepatitis B can get a vaccine to protect them from getting it.

Hepatitis B test results will be kept confidential. People with Hepatitis B cannot be forced to leave the United States. They also cannot be fired from a job, or forced to leave school.

How is Hepatitis B treated?

People who have hepatitis B should see a doctor who is very knowledgeable about the disease. The doctor can give medicines that will slow down liver damage. It is important to ask the doctor before taking any Eastern liver remedies because they might hurt the liver or cause problems with some of the medicines prescribed by your doctor.

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June 2013

Publication No. 220383

APPENDIX 2 – CDC Hepatitis B Resources CONT'D

2c -

HEPATITIS B: ARE YOU AT RISK?

KNOW HEPATITIS B™

Information for Native Hawaiians and Pacific Islanders

What is Hepatitis B?

Hepatitis B is a liver disease. It is caused by the Hepatitis B virus. For some people who get Hepatitis B, the virus stays in the body, causing a lifelong illness. Hepatitis B can cause serious health problems over time. These problems can include liver cancer and liver failure.

How is Hepatitis B spread?

Hepatitis B is spread when someone comes in contact with blood from a person who has the disease. Hepatitis B can be passed from an infected mother to her baby at birth or from a family member to young children. Most people living with Hepatitis B got infected as infants or young children.

Hepatitis B is not a genetic disease. People also do not get Hepatitis B from sharing meals, bowls or utensils with someone who has the disease. Hepatitis B is not spread through breastfeeding, hugging, kissing, holding hands, coughing, or sneezing.

If you or your parents were born in Hawaii or the Pacific Islands, talk to your doctor about getting tested for Hepatitis B.

How common is Hepatitis B?

Hepatitis B is very common in Hawaii and the Pacific Islands, as well as many parts of Asia. Approximately 1 in 12 Asian Americans, which includes Native Hawaiians and Pacific Islanders, are living with Hepatitis B. Unfortunately, most people do not know they are infected.

What are the symptoms of Hepatitis B?

Most people who have Hepatitis B do not know they have it. The disease does not always cause symptoms. Hepatitis B can stay hidden in the body. Many people can live with Hepatitis B for many years without feeling sick. Still, liver damage from the disease can take place during this time.

How serious is Hepatitis B?

Hepatitis B can become very serious. For some people, Hepatitis B can cause liver damage, and can even lead to liver failure or cancer.

How do people know if they have Hepatitis B?

A Hepatitis B test lets people know if they have it. This is a simple blood test that takes only a little bit of blood from a person's arm. Doctors do not always do this test, so it is important to ask to be tested.

Who should be tested for Hepatitis B?

Hepatitis B testing is recommended for:

- People born in a region of the world where Hepatitis B is common. This includes Hawaii, the Pacific Islands and Asia.
- People with a parent born in a region of the world where Hepatitis B is common.
- People who live with someone who has Hepatitis B.

Why should people be tested for Hepatitis B?

Getting tested lets a person know if he or she has Hepatitis B. There are treatments available for Hepatitis B that can help prevent serious liver damage. People who find out they have Hepatitis B can also keep other family members healthy. This is why women are always tested for Hepatitis B when they are pregnant. Family members who have never had Hepatitis B can get a vaccine to protect them from getting it. Hepatitis B test results will be kept confidential.

How is Hepatitis B treated?

People who have hepatitis B should see a doctor who is very knowledgeable about the disease. The doctor can help manage and monitor the disease. The doctor can give medicines that will slow down liver damage.

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APPENDIX 2 - CDC Hepatitis B Resources CONT'D

2d -

HEPATITIS B: ARE YOU AT RISK?

Information for People from Africa

What is Hepatitis B?

Hepatitis B is a disease caused by the Hepatitis B virus. It can cause serious health problems over time. The virus can make some people very sick. The disease is very common in many parts of the world, including Africa.

How is Hepatitis B spread?

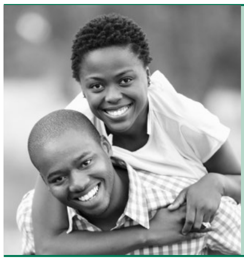
People get Hepatitis B when they come into contact with blood from a person who has the virus. Hepatitis B can be passed from an infected mother to her baby at birth or from a family member to young children. The virus can also be spread through sex with an infected person. Hepatitis B is passed the same way as HIV, but spreads more easily. Hepatitis B is not spread through breastfeeding, hugging, kissing, holding hands, coughing, or sneezing.

Do people with Hepatitis B feel sick?

Most people can live with Hepatitis B for many years without feeling sick. Over time, Hepatitis B can lead to liver damage, liver failure, and even liver cancer.

How do people know if they have Hepatitis B?

The only way people know if they have Hepatitis B is if they get a blood test for Hepatitis B. This is a simple test that takes only a little bit of blood from a person's arm. People should ask their doctors if they should be tested for Hepatitis B.



If you or your parents were born in Africa, talk to your doctor about getting tested for Hepatitis B

Who should be tested for Hepatitis B?

Hepatitis B testing is recommended for:

- People born in most African countries, especially countries in Sub-Saharan Africa
- People whose parents were born in Sub-Saharan Africa
- People who live with someone who has Hepatitis B

Why should people be tested for Hepatitis B?

It's important for people to know if they have Hepatitis B. There are treatments available for Hepatitis B that can help prevent serious health problems. People who find out they have Hepatitis B can also take steps to prevent passing the virus to others, such as using a condom when having sex with a partner who does not have Hepatitis B. Those who have never had Hepatitis B can get a vaccine to protect them from getting the virus.

For More Information

Talk to your doctor, call your local health department, or visit www.cdc.gov/hepatitis for information in English.

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

www.cdc.gov/hepatitis

October 2013

APPENDIX 2 - CDC Hepatitis B Resources CONT'D

2e -

HEPATITIS B

KNOW HEPATITIS B™

When Someone in the Family has Hepatitis B

What is Hepatitis B?

Hepatitis B is a liver disease. It is caused by the Hepatitis B virus. For some people who get Hepatitis B, the virus stays in the body, causing a lifelong illness. Hepatitis B can cause serious health problems over time. These problems can include liver failure and liver cancer.

What are the symptoms of Hepatitis B?

Most people who have Hepatitis B do not know they have it. The disease does not always cause symptoms. Hepatitis B can stay hidden in the body. Many people can live with Hepatitis B for 20 years without feeling sick. Still, liver damage from the disease can take place during this time.

How is Hepatitis B spread?

Hepatitis B is spread when someone comes in contact with blood from a person who has the disease. Most people born in China and other Asian countries who have Hepatitis B were infected as infants or young children. Hepatitis B can be passed from an infected mother to her baby at birth or from a family member to young children. People living with someone who has Hepatitis B are more likely to get the disease.

Hepatitis B is not a genetic disease. People also do not get Hepatitis B from sharing meals, bowls or utensils with someone who has the disease. Hepatitis B is not spread through breastfeeding, hugging, kissing, holding hands, coughing, or sneezing.

What should be done when a family member has Hepatitis B?

Doctors will want to test all family members of people with Hepatitis B. This includes adults and children living in the same house. The test involves a simple blood test that takes only a small amount of blood from a person's arm.

Testing family members is important. Family members who have Hepatitis B should get medical treatment. Other family members who do not have the disease should get the Hepatitis B vaccine. This protects them from getting the disease.

Hepatitis B test results will be kept confidential. People with Hepatitis B cannot be forced to leave the United Sates. They also cannot be fired from a job, or forced to leave school.

Why is the Hepatitis B vaccine important?

The vaccine protects people who have never had Hepatitis B from getting it. All babies born in the United States and many other countries get the vaccine as infants. Any other family members of people with Hepatitis B should also get the vaccine. The vaccine is safe. It also prevents people from getting Hepatitis B. This helps prevent liver disease and liver cancer that comes from getting Hepatitis B.

What is the Hepatitis B vaccine series?

For adults, the vaccine is three shots given over six months. People should get all three shots to keep them from getting Hepatitis B.

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June 2013

Publication No. 220397

APPENDIX 2 - CDC Hepatitis B Resources CONT'D

2f -

HEPATITIS B & YOUR FAMILY

KNOW HEPATITIS B™

Information for Native Hawaiians and Pacific Islanders

What is Hepatitis B?

Hepatitis B is a liver disease. It is caused by the Hepatitis B virus. For some people who get Hepatitis B, the virus stays in the body, causing a lifelong illness. Hepatitis B can cause serious health problems over time. These problems can include liver failure and liver cancer.

What are the symptoms of Hepatitis B?

Most people who have Hepatitis B do not know they have it. The disease does not always cause symptoms. Hepatitis B can stay hidden in the body. Many people can live with Hepatitis B for many years without feeling sick. Still, liver damage from the disease can take place during this time.

Getting tested for Hepatitis B can help you take care of yourself and protect your family.

How is Hepatitis B spread?

Hepatitis B is spread when someone comes in contact with blood from a person who has the disease. Hepatitis B can be passed from an infected mother to her baby at birth or from a family member to young children. Most people living with Hepatitis B got infected as infants or young children. People living with someone who has Hepatitis B are also more likely to get the disease.

Hepatitis B is not a genetic disease. People also do not get Hepatitis B from sharing meals, bowls or utensils with someone who has the disease. Hepatitis B is not spread through breastfeeding, hugging, kissing, holding hands, coughing, or sneezing.

What should be done when someone has Hepatitis B?

Doctors will want to test all family members of people with Hepatitis B. This includes adults and children living in the same house. The test involves a simple blood test that takes only a small amount of blood from a person's arm.

Testing family members is important. Family members who have Hepatitis B should see a doctor. Other family members who do not have the disease should get the Hepatitis B vaccine. This protects them from getting the disease.

Hepatitis B test results will be kept confidential. People with Hepatitis B cannot be forced to leave the United Sates. They also cannot be fired from a job, or forced to leave school.

Why is the Hepatitis B vaccine important?

The vaccine protects people who have never had Hepatitis B from getting it. All babies born in the United States and many other countries get the vaccine as infants. Any other family members of people with Hepatitis B should also get the vaccine. The vaccine is safe. It also prevents people from getting Hepatitis B. This helps prevent liver disease and liver cancer that comes from getting Hepatitis B.

What is the Hepatitis B vaccine series?

For many people, the vaccine is usually three shots given over six months. People should get all three shots to keep them from getting Hepatitis B.

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APPENDIX 2 – CDC Hepatitis B Resources CONT'D

2g -

HEPATITIS B & YOUR FAMILY

Information for People from Africa

What is Hepatitis B?

Hepatitis B is a disease caused by the Hepatitis B virus. It can cause serious health problems over time. The virus can make some people very sick. The disease is very common in many parts of the world, including Africa.

How is Hepatitis B spread?

People get Hepatitis B when they come into contact with blood from a person who has the virus. Hepatitis B can be passed from an infected mother to her baby at birth or from a family member to young children. The virus can also be spread through sex with an infected person. Hepatitis B is passed the same way as HIV, but spreads more easily. Hepatitis B is not spread through breastfeeding, hugging, kissing, holding hands, coughing, or sneezing.

Do people with Hepatitis B feel sick?

Most people live with Hepatitis B for many years without feeling sick. Over time, Hepatitis B can lead to liver damage, liver failure, and even liver cancer. Getting tested for Hepatitis B is usually the only way for people to know if they have Hepatitis B.

Should other people be tested for Hepatitis B?

Yes. When a person has Hepatitis B, doctors will want to test all sexual partners, family members, and people living in the same house for Hepatitis B. It is important for these people to get tested because doctors can help them stay healthy. People who have Hepatitis B should get medical treatment. Others who do not have the disease should get the Hepatitis B vaccine. This protects them from getting the virus.

Getting tested for Hepatitis B can help you take care of yourself and protect your family.

Why is the Hepatitis B vaccine important?

A Hepatitis B vaccine prevents people from getting Hepatitis B. All babies born in the United States and many other countries get the vaccine at birth. Any other family member or sexual partner of people with Hepatitis B should also get the vaccine. The vaccine is safe and works for people who have never been infected with Hepatitis B.

For More Information

Talk to your doctor, call your local health department, or visit www.cdc.gov/hepatitis for information in English.

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

www.cdc.gov/hepatitis

October 2013

APPENDIX 2 - CDC Hepatitis B Resources CONT'D

2h -

HEPATITIS B & SEXUAL HEALTH

What is Hepatitis B?

Hepatitis B is a liver disease that results from infection with the Hepatitis B virus. When first infected, people can develop an acute infection, which can range in severity from a very mild illness with few or no symptoms to a serious condition requiring hospitalization. **Acute** Hepatitis B refers to the first 6 months after someone is exposed to the Hepatitis B virus. Some people are able to fight the infection and clear the virus.

For others, the infection remains and leads to a "chronic," or lifelong, infection. Over time, **chronic** Hepatitis B can cause serious health problems including liver damage, liver failure, and even liver cancer.

How is Hepatitis B spread?

Hepatitis B is usually spread when blood, semen, or other body fluids from a person infected with the Hepatitis B virus enter the body of someone who is not infected. This can happen through sexual contact with an infected person; sharing needles, syringes, or other equipment to inject drugs; or from an infected mother to her baby at birth.

Can Hepatitis B be spread through sex?

Yes. Hepatitis B is easily transmitted through sexual activity. In fact, sexual contact is the most common way Hepatitis B is spread in the United States. Hepatitis B is 50-100 times more infectious than HIV.

If you are sexually active, get vaccinated against Hepatitis B and talk to your health professional about your risk for STDs and HIV.

The best way to prevent Hepatitis B is to get vaccinated.

Can Hepatitis B be prevented?

Yes. The best way to prevent Hepatitis B is by getting vaccinated. For adults, the vaccine is usually given as a series of 3 shots over a period of 6 months. The entire series of shots is needed for long-term protection.

There is also a combination vaccine that protects against both Hepatitis A and Hepatitis B. People should talk to their health professional about which vaccine is best for them.

Who should be vaccinated against Hepatitis B?

The vaccine is safe and effective and recommended for sexually active adults, especially:

- People with multiple sex partners
- Anyone with a sexually transmitted disease (STD)
- Men who have sexual encounters with other men
- Anyone having sex with an infected partner

Continued on next page

APPENDIX 2 - CDC Hepatitis B Resources CONT'D

2i -

VIRAL HEPATITIS

Information for Gay and Bisexual Men

What is viral hepatitis?

Viral hepatitis is an infection of the liver caused by one of several viruses. In the United States, the most common types of viral hepatitis are Hepatitis A, Hepatitis B, and Hepatitis C. While all three types of hepatitis can cause similar symptoms, each virus is spread in different ways.

Are gay and bisexual men at risk for viral hepatitis?

Yes. Among adults, an estimated 10% of new Hepatitis A cases and 20% of new Hepatitis B cases occur in gay or bisexual men. Gay and bisexual men are at increased risk for Hepatitis C if they are involved in high-risk behaviors.

Sharing needles or other equipment used to inject drugs puts a person at risk for Hepatitis B, Hepatitis C, and HIV. Of people with HIV infection, 10% also have Hepatitis B and 25% also have Hepatitis C. New research shows that gay men who are HIV-positive and have multiple sex partners may increase their risk for Hepatitis C.

How is viral hepatitis spread?

- **Hepatitis A** is usually spread when a person ingests fecal matter—even in microscopic amounts—from an infected person. Among men who have sexual contact with other men, Hepatitis A can be spread through direct anal-oral contact or contact with fingers or objects that have been in or near the anus of an infected person. Hepatitis A can also be spread through contaminated food or water, which most often occurs in countries where Hepatitis A is common.
- **Hepatitis B** is spread when body fluids—such as semen or blood—from a person infected with the Hepatitis B virus enter the body of someone who is not infected. The Hepatitis B virus is 50–100 times more infectious than HIV and is easily transmitted during sexual activity. Hepatitis B also can be spread through sharing needles, syringes, or other equipment used to inject drugs.
- **Hepatitis C** is spread through contact with the blood of an infected person, primarily through sharing needles, syringes, or other injection drug equipment. Hepatitis C can also be spread when getting tattoos and body piercings in informal settings or with non-sterile instruments. Although uncommon, Hepatitis C can also be spread through sexual contact. Having a sexually transmitted disease (STD) or HIV, sex with multiple partners, or rough sex appears to increase a person's risk for Hepatitis C.

The best way to protect yourself from Hepatitis A and B is to get vaccinated.

Continued on next page

APPENDIX 2 - CDC Hepatitis B Resources CONT'D

2j (page 1) -

Protect Your Baby for Life

When a Pregnant Woman Has Hepatitis B

Why should pregnant women be concerned about Hepatitis B?

Hepatitis B is a serious liver disease that can be easily passed to others. It is important for a woman to find out if she has Hepatitis B, so she can get medical care. It is also possible for a pregnant woman with Hepatitis B to pass the virus to her baby at birth. Fortunately, there is a vaccine to prevent babies from getting Hepatitis B.

What is Hepatitis B?

"Hepatitis" means inflammation of the liver. Hepatitis B is a contagious liver disease that results from infection with the Hepatitis B virus. When a person becomes infected, the Hepatitis B virus can stay in the person's body for the rest of his or her life and cause serious liver problems.

Can Hepatitis B be spread to babies?

Yes. The Hepatitis B virus can be spread to a baby during childbirth. This can happen during a vaginal delivery or a c-section.

How else is Hepatitis B spread?

Hepatitis B can also be spread when blood, semen, or other bodily fluids from a person with the virus enter the body of someone who is not infected. The virus is very infectious and is passed easily through breaks in the skin or in soft tissues such as the nose, mouth, and eyes.

This can happen through direct contact with blood from an infected person, even in tiny amounts too small to see. Hepatitis B can also be spread through sex with an infected person.

> **CDC recommends that babies get the HBIG shot and the first dose of Hepatitis B vaccine within 12 hours of being born.**

How serious is Hepatitis B?

When babies become infected with Hepatitis B, they have a 90% chance of developing a lifelong, chronic infection. As many as 1 in 4 people with chronic Hepatitis B develop serious health problems. Hepatitis B can cause liver damage, liver disease, and liver cancer.

How common is Hepatitis B?

About 350 million people worldwide and 1.2 million people in the United States are infected with Hepatitis B.

Can doctors prevent a baby from getting Hepatitis B?

Yes. Babies born to women with Hepatitis B get two shots soon after birth. One is the first dose of the Hepatitis B vaccine and the other shot is called HBIG. The two shots help prevent the baby from getting Hepatitis B. The shots work best when they are given within 12 hours after being born.

What is HBIG?

HBIG is a medicine that gives a baby's body a "boost" or extra help to fight the virus as soon as he or she is born. The HBIG shot is only given to babies of mothers who have Hepatitis B.

APPENDIX 2 – CDC Hepatitis B Resources CONT'D

2j (page 2) -

How can I make sure my family is protected from Hepatitis B?

Get everyone tested for Hepatitis B
Your baby's father and everyone else who lives in your house should go to the doctor or clinic to be tested. Testing your family members helps to tell if they have Hepatitis B. If they do not have Hepatitis B, the doctor will talk to them about getting the Hepatitis B vaccine to protect them from getting the infection.

Cover cuts and sores
Since Hepatitis B is spread through blood, people with Hepatitis B should be careful not to expose other people to things that could have their blood on them. It is important not to share personal items such as razors, nail clippers, toothbrushes, or glucose monitors. Cuts and sores should be covered while they are healing.

Do not chew food for your baby
Tiny amounts of blood can sometimes be in a person's mouth. Do not pre-chew food before you feed it to your baby.

Publication No. 22-0432

How many Hepatitis B shots does my baby need?

Your baby will get 3 or 4 shots, depending on which brand of vaccine is used. After the first dose is given in the hospital, the next dose is given at 1-2 months of age. The last dose is usually given by the time your baby is one year old. Ask your doctor or nurse when your baby needs to come back for each shot.

Does my baby need all the shots?

All the Hepatitis B shots are necessary to help keep your baby from getting Hepatitis B.

Prevent Hepatitis B.
Get your baby vaccinated.

How do I know my baby is protected?

After getting all the Hepatitis B shots, your doctor will test your baby's blood. The blood test tells you and your doctor that your baby is protected and does not have Hepatitis B. The blood test is usually done 1-2 months after the last shot. Be sure to bring your baby back to your doctor for this important blood test.

Hepatitis B is not spread by:

Breastfeeding
It is safe for you to breastfeed your baby. You cannot give your baby Hepatitis B from breast milk.

Cooking and eating
It is safe for you to prepare and eat meals with your family. Hepatitis B is not spread by sharing dishes, cooking or eating utensils, or drinking glasses.

Hugging and kissing
You can hug and kiss your baby, family members, or others close to you. You cannot give anyone Hepatitis B from hugging and kissing them. Also, Hepatitis B is not spread through sneezing or coughing.

For more information

Talk to your health professional, call your health department, or visit www.cdc.gov/hepatitis

DEPARTMENT OF HEALTH & HUMAN SERVICES
Centers for Disease Control and Prevention
Division of Viral Hepatitis

www.cdc.gov/hepatitis

October 2010

APPENDIX 2 - CDC Hepatitis B Resources CONT'D

2k (page 1) -

Protect Your Baby for Life

Hepatitis B and Your Baby

Why should pregnant women be concerned about Hepatitis B?

Hepatitis B is a contagious liver disease that can be easily passed from a pregnant woman to her baby at birth. Fortunately, there is a vaccine to prevent babies from getting Hepatitis B.

How is Hepatitis B spread?

Hepatitis B is spread when blood, semen, or other body fluids from a person with the Hepatitis B virus enter the body of someone who is not infected. The virus is very infectious and is easily spread to others. This can happen through:

- An infected mother passing it to her baby at birth
- Sex with an infected person
- Direct contact with blood from an infected person, even in tiny amounts too small to see

What is Hepatitis B?

"Hepatitis" means inflammation of the liver. Hepatitis B is a liver disease that results from infection with the Hepatitis B virus. Some people are able to fight the infection and clear the Hepatitis B virus. For others, the virus remains in their body and becomes a chronic, or lifelong, illness. Over time, Hepatitis B can cause serious health problems.

How serious is Hepatitis B?

As many as1 in 4 people with Hepatitis B develop serious liver problems including liver damage, liver failure, and even liver cancer. Every year, approximately 3,000 people in the United States die from Hepatitis B-related liver disease.

Prevent Hepatitis B.
Get your baby vaccinated.

How common is Hepatitis B?

It is estimated that 350 million people worldwide and 1.2 million people in the United States are infected with Hepatitis B. For every 1,000 pregnant women that give birth each year, 1 to 2 of them have Hepatitis B.

Are babies at risk for Hepatitis B?

Yes. When a pregnant woman has Hepatitis B it can be spread easily to her baby. Babies and young children can also get Hepatitis B from close contact with family members or others who might be infected. Infants who become infected with Hepatitis B have a 90% chance of developing a lifelong, chronic infection.

Are pregnant women tested for Hepatitis B?

Yes. Many women do not know they are infected, since people with Hepatitis B often have no symptoms. As a result, all pregnant women are given a blood test for Hepatitis B as part of their prenatal care. The test is usually performed during the first prenatal visit. If a woman has not received prenatal care, then she will be tested at the hospital before she delivers her baby.

Why are women tested for Hepatitis B?

Pregnant women are routinely tested for Hepatitis B, along with other diseases. These tests are done to find health problems that can be prevented or treated in both a woman and her baby.

APPENDIX 2 - CDC Hepatitis B Resources CONT'D

2k (page 2) -

Can Hepatitis B be prevented?

Yes. A vaccine for Hepatitis B has been used for about 30 years. The vaccine has been recommended for infants beginning in 1991. Since then, experts believe that the vaccine has prevented more than half a million children in the United States from getting Hepatitis B.

When does my baby get the first dose of the Hepatitis B vaccine?

CDC recommends that the first dose of vaccine be given to your baby before leaving the hospital.

How many Hepatitis B doses does my baby need?

The vaccine is given as 3 or 4 shots, depending upon the brand of vaccine used. After the first shot is given in the hospital, the next shot is usually given at 1-2 months of age. The last shot is given between 6 months and 18 months of age. Ask your doctor when your baby needs to come back for the next shot in the series.

CDC recommends that babies get the first dose of the Hepatitis B vaccine before leaving the hospital.

Why are these shots important?

Vaccines are one of the most important and effective ways to prevent diseases. Millions of babies have received Hepatitis B shots in the U.S. Experts believe that this vaccine has helped to reduce the number of children getting Hepatitis B by more than 90% over the last 20 years.

For more information

Talk to your health professional, call your health department, or visit www.cdc.gov/hepatitis.

DEPARTMENT OF HEALTH & HUMAN SERVICES
Centers for Disease Control and Prevention
Division of Viral Hepatitis

www.cdc.gov/hepatitis

October 2010

Publication No. 22-0427

APPENDIX 2 - CDC Hepatitis B Resources CONT'D

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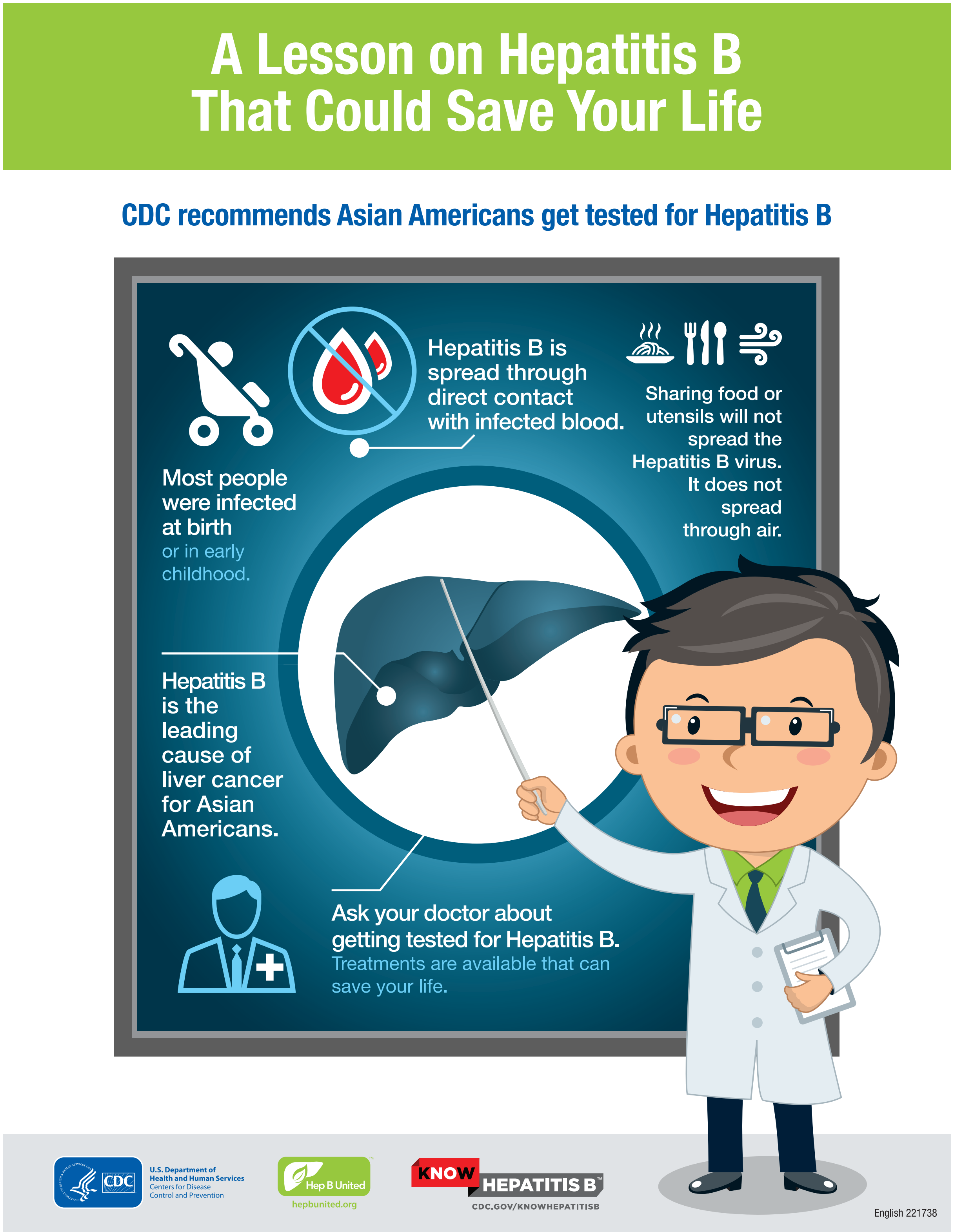

A Lesson on Hepatitis B That Could Save Your Life

CDC recommends Asian Americans get tested for Hepatitis B

Hepatitis B is spread through direct contact with infected blood.

Sharing food or utensils will not spread the Hepatitis B virus. It does not spread through air.

Most people were infected at birth or in early childhood.

Hepatitis B is the leading cause of liver cancer for Asian Americans.

Ask your doctor about getting tested for Hepatitis B. Treatments are available that can save your life.

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

Hep B United
hepbunited.org

KNOW HEPATITIS B
CDC.GOV/KNOWHEPATITISB

English 221738

APPENDIX 3 – Quiz: How Well Do You Know Hepatitis B? (CDC)

HOW WELL DO YOU KNOW

HEPATITIS B

TRUE	FALSE	
☐	☐	1. Hepatitis B is spread through direct contact with infected blood.
☐	☐	2. Hepatitis B cannot be spread through the air.
☐	☐	3. Hepatitis B cannot be spread through sharing meals, bowls or utensils with someone who has the disease.
☐	☐	4. 1 in 12 Asian Americans has Hepatitis B.
☐	☐	5. Many people with Hepatitis B don't have symptoms and don’t look or feel sick.
☐	☐	6. A Hepatitis B blood test is the only way to know if you are infected with the virus.
☐	☐	7. The CDC recommends that people born in Asia or the Pacific Islands be tested for Hepatitis B.
☐	☐	8. Treatments are available that can help prevent serious liver damage from Hepatitis B.
☐	☐	9. Most people infected with Hepatitis B were infected at birth or in early childhood.
☐	☐	10. Hepatitis B is the leading cause of liver cancer among Asian Americans.

ANSWER:
1. TRUE 2. TRUE 3. TRUE 4. TRUE 5. TRUE
6. TRUE 7. TRUE 8. TRUE 9. TRUE 10. TRUE

APPENDIX 4 – Hepatitis B Fast Facts Everything you need to know in 2 minutes or less! (Hepatitis B Foundation)

Hepatitis B Foundation
Cause for a Cure

www.hepb.org

Hepatitis B Fast Facts
Everything you need to know in 2 minutes or less!

Hepatitis B is the most common serious liver infection in the world. It is caused by the hepatitis B virus (HBV) that attacks liver cells and can lead to liver failure, cirrhosis (scarring) or cancer of the liver. The virus is transmitted through contact with blood and bodily fluids that contain blood.

Most people are able to fight off the hepatitis B infection and clear the virus from their blood. This may take up to six months. While the virus is present in their blood, infected people can pass the virus on to others.

Approximately 5-10% of adults, 30-50% of children, and 90% of babies will **not** get rid of the virus and will develop chronic infection. Chronically infected people can pass the virus on to others and are at increased risk for liver problems later in life.

The hepatitis B virus is 100 times more infectious than the AIDS virus. Yet, hepatitis B can be prevented with a safe and effective vaccine. For the 400 million people worldwide who are chronically infected with hepatitis B, the vaccine is of no use. However, there are promising new treatments for those who live with chronic hepatitis B.

In the World:

- This year alone, 10 to 30 million people will become infected with the hepatitis B virus (HBV).
- The World Health Organization estimates that 400 million people worldwide are already chronically infected with hepatitis B.
- HBV infection leads to over 1 million deaths each year.

In the US:

- This year alone, up to 100,000 new people will become infected with HBV.
- The Centers for Disease Control and Prevention (CDC) estimate that 1.25 million Americans are already chronically infected with hepatitis B.
- Between 5,000 and 6,000 Americans die of hepatitis B-related liver complications each year.

How is Hepatitis B Transmitted?
Hepatitis B is most efficiently transmitted through blood and infected bodily fluids. This can occur through direct blood-to-blood contact, unprotected sex, illicit drug use, and from an infected woman to her newborn during pregnancy or the delivery process.

APPENDIX 4 – Hepatitis B Fast Facts Everything you need to know in 2 minutes or less! (Hepatitis B Foundation) CONT'D

Hepatitis B can be spread by

- unprotected sex
- sharing IV drug needles
- living in a household with an infected person
- an infected mother to her newborn child at birth
- sharing earrings, razors, or toothbrushes with an infected person
- unsterilized needles, including tattoo or piercing needles
- human bites

Hepatitis B is not spread by

- kissing on the cheek or lips
- coughing or sneezing
- casual contact such as hugging or holding hands
- eating food prepared by an infected individual

People are most at risk for hepatitis B if they

- are born to mothers who are infected with HBV
- live in close household contact with a chronically infected individual
- adopt a child from a country where HBV is prevalent
- have unprotected sex or have more than one sexual partner in a six month period
- have ever been diagnosed with a sexually transmitted disease (STD)
- men who have sex with men
- share needles and syringes
- are a health care provider or emergency responder with possible contact with bodily fluids
- are a patient on kidney dialysis
- live or work in an institutional setting, such as a prison or group home

Can hepatitis B be prevented?

YES! Ask your doctor about the safe and effective vaccine and protect yourself and your loved ones for a lifetime. The CDC and the American Academy of Pediatrics recommend that all infants, children and adolescents up to age 18 receive the HBV vaccine. The vaccine is also recommended for all adults who may be at high risk for infection.

The cost for the vaccine varies in the US, but most insurance plans cover infants and children to 18 years of age. Some people can receive the vaccine free of charge from their local public health clinic. High-risk adults may also be covered by their health insurance or can receive the vaccine through an STD or family planning clinic.

Remember, it only takes three shots to provide a lifetime of protection!

Additional hepatitis B resources

Visit our website at www.hepb.org
Centers for Disease Control and Prevention (CDC) hepatitis branch at www.cdc.gov/hepatitis
American Liver Foundation at www.liverfoundation.org
Immunization Action Coalition at www.immunize.org

02/07

APPENDIX 5 – Additional Hepatitis B Resources and Campaigns

5a - **Hepatitis B Policy Brief (AAPCHO)**
http://www.aapcho.org/resources_db/hepatitis-b-policy-brief

5b - **Know Hepatitis B (CDC)**
https://www.cdc.gov/knowhepatitisb

5c - **#justB Storytelling Campaign (Hepatitis B Foundation)**
http://www.hepb.org/research-and-programs/patient-story-telling-project

5d - **Living with Hepatitis B Cultural Barriers, Stigma, and Institutional Discrimination webinar (Hep B United)**
Recording: https://youtu.be/Dit4f5KHEQ8
Slides: http://hepbunited.org/wp-content/uploads/2015/03/SL_Slides.pdf

5e - **"The Test" Hepatitis B Comic Book (Charles B. Wang Community Health Center)**
http://www.cbwchc.org/Docs/HepBComicEnglish.pdf

APPENDIX 6 – Toolkit Feedback Form

Understanding and Combating Stigma: A Toolkit for Improving Care and Support for People Affected by HBV

Toolkit Feedback Form

Please help us improve this toolkit by completing this feedback form.

1. I am a (check all that apply):
   - ☐ Health care provider (health center, hospital, etc.)
   - ☐ Person living with HBV
   - ☐ A family member/friend/community member of a person living with HBV
   - ☐ Other: ____

2. How did you find out about this toolkit (check all that apply)?
   - ☐ AAPCHO communication or event/training (email, website, social media, conference, webinar, etc.)
   - ☐ Word of mouth
   - ☐ Other

3. What exercises did you use?

4. What kind of training did you use the exercises for and who was the target audience?

5. Which exercises worked well? Why?

6. Which exercises did not work well? Why?

7. Please describe any changes or improvements you made to any exercises.

8. What ADDITIONAL TOPICS need to be added to the toolkit?

9. Have you developed any resources on reducing stigma associated with HBV? If yes, please describe and, if possible, share them with AAPCHO.

10. If you are willing for us to contact you further about this toolkit and feedback, please provide your contact information below.

    Name: _____________________________________ Email: _________________________________

Thank you for your feedback. Please send completed forms to:

AAPCHO
101 Callan Avenue, Suite 400
San Leandro, CA 94577
HBVStigmaToolkit@aapcho.org

Association of Asian Pacific Community Health Organizations
101 Callan Avenue, Suite 400
San Leandro, CA 94577
(510) 272-9536
HBVStigmaToolkit@aapcho.org
www.aapcho.org