Unit 4: Stigma and Infectious Diseases

Instructional Activities for Teens

PKIDs’ Infectious Disease Workshop

Made possible by grants from the Northwest Health Foundation, the Children’s Vaccine Program at PATH and PKIDs.
PKIDs’ Infectious Disease Workshop
Acknowledgements

Producing this workshop has been a dream of ours since PKIDs’ inception in 1996. It has been more than two years since we began work on this project, and many people helped us reach our goal. It’s not done, because it is by nature a living document that will evolve as science makes strides in the research of infectious diseases, but it’s a great beginning.

There are people who’ve helped us whose names are not on this printed list. That omission is not deliberate, but rather from our own clumsiness in losing important pieces of paper, and we apologize.

Without the funding and support of the Northwest Health Foundation and the Children’s Vaccine Program at PATH (Program for Appropriate Technology in Health), this would have been an impossible task. Dr. Katherine Vaughn, PKIDs’ Medical Director and Dr. Karen Steingart, scientific advisor to PKIDs, provided excellent guidance through their editorial oversight and knowledgeable contributions to the Infectious Disease Workshop.

On PKIDs’ staff are three individuals without whom this publication would never have been finished—Franji Mayes, Mylei Basich and Christine Kukka, all of whom gave their very best to ensure this workshop is accurate and user-friendly.

We are indebted to the following individuals who cheerfully gave us hours of their time and access to their resources: the American Society for Microbiology; Kathy A. Bobula, Ph.D., Coordinator, Early Childhood Education, Clark College, Vancouver, Wash.; Claudia Bratt, elementary school teacher, Truman Elementary, Vancouver, Wash.; Sue Campbell, Early Childhood Educator, Kindercare; many wonderful and helpful people at the Centers for Disease Control and Prevention, Atlanta, Georgia; Rachel Coyle, Case Aide and Residential Care Staff Lead, Jonathan’s Place; Tammy Dunn, Early Childhood Director, Portland Christian Schools, Portland, Oregon; Bruce Gellin, M.D., Director of the National Vaccine Program Office in the Office of the Assistant Secretary for Health, Department of Health and Human Services; Shannon Harrison, M.D., Internal Medicine and Infectious Diseases, Teton Hospital, Jackson, Wyoming; the Immunization Action Coalition; Brad Jensen, M.D., Southwest Washington Medical Center Pathology Department; Edgar Marcuse, M.D., Professor of Pediatrics, University of Washington and Director of Medical Services, Seattle Children’s Hospital and Regional Medical Center; Zack Mittge, law student, University of Oregon; the National Network for Immunization Information; Paul Offit, M.D., Chief, Section of Infectious Diseases and the Henle Professor of Immunologic and Infectious Diseases at The Children’s Hospital of Philadelphia; Carol Porter, Red Cross health room volunteer, Garland Independent School District, Garland, Texas; Sarah Theberge, Curriculum Instructor, Early Childhood Education, Clark College, Vancouver, Wash.; James Whorton, Ph.D., Professor, Department of Medical History and Ethics, University of Washington School of Medicine.

We thank the following for providing nonprofit rates for their microscopic images: Dennis Kunkel Microscopy, Inc., and Science Photo Library/Photo Researchers, Inc.
(Cover photo: Dennis Kunkel Microscopy, Inc./www.denniskunkel.com)

Additional funding for this project provided by PKIDs (Parents of Kids with Infectious Diseases).

©PKIDs 2004
# Table of Contents

Introduction ................................................................................................................................. 5

Letter from Teachers to Parents................................................................................................6

1. Stigma and You: Pre– and Post-Workshop Assessments .................................................... 7
   Self-Assessment Handout ........................................................................................................ 8

2. Stigma: Is It Logical? ............................................................................................................ 10
   Worksheet ............................................................................................................................... 11

3. Infectious Disease: It Could Happen to YOU ................................................................. 12
   Labels ..................................................................................................................................... 14
   Overhead/Printout .................................................................................................................. 15

4. HIV/AIDS: Examining the Impacts of Public Health Policy on an Epidemic ................. 16
   Handout .................................................................................................................................. 17

5. A Tale of Two Cities: Ryan White’s Struggle with Stigma .............................................. 21
   Story ....................................................................................................................................... 22

6. Telling the Stories .................................................................................................................. 25
   Handout .................................................................................................................................. 26

7. Stigma Awareness Statement ............................................................................................ 27
   Handout .................................................................................................................................. 28

Bibliography .............................................................................................................................. 29

Additional Activities and Resources ........................................................................................ 30

To navigate this document, use the bookmarks to the left or select an item on this page.

Click here to go back to the PKIDs' IDW website.

This publication contains the opinions and ideas of its authors. It is intended to provide helpful and informative material on the subject matter covered. Any information obtained from this workshop is not to be construed as medical or legal advice. If the reader requires personal assistance or advice, a competent professional should be consulted.

The authors specifically disclaim any responsibility for any liability, loss, or risk, personal or otherwise, which is incurred as a consequence, directly or indirectly, of the use and application of any of the contents of this workshop.
Introduction

PKIDs (Parents of Kids with Infectious Diseases) is a national nonprofit agency whose mission is to educate the public about infectious diseases, the methods of prevention and transmission, and the latest advances in medicine; to eliminate the social stigma borne by the infected; and to assist the families of the children living with hepatitis, HIV/AIDS, or other chronic, virulent infectious diseases with emotional, financial and informational support.

Remaining true to our mission, we have designed the Infectious Disease Workshop (IDW), an educational tool for people of all ages and with all levels of understanding about infectious diseases. In this workshop, you will learn about bacteria and viruses, how to prevent infections, and how to eliminate the social stigma that too often accompanies diseases such as HIV or hepatitis C.

We hope that both instructors and participants come away from this workshop feeling comfortable with their new level of education on infectious diseases.

The IDW is designed to “train-the-trainer,” providing instructors not only with background materials but also with age-appropriate activities for the participants. Instructors do not need to be professional educators to use these materials. They were designed with both educators and laypersons in mind.

The IDW is comprised of a master Instructor’s Background Text, which is divided into six units: Introduction to Infectious Diseases, Disease Prevention, Sports and Infectious Disease, Stigma and Infectious Disease, Civil Rights and Infectious Disease, and Bioterrorism and Infectious Disease.

For each unit, instructors will find fun and helpful activities for participants in five age groups: 2 to 6 years of age, 6 to 9 years of age, 9 to 12 years of age, 13 to 18 years of age and adults.

*We welcome any questions, comments, or feedback you may have about the IDW or any other issue relating to infectious diseases in children.*

PKIDs
P.O. Box 5666
Vancouver, WA 98668
VOICE: (360) 695-0293 or toll-free 877-557-5437
FAX: (360) 695-6941
EMAIL: pkids@pkids.org
WEBSITE: www.pkids.org
Dear Parents,

Our class will soon be studying infectious diseases. We will learn about what germs are and ways we can keep from spreading germs. We will also learn that people who have infectious diseases don’t have to be treated differently or singled out just because they have a disease.

The workshop we will use has been created by PKIDs (Parents of Kids with Infectious Diseases), a national nonprofit organization dedicated to supporting families touched by infectious diseases.

Your child may have questions about germs or may come home with new ideas about preventing the spread of germs. Here are a few ways you can stay informed:

View PKIDs’ website. PKIDs’ website can be found at www.pkids.org. You may also request information by calling PKIDs at 1-877-55-PKIDS.

View the instructor’s background text for the Infectious Disease Workshop (IDW). The primary purpose of this text is to provide teachers with background information on infectious diseases. It is a good text for anyone seeking general information on infectious diseases. The text provides information about specific diseases, methods of disease prevention, and civil rights for those affected by infectious disease. Visit www.pkids.org for a link to the IDW background texts in PDF format.

View descriptions of the activities we will be doing in class. Visit www.pkids.org for a link to the activities and handouts in PDF format.

The world becomes smaller every day and germs from near and far continue to threaten our health. It is extremely important to educate our young people, equipping them with prevention methods to protect their health and stop the spread of disease.

As always, please feel free to contact me with any questions!

Sincerely,
STIGMA AND YOU
Pre- and Post-Workshop Self-Assessments

LEVEL
Teens

OBJECTIVE
• Students will assess their own beliefs regarding infectious diseases.
• Students will assess their own behaviors toward people with infectious diseases.

MATERIALS
2 copies of the self-assessment worksheet (included) for each student—1 for before the workshop begins and 1 for after its conclusion.

PREP
None. *This exercise should be done 1) prior to any other activities in the stigma unit and 2) after completion of the stigma activities.*

INSTRUCTIONAL COMPONENTS
1. Introduce the Infectious Disease Workshop. Explain that through a series of activities, students will learn about 1) infectious diseases and disease transmission, 2) what we can do to minimize and prevent transmission, and 3) the social stigma that is borne by people living with infectious diseases.
3. Instruct students that no one (not even the teacher) will read what they have written—what they write is for their eyes only.
4. Students should read and complete the handout individually, either in class or outside of class.
5. The self-assessments should be collected and stored in a safe/confidential place (or students could keep them) for later reference.
6. After students have completed the stigma activities, pass out another copy of the self-assessment for them to complete.
7. Pass back their original, pre-workshop assessments. Give them time to compare.

ASSESSMENT
• Students may do a short write-up commenting on how their beliefs about their behaviors in the various situations have or have not changed.
• The class could also have an open discussion on the topic.
STIGMA AND YOU
Pre– and Post-Workshop Self-Assessment

The purpose of this self-assessment is to help you understand your current beliefs regarding infectious diseases and how you might behave in various situations when dealing with infectious diseases and the people who may have them. Later, you can review your answers to see if your beliefs have changed or remained the same.

1. You are a clerk in a bookstore. You notice that a stack of books has been left out on a play table in the children’s section. You set them aside, intending to shelve them later. Suddenly, an anxious parent approaches you, asking if those books were found on a play table. You say that they were. She informs you that her child, who has hepatitis C, was playing with the books when she got a paper cut. You look at the books again and see that there are indeed small spots of blood on the books.

How would you feel? Do you think your true feelings would be different than what you hope they would be? Why?

How would you react to the parent? To the child? To the circumstance? Why?

2. You are a parent. Your child is enrolled in a daycare program. One day, the teacher calls you to say she has been informed that one of the other children has a bloodborne, infectious disease—HIV. What is your “gut” reaction?

What action(s), if any, would you take? Why?
3. You happen to know that Person X has hepatitis B. One day, as you are approaching the water fountain for a drink, you see Person X taking a drink from the same fountain.

What do you do? Why?

4. You have just discovered you have an infectious disease; perhaps hepatitis C. You are playing football with some friends. In your excitement, you collide with one of your buds. You stop and notice your blood on your pal’s arm. He shrugs it off and returns to the game.

What do you do?

Is what you feel you should do different than what you would actually do? Why?

5. You are playing soccer with some friends. In your excitement, you collide with one of your buds. You stop and notice your pal’s blood on your arm. She has never said anything to you about having an infectious disease.

What do you do?

Is what you feel you should do different than what you would actually do? Why?

6. You are ice skating with some friends. In your excitement, you collide with one of your buds. You stop and notice your blood on your pal’s arm. He shrugs it off and returns to the game. You have no reason to believe you may have an infectious disease.

What do you do?

Is what you feel you should do different than what you would actually do? Why?
STIGMA
Is It Logical?

LEVEL
Teens

OBJECTIVE
• Students will calculate percentages as they apply to infectious diseases.
• Based on their calculations, students will draw conclusions as to whether or not it is logical to single out a person who is known to have an infectious disease.

MATERIALS
• 1 copy of the included handout for each student.
• Calculator for each student.

PREP
None

INSTRUCTIONAL COMPONENTS
1. Pass out handout.
2. Allow students time to read and complete, either in or out of class.

ASSESSMENT
Discuss results and impressions.
STIGMA: IS IT LOGICAL?

You Do the Math

Sometimes, when we find out a person has an infectious disease, we stigmatize that person. Maybe we avoid that person, or we tell others that person has an infectious disease. We think that by singling out this one person, we can protect ourselves and other people from the disease. Is that really the case? Let’s find out. We’ll use hepatitis C—just one of many infectious diseases—as an example.

1. First, make a rough estimate of how many people you know:
   Co-workers: ____
   People in your school: ______
   Friends outside of work/school: ____
   Family: _____
   People in recreational or church groups: _____
   TOTAL:_______

2. Now, how many of these people have hepatitis C (that you know of)? _____. (This number will probably be very low, if any).

3. The Centers for Disease Control and Prevention (CDC) estimates that about 1.8 percent of Americans have been infected with hepatitis C. Multiply the number of people you know by 0.018. Write that number here: _______. This is roughly the number of people you know who probably have or had hepatitis C; you may simply not be aware of their infection.

4. The CDC estimates that about 80 percent of people infected with hepatitis C experience no signs or symptoms of the disease. Let’s assume, therefore, that these 80 percent do not know they have the disease at all. Multiply the number in Question 3 by 0.8. Write that number here: _______. This is roughly the number of people you know who probably have hepatitis C and don’t even know it. This means you don’t know it, either.

5. So what does this mean? It means that, for example, even if you do know 1 person out of 250 with hepatitis C, there are probably 3-4 other people who have chosen not to tell you of their infection, or they are simply unaware of it themselves (1.8 percent of 250 is 4.5 people). So, even if you were to stigmatize (e.g., avoid) the 1 person, you would still encounter 3-4 other unknown infected people. Infectious diseases, like hepatitis C, are found throughout our population—rich and poor, uneducated and educated, Catholics and Muslims—no one group seems to be completely immune.

6. So far, we’ve only talked about one disease—we haven’t even mentioned herpes, cytomegalovirus, hepatitis B, HIV/AIDS or any of the other diseases waiting to infect us. Do you think you could keep yourself safe from infectious disease by stigmatizing that one person whose infection status you know? Write your answer here: __________.
INFECTIONOUS DISEASE
It Could Happen to YOU

LEVEL
Teens

OBJECTIVE
• Students will discuss the experience of being statistically diagnosed with AIDS.
• Students will form judgments regarding their own potential actions if they were to discover
  they had contracted an infectious disease.

MATERIALS
• Scissors.
• Sheets of labels (included with lesson plan).
• Non-transparent container(s) to hold slips of paper.
• Timer.
• “Many people…” handout (included with lesson plan).

PREP
This activity should be done during some other class activity, preferably the PKIDs’ IDW AIDS
Timeline Study.
1. Determine how long your instruction time will be (in minutes). Divide that time by 13. The
resulting number is the number of students who will become statistically “HIV positive”
during the class period (roughly 4 per hour).
2. If your number of “HIV positive” students will be 4, then you will need 4 copies of the at-
tached label sheet. The attached sheet of labels contains 30 labels. You will need one label
for each person in the class, per set of labels.
3. Place each set of labels into a non-transparent container. (If you just have 1 container, put
the first set into the container and keep the others in separate piles. Remember, there must
be one “HIV positive” label in every set.)
4. Print out the “Many people…” handout (included with this lesson plan), either as a handout
or for display on overhead projector.

INSTRUCTIONAL COMPONENTS
1. Just before class begins, display “Many people…” on overhead projector, or place it on
each student’s desk/seat as a handout for them to read as class begins.
2. When class begins, set a timer for 13 minutes. It is OK for the students to see you do this,
but it is not necessary to comment on what you are doing. The activity will probably be
more effective if it is not discussed prior to onset.
3. Proceed with activities as normal.
4. At the end of 13 minutes, pass the container of labels around the class. Each student should
take one and place it on their desk (if desks are being used).
5. Set the timer again for 13 minutes and repeat the process, allowing some time at the end of
class for questions/discussion.
**ASSESSMENT**

1. How did your perception of HIV infection change (or not change) because of this activity?
2. Do you feel the activity accurately demonstrated the potential for HIV infection? Why or why not?
3. What, if anything, did you find most striking about this activity?
<table>
<thead>
<tr>
<th>HIV POSITIVE</th>
<th>HIV NEGATIVE</th>
<th>HIV NEGATIVE</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV NEGATIVE</td>
<td>HIV NEGATIVE</td>
<td>HIV NEGATIVE</td>
</tr>
<tr>
<td>HIV NEGATIVE</td>
<td>HIV NEGATIVE</td>
<td>HIV NEGATIVE</td>
</tr>
<tr>
<td>HIV NEGATIVE</td>
<td>HIV NEGATIVE</td>
<td>HIV NEGATIVE</td>
</tr>
<tr>
<td>HIV NEGATIVE</td>
<td>HIV NEGATIVE</td>
<td>HIV NEGATIVE</td>
</tr>
<tr>
<td>HIV NEGATIVE</td>
<td>HIV NEGATIVE</td>
<td>HIV NEGATIVE</td>
</tr>
<tr>
<td>HIV NEGATIVE</td>
<td>HIV NEGATIVE</td>
<td>HIV NEGATIVE</td>
</tr>
<tr>
<td>HIV NEGATIVE</td>
<td>HIV NEGATIVE</td>
<td>HIV NEGATIVE</td>
</tr>
<tr>
<td>HIV NEGATIVE</td>
<td>HIV NEGATIVE</td>
<td>HIV NEGATIVE</td>
</tr>
<tr>
<td>HIV NEGATIVE</td>
<td>HIV NEGATIVE</td>
<td>HIV NEGATIVE</td>
</tr>
<tr>
<td>HIV NEGATIVE</td>
<td>HIV NEGATIVE</td>
<td>HIV NEGATIVE</td>
</tr>
</tbody>
</table>
Many people don’t even know they have an infectious disease.

Contracting an infectious disease is not always a matter of choice, but it is sometimes a matter of chance. While it is important to avoid behaviors that put you at greater risk for contracting an infectious disease, not everyone who has an infectious disease was participating in risky behaviors when they contracted the disease.

HIV is one of many infectious diseases prevalent in the United States, with an estimated 40,000 new HIV infections occurring every year. This means that…

…about every 13 minutes, a new HIV infection occurs.
HIV/AIDS
Examining the Impacts of Public Health Policy on an Epidemic

LEVEL
Teens

OBJECTIVE
• Students will discuss political and social events surrounding the AIDS epidemic in the U.S.
• Students will form judgments regarding the effects of these events on the public’s fears and subsequent stigmatization of people with infectious diseases.

MATERIALS
4-page AIDS timeline handout (accompanies this lesson plan)—1 per student.

PREP
None

INSTRUCTIONAL COMPONENTS
1. Toward the end of the instructional period, pass out the handout. Allow time for students to read it and ask questions, if any.
2. In the following class period, discuss students’ answers. You may wish to allow class time for the peer responses (see ASSESSMENT) to be composed following the discussion.

ASSESSMENT
1. Students will compose short essay answers to the questions at the end of the handout.
2. Students will select 1-3 responses of their peers in a short, informal written essay response.
HIV/AIDS
How public health policy impacts an epidemic

U.S. HIV/AIDS EPIDEMIC TRENDS
(Source: CDC)

HIV incidence prior to 1990 is based on back calculation of actual AIDS cases; figures after 1990 are CDC estimates based on available studies of incidence, prevalence, and size of risk populations.

Infectious disease epidemics are rarely static or predictable. Like a flood, they change course and infect new geographic regions and populations. What dictates their growth or disappearance is the effectiveness of health authorities in containing the infection, educating the public about its prevention, and developing an effective vaccine.

Integral to containing an epidemic is removing any stigma surrounding the disease so people can freely discuss the disease and learn how to prevent it. When people are willing to be tested, new infections can be prevented.

The HIV/AIDS pandemic in the United States and around the world illustrates how diseases spread when proper precautions and containment do not occur.
TIMELINE OF POLITICAL AND SOCIAL EVENTS

1920s-1940s: Some scientists believe HIV spread from monkeys to humans around this time.

1959: A man died in the Congo from what scientists now believe was the first proven AIDS case.

1978: Gay men in the United States and Sweden, as well as heterosexuals in Tanzania and Haiti, begin showing symptoms of what will later be called AIDS.

1981: The CDC notices an increase in Kaposi’s Sarcoma (a rare cancer) in otherwise healthy gay men.

1982: The term “AIDS” (Acquired Immune Deficiency Syndrome) is first used.

1983: The CDC warns blood banks of a possible problem with the blood supply. Scientists discover the HIV virus. The CDC establishes a national AIDS hotline. The first prevention recommendations are issued by the CDC, FDA, and NIH.

1984: AIDS is identified as being caused by HIV.

1985: The FDA approves the first test kit to screen for HIV antibodies. State and local health departments receive funding for HIV prevention programs. The first guidelines for blood screening are issued.


1987: President Ronald Reagan addresses the AIDS epidemic for the first time in public. A family in Florida with three HIV-positive hemophiliac sons, who contracted the infections through blood products, is driven from its home, which is torched by an arsonist. The FDA approves AZT (the first drug for the treatment of AIDS), sanctions the first human testing of potential AIDS vaccines. The AIDS memorial quilt is started.

1988: The U.S. government mails out 107 million copies of the booklet “Understanding AIDS.” The government bans discrimination against federal workers with HIV. Universal Precautions are established for health care workers.

1989: The price of AZT is lowered after 2 years of protests by the group ACT UP. Community-based organizations are funded to reach underserved African-American communities.

1990: Ronald Reagan apologizes for his neglect of the epidemic during his presidency. Ryan White—the young man who was prevented from attending school and driven from his hometown because of his AIDS—dies. Congress provides legal protection (ADA) for people with AIDS.
1991: About 10 million people worldwide are believed to be infected with HIV. Magic Johnson announces he is HIV-positive.


1993: Studies show condoms are 98 percent effective against HIV.

1994: Perinatal HIV prevention guidelines are issued after identification of first preventive regimen.

1995: 500,000 cases of AIDS have been reported.

1996: Regimen identified for reducing perinatal HIV transmission in the developing world.

1997: Annual AIDS deaths drop in the U.S.—the first decline reported.

1998: Congressional Black Caucus provides additional funding to minority prevention programs.

1999: The FDA approves a drug for treatment of pediatric AIDS. Number of annual AIDS cases due to perinatal transmission declines to an all-time low (144 annually).

2000: An estimated 800,000 to 900,000 people are living with HIV in the United States.

The epidemic that began primarily among homosexual men more than 20 years ago has changed dramatically.

Today, about 40,000 new HIV infections occur every year in the U.S. Of these, roughly 30 percent are women. Females make up nearly half (47 percent) of HIV cases in the 13- to 24-year-old age group. In young people between the ages of 13 and 19, there is an even greater proportion of HIV infections in females (61 percent) than males (39 percent).

Cumulatively, young African-Americans are most heavily affected, accounting for 65 percent of all HIV cases ever reported among 13- to 24-year-olds.

CDC studies also show that at least 50 percent of all new HIV infections are among those under age 25. This means that about 20,000 young people are infected with HIV every year. In other words, two young Americans between the ages of 13 and 24 are contracting HIV every hour.
Discussion topics/questions:
1. Discuss how various political and social events may have affected the rise and decline of HIV infection rates in the U.S.
2. How might the timeline of this epidemic have changed if the U.S. government had acted differently? What should or should not have happened?
3. How has stigma impacted the course of this disease?
4. Do you think most young people—especially women—today consider themselves at risk for HIV/AIDS? Do you consider yourself at risk? Why or why not?
5. Given that teens and people in their early 20s are contracting HIV at alarming rates, why do you think so many are reluctant to abstain from sex or use condoms? Do you think boys and girls view this issue differently?
6. Imagine you have a friend who practices unsafe sex or is an injection drug user. What would you say to encourage him or her to stop or change this behavior?
A TALE OF TWO CITIES
Ryan White’s Struggle with Stigma

LEVEL
Teens

OBJECTIVE
• Students will analyze differing reactions to people with AIDS.
• Students will apply concepts learned from Ryan White’s struggle with stigma to their own lives.

MATERIALS
Included handout.

PREP
• Copy handout (unless the handout will be read to the class).
• Predetermine groups, if desired.

INSTRUCTIONAL COMPONENTS
1. Read the handout to the students or have students read it separately. Students can read the included handout in class or for homework.
2. Have students answer discussion questions either in class or outside of class, individually or in groups. If answered individually, students should discuss their answers with the class.

ASSESSMENT
See handout for questions.
A TALE OF TWO CITIES
Ryan White’s Struggle with Stigma

In 1984, Ryan White was diagnosed with AIDS. Ryan was 13 years old at the time, living in Kokomo, Indiana, with his mother, Jeanne, and younger sister, Andrea. Ryan was born with hemophilia, a genetic disorder that causes the body to be deficient in a protein that helps blood to clot. As a hemophiliac, Ryan had already learned that in order to have any fun in life, he had to stay tough and optimistic, despite potential physical limitations.

Ryan contracted HIV and eventually developed AIDS due to contaminated blood products he had to take for his hemophilia. Despite a bleak prognosis, Ryan lived 5 more years and inspired many people because of his undying optimism and desire to enjoy life despite AIDS, and despite the many people who stigmatized him.

During the 1980s, HIV/AIDS was viewed as a “gay” disease. Some individuals believed AIDS was a punishment for “immoral” behavior. While AIDS education has helped correct this viewpoint, it still lingers with some.

Ryan White wanted to lead a normal, healthy life. He liked skateboarding and worked at a skateboard store. He had an avid interest in comic books and cars. And like many kids, he had a teen idol—actress Alyssa Milano.

After word of Ryan’s AIDS status spread, people in his town stigmatized him, treating him differently from others. Ryan and his family found comfort in their faith but little in their church, as members of their congregation would not even shake hands with the Whites. They decided to leave Kokomo in the hope of finding a town where people would not be afraid of them and where the stigma that was such an emotional burden would not follow. In 1987, they moved to Cicero, Indiana, where they were generally welcomed and were able to live lives relatively free of social stigma.

It would be unfair to say that all people in Kokomo stigmatized Ryan; it would also be unfair to say that all people in Cicero welcomed his family. Ryan’s family and the town of Kokomo were surprised by the discovery of Ryan’s infection. Cicero, on the other hand, had time to prepare for Ryan’s arrival—and the fact that he had this disease. People in both towns had fears about AIDS – the difference was in how those fears were dealt with. Let’s look at some differences in how Ryan and his family were treated in Kokomo and Cicero:

KOKOMO
- Some people at church refused to shake hands with Ryan and his family or use the restroom after him.
- Some parents of Ryan’s schoolmates took legal action designed to prevent Ryan from attending school.
- For a time, Ryan was only allowed to “attend” school by phone from his
home.
• When Ryan was allowed to attend school, other kids refused to be his lab partner or sit by him in class. Some parents started a separate school for their children to attend.
• In school, Ryan was openly ridiculed and his locker was vandalized with obscene language and insults.
• “Ryan White” jokes were spread.
• On Valentine’s Day, someone bugged the computer department’s dating service so that Ryan was matched with boys, and his sister was matched with girls.
• Ryan was accused of spitting on grocery store produce, urinating on restroom walls, and biting people.
• Ryan was banned from the swimming pools in town.
• Some store clerks dropped change into Jeanne White’s hands instead of handing it to her.
• One restaurant threw away dishes used by the family.
• Some people threw garbage on the White’s lawn and yelled obscene insults at them.
• Someone flattened the tires of the family car.
• Someone shot a bullet through the window of their home.
• No one was interested in buying their house—“the AIDS house”—when they moved.

CICERO
• During the summer, the student body president stopped by Ryan’s house to welcome him.
• Ryan’s new school, Hamilton Heights High School, brought in AIDS experts to talk with teachers and students about AIDS.
• The school also sent speakers to churches and public meetings.
• Students were able to ease their parents’ fears by telling them about AIDS.
• The school respected Ryan’s wishes when it came to publicity and the media.
• Kids asked him to sit with them in class or the cafeteria.
• Ryan went to dances and parties and hung out with friends.
• The school set up a locker where students could anonymously submit questions about AIDS. The answers to these questions were posted on a bulletin board. Students submitted many questions asking for ways in which they could help Ryan.

Ryan’s fight for equal treatment was widely publicized. The Landsburg Company made a TV movie about his family’s struggle, and he met many celebrities. While he always said that he would trade fame for health any day, Ryan did try to make the most of the times he agreed to speak publicly. He hoped that because of him, other people with AIDS would not be treated so cruelly. Ryan pointed out how illogical some people were at times—they would not sit next to him, but they would sit next to people who did sit beside him. Ryan’s goal was to “make AIDS a disease—not a dirty word.”

QUESTIONS
1. In your opinion, why did some people in Kokomo stigmatize Ryan and his family? Have you seen examples of this happening in your school? Explain.
2. In your opinion, why did many people in Cicero react positively to Ryan? Have you seen examples of this happening in your school? Explain.

3. In the 1980s, AIDS was a highly feared, newly discovered disease. What diseases can you think of that are like this today?

4. What can we learn from Ryan’s story to help us avoid stigmatizing people with infectious diseases? If you were to meet somebody with an infectious disease that you don’t know much about, what would you do?
TELLING THE STORIES

LEVEL
Teens

OBJECTIVE
Students will explore the phenomenon of stigma by creating a visual presentation of a stigmasized life.

MATERIALS
• “Telling the Stories” assignment handout.
• Students will need access to research materials.

PREP
1. Determine how much time you will allow for the project’s completion.
2. Determine where the projects will be displayed, and whether or not this location limits the size and/or format of the projects.
3. Determine whether the assignment will be individual or small group.

INSTRUCTIONAL COMPONENTS
Students should take the initiative on this project. The teacher will determine parameters (noted in the PREP section), field questions, and offer general direction.

ASSESSMENT
• Minimum: Did the student meet the required parameters of the project?
• Maximum: Does the student’s presentation evoke a reflective response in the viewer?
TELLING THE STORIES

Stigma… What exactly is it? It is an image that other people attach to someone… an image that makes other people not want to work with that him… or play with him… or shake hands with him, or even be in the same room with him.

Stigma is born out of ignorance. Most of us are afraid of the unknown. When it comes to disease, if we don’t know how a particular disease is transmitted, we might be afraid to be near someone who has it.

This assignment will cause you to explore the lives of people who have experienced the effects of being stigmatized by strangers—and loved ones. Your goal is to create a visual presentation of someone’s stigma-related life experiences. Your hope is that other people will see your presentation and think twice about how they treat people who seem different.

You will need to focus on people who have been separated from society or avoided because of medical problems—a disability… a disease… a disfiguration. Categories of people include:

1) **Well-known individuals**, like Ryan White, who suffered from AIDS in the 1980s, or “Typhoid Mary” Mallon, a known typhoid carrier who was isolated in the early 1900s, or Magic Johnson. The situations, stigmas, and societal reactions surrounding the lives of these people are very different, as they will be with other lives you may choose to research.

2) **General groups of people**. Those infected with leprosy, for example, were shunned and isolated from their communities. If you choose to explore the stigmatization of a general group of people, you must write in the first person—as though you yourself are a member of that group.

3) **Personal interview**. Perhaps you have a friend or family member who would be willing to share their experiences with you. If you choose this option, you must make sure that you do not disclose that person’s identity, or inadvertently give “hints” that would disclose that person’s identity. Be sure to have that person view your finished presentation before anyone else sees it. This process, the struggle to protect someone from the rest of society, will help make real the effects of living a stigmatized life.

Remember: stigmatization is a global phenomenon. Exploring a stigmatized life from another culture will reveal not only interesting differences, but probably also some striking similarities.

Lastly, be creative. You may choose to write a poem to use in your display. You may be able to include artwork that person has created. Remember that your goal is to cause your project’s audience to understand 1) how this particular person has been stigmatized, 2) the struggle to deal with the effects of stigmatization, and 3) how this struggle has changed the person he/she is.
STIGMA AWARENESS STATEMENT
For Students

LEVEL
Teens

OBJECTIVE
• Students will understand the impact of stigma on stigmatized people.
• Students will commit to preventing stigma.

MATERIALS
One copy of the Stigma Awareness Statement (included with lesson plan) per student.

PREP
Determine when students will receive the Stigma Awareness Statement and when they will submit the signed portion.

INSTRUCTIONAL COMPONENTS
1. Discuss concepts with students.
2. Encourage them to discuss issues with their parents.
3. Remind students when the signed statement should be returned.

ASSESSMENT
Students will submit signed statement.
STIGMA AWARENESS STATEMENT

*Stigma* is defined by Webster’s dictionary as “something that detracts from the character or reputation of a person, group, etc.; mark of disgrace or reproach…indicating that something is not considered normal or standard.”

Sometimes we act differently toward people who are “different” than us. In the United States, we are very familiar with racial discrimination, but less familiar with other types of discrimination, such as discrimination against people with infectious diseases. Instead of getting to know that person and educating ourselves about infectious diseases, we choose to avoid people with infectious diseases, or we put them down with derogatory comments. Some of us tend to think that people with infectious diseases have done something to “deserve” that disease.

In doing these things, we attach a social stigma to people—a burden no one should ever be forced to carry.

By signing this statement, you are committing yourself to the following:

1. I am aware of the fact that many people do not know they have an infectious disease.
2. I am aware of the fact that many people have no idea when, where or how they contracted the disease and have no identifiable risk factors that would suggest a mode of transmission.
3. I am aware of the fact that I myself may have an infectious disease.
4. I am committed to educating myself about infectious diseases and their modes of transmission so that I may work to prevent the spread of disease, thereby protecting myself from others and others from myself, in case I do have an infectious disease.
5. In the event that I am informed of a person’s infectious disease status, whether by that person or someone else, I will maintain confidentiality regarding that person’s infectious disease status.
6. I commit myself to treating others with dignity and respect at all times and under all circumstances.

I, __________________________________________ (print your name) acknowledge that I have received and read the Stigma Awareness Statement. By signing below, I acknowledge that I understand the Statement and that I will commit myself to adhering to the principles outlined in this Statement.

Signed: __________________________________________

Date: __________________________________________
Bibliography

Aegis: Timeline of the AIDS Pandemic
www.aegis.com

AIDS Action
www.aidsaction.org

AIDS Clinical Trials Information Service
www.actis.org

www.thebody.com

HIV/AIDS Treatment Information Service
www.hivatis.org

Margolis, Dr. Harold, Director of the Division of Viral Hepatitis at the Centers for Disease Control and Prevention (CDC). Interview July 2001.

National Parent-Teacher Association: Health and Safety; Six Things to Do If Someone in Your Child’s School Has AIDS.
www.pta.org

PEW International Journalism Program: AIDS Stigma in South Africa by Kai Wright
www.pewfellowships.org

Seattle-King County Department of Public Health FLASH Curriculum: Teaching About Values

UNAIDS
www.unaids.org

U.S. Department of Education Office for Civil Rights: Questions and Answers on Disability Discrimination under Section 504 and Title II
www.ed.gov

U.S. Department of Justice: The Americans with Disabilities Act
www.usdoj.gov
Additional Activities and Resources
for Teachers, Students and Parents

Tells the story of children in a multicultural daycare, one of whom has AIDS.

San Francisco Chronicle reporter Randy Shilts examines the making of the AIDS epidemic.

An eight year old girl with AIDS talks about her illness.

Humanizes AIDS through the voices of its victims and their families in a collection of drawings and writings done by children involved in treatment or counseling at the National Cancer Institute in Bethesda, Maryland.

Ryan White, a 13 year old diagnosed with AIDS, tells how he fought for his beliefs and how he lived.