



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 35 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 case study.

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SNEAK PEEK COPY

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SNEAK PEEK COPY

ABOUT HBV

Hepatitis B is the most common serious liver infection in the world and is a global public health problem. Hepatitis B is caused by the hepatitis B virus (HBV), which is up to 100 times more infectious than HIV and often goes undetected. Two billion people (1 in 3) have been infected with HBV and more than 240 million people are living with a chronic hepatitis B infection. HBV attacks the liver, leading to chronic (lifelong) infection, cirrhosis (scarring) of the liver, liver cancer, liver failure, and even death. Chronic hepatitis B is the primary cause of liver cancer, which is the second leading cause of cancer deaths in the world.

HBV is most commonly spread through contact with infected blood and other body fluids, unprotected sex, contaminated needles (e.g., injecting drugs, tattooing or using improperly sterilized medical or dental equipment), and from an infected mother to her newborn during pregnancy and childbirth. Hepatitis B is not transmitted through casual contact. It can't be spread through doorknobs, toilet seats, sneezing, coughing, hugging or sharing food.

Hepatitis B is preventable and treatable. There is an effective and safe vaccine to prevent hepatitis B, and there are effective drug therapies that can manage a chronic hepatitis B infection. When a person is first infected with HBV, it's called an "acute infection" or a new infection. Most adults are able to get rid of the virus without any problem but some adults are unable to get rid of the virus after six months and are diagnosed with a "chronic infection." An inexpensive and simple blood test is the only way to diagnose an acute or chronic hepatitis B infection. While chronic hepatitis B is not curable, it is treatable and there are effective treatments that can control and even stop HBV from further damaging a liver. There are also promising new drugs that could provide a cure in the near future.



HEPATITIS B IS PREVENTABLE AND TREATABLE.

HBV, AAPIS AND OTHER AT-RISK GROUPS

In the United States, up to 12 million (1 in 20) people are infected with HBV. Nationally, Asian Americans and Pacific Islanders (AAPIs) account for more than 50 percent (1 in 12) 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. 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).

HBV AND STIGMA

HBV-related stigma refers to the devaluation of people living with or affected by HBV. 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 HBV prevention, care and treatment, and helps fuel the global hepatitis B epidemic.

FIVE STEPS TO STOP HBV STIGMA

KNOW THE FACTS

Educate Even if you know about HBV, make sure you understand yourself about HBV. Seek accurate information about how HBV is transmitted, who is at risk, and how to improve effective care and support is implemented for people affected by HBV. ***Learn the facts and address the myths.***

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. ***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.***

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, interventions must work on the individual, environmental and policy levels

There is increasing evidence of the benefits of supportive and stigma-free 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.

HOW TO USE THIS TOOLKIT

This toolkit is written for community health advocates and anyone who wants to improve 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, and 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 community.

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 but 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, and 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 in this toolkit have been adapted from Ross Kidd and Sue Clay, “Understanding and Challenging HIV Stigma: Toolkit for Action,” International Center for Research on Women, September 2003. Exercises are in the process of being pilot-tested.

MODULE A



UNDERSTANDING AND CONFRONTING STIGMA

SNARK PEEK COPY

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 SOCIAL AND PERCEIVED/SELF-STIGMA. BOTH FORMS CAN EXHIBIT THEMSELVES IN THE FOLLOWING WAYS:

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- 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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- Lack of self-worth and despair (can lead to depression, suicide, alcoholism, etc.)
- Kicked out of family, house, work, rented accommodation, organization, etc.
- Dropout from school due to bullying
- Climate of fear that contributes to keeping people from seeking prevention, care and treatment, which leads to poor health outcomes 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



A1 // ACTIVITIES

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

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 – OUR EXPERIENCE AS STIGMATIZER AND STIGMATIZED



A2 // ACTIVITIES

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

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.

EXERCISE A3 – STIGMA TREE: FORMS, EFFECTS AND CAUSES



A1 // ACTIVITIES

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OBJECTIVES :

Participants will be able to:

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

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?”



TIME :

1-2 hours



MATERIALS :

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

HBV STIGMA EXAMPLES

FORMS

Name calling; scapegoating; finger pointing; teasing; 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 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).

APPENDIX A



PICTURES FOR EXERCISES

A1

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COPY

A2

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A2

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SNEAK