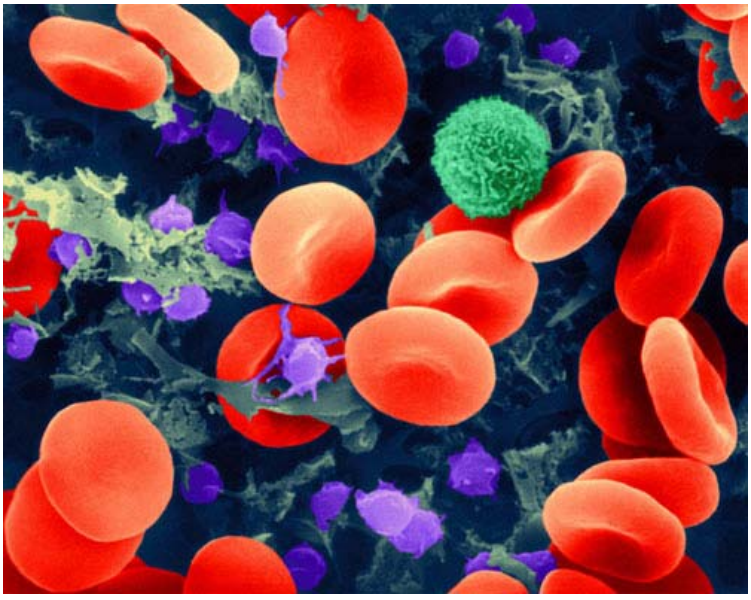
UNIT 5

Civil Rights and Infectious Diseases

Instructor's Background Text



PKIDs' Infectious Disease Workshop

Made possible by grants from the Northwest Health Foundation,
the Children's Vaccine Program at PATH and PKIDs

Acknowledgements

Producing this workshop has been a dream of ours since PKIDs' inception in 1996. This project was two years in the making, 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.

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For educational activities and resources, please visit www.pkids.org/idw.

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, viral 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.

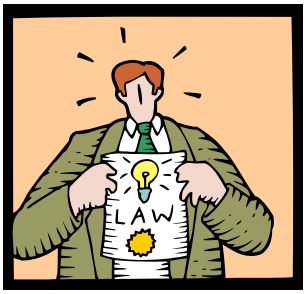
We welcome any questions, comments, or feedback you may have about the IDW or any other issue relating to infectious diseases in children.

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

PKIDs' INFECTIOUS DISEASE WORKSHOP

Civil Rights and Infectious Diseases

Most people are familiar with the Civil Rights Movement of the 1950s and '60s, which sought basic human rights for African-Americans. However, it wasn't until late in the 20th century that the general population became familiar with the civil rights movement for those with disabilities, which began in the late 1960s at the University of Illinois and the University of California at Berkeley. Fed up with having to cope with incompatible environments, students with disabilities at these universities began working to eliminate the architectural and transportation barriers that prevented them from moving about their campuses. Their frustrations were compounded by the fact that, in addition to physical barriers, people with disabilities suffered the effects of severe social discrimination, such as denied employment or refused admission to movie theaters.



Often, the term *disability* brings to mind visible disabilities, such as loss of limb or paralysis requiring the use of a wheelchair. However, mental and emotional illnesses, certain learning disabilities, and various infectious diseases, sometimes referred to as hidden disabilities, are included in the Federal Government's legal definition of potential or perceived disability.

While much disability legislation speaks to accessibility, it also speaks to discrimination based on disability. People with infectious diseases may not have trouble climbing stairs or need special accommodations in order to carry out the functions of their occupations; but they do suffer the same discriminations people with visible disabilities encounter when applying for jobs, attending schools, or even seeking housing. Therefore, people with infectious diseases are covered under disability rights laws in certain circumstances.

Currently, there are several laws protecting disabled people from unequal treatment. These include:

- Americans with Disabilities Act (1990)
- Telecommunications Act (amended 1996)
- Fair Housing Act (amended 1988)
- Air Carrier Access Act
- Voting Accessibility for the Elderly and Handicapped Act (1984)
- National Voter Registration Act (1993)
- Civil Rights of Institutionalized Persons Act
- Individuals with Disabilities Education Act (1975)
- Rehabilitation Act (1973)
- Architectural Barriers Act (1968)

Although people with infectious diseases find protection under a number of these laws, the most

significant laws protecting infected persons are Section 504 of the Rehabilitation Act and the Americans with Disabilities Act (ADA). Additionally, infected students are specifically protected by the Individuals with Disabilities Education Act (IDEA) and the Family Educational Rights and Privacy Act of 1974 (FERPA). The following are brief explanations of some of the various Acts under which those living with infectious diseases may find protection:

The Fair Housing Act

As it applies to people with infectious diseases, the Fair Housing Act states that it is against the law to discriminate against a disabled individual in selling or renting housing. It covers private housing, housing that receives federal financial assistance, and state and local government housing. It is unlawful to discriminate in any aspect of selling or renting housing or to deny a dwelling to a buyer or renter because of the individual's disability, an individual associated with the buyer or renter, or an individual who intends to live in the residence. Other covered activities include financing, zoning practices, new construction design and advertising.

Section 504 of the Rehabilitation Act

Section 504 states that "no qualified individual with a disability in the United States shall be excluded from, denied the benefits of, or be subjected to discrimination" by any federal employer or contractor or under any program funded by federal money. The ADA and the Rehabilitation Act are similar in purpose, but the Rehabilitation Act is restricted to *federal* programs and employers.

Individuals with Disabilities Education Act

The Individuals with Disabilities Education Act (IDEA) was originally titled the Education for All Handicapped Children Act (Public Law 94-142). It was later renamed and amended in 1997. IDEA protects infected children, declaring that they are entitled to receive an education in the "least restrictive environment."

Family Educational Rights and Privacy Act of 1974

All public schools keep records and files on each student. Academic grades, teacher evaluations, disciplinary actions, I.Q. and achievement scores and medical and immunization reports are all kept in a student's file.

Until 1974, this information was made available to almost everyone—potential employers, colleges, draft boards, and police—but not to students or their parents.

In 1974, the federal Family Educational Rights and Privacy Act (FERPA, also called the Buckley Amendment) became law. This law gives parents and adult or emancipated students

access to student records and prevents the release of these records to third parties without written consent. All public schools and institutions receiving federal funds are subject to this law.

According to the U.S. Department of Education, the only people who may access student records without consent are school officials with "legitimate educational interests," such as school officials at a school to which a student is transferring, certain state and federal educational agencies, financial aid personnel (only financial information), research organizations as long as the information remains confidential, accrediting organizations, health officials if such access is necessary to protect community health and, in complying with a court order, law enforcement officials, probation officers and court personnel.

FERPA requires that each school annually prepare a statement that explains the procedure for examining a student's records; parents and eligible students are entitled to copies of these procedures. The law provides procedures for parents and students to change or eliminate incorrect or misleading records.

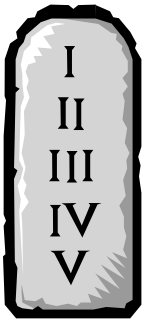
These procedures require the parent or student to first request the change in writing. If the school refuses, a hearing is held before a neutral hearing officer in which witnesses may testify and written evidence may be introduced.

If the hearing officer decides in favor of the school, the parents have the right to include a statement in the records explaining why they believe the information is wrong. The school must include this statement every time the records are released to a third party.

The Americans with Disabilities Act

The ADA defines disability as "a physical or mental impairment that substantially limits one or more of the major life activities…a record of such an impairment, or being regarded as having such an impairment." The ADA consists of five *titles*, each containing several *sections*.

TITLE I: Employment. This title prohibits employers from discriminating against a qualified individual with a disability. It also obligates employers to provide "reasonable" accommodations to employees with disabilities (accommodations that do not impose undue financial hardship).



TITLE II: Public Services. This title states that no state or local government may discriminate against a qualified individual with disabilities. It also addresses public transportation accommodation issues (where the transportation is provided by public transit authorities).

TITLE III: Public Accommodations and Services Operated by Private Entities. This title states that individuals with disabilities must be given equal access to

goods and services offered to the public by private entities. Examples of "private entities" would be supermarkets, restaurants, or hotels. This also includes public transportation provided by privately owned entities.

TITLE IV: Telecommunications. This title states that telephone services must provide the same services to "nonvoice" users as they provide to voice users.

TITLE V: Miscellaneous Provisions. This title contains various prohibitions, provisions, and clauses referring to such items as attorney's fees, insurance underwriting, and the relation of the ADA to other federal and state laws.

How Does the ADA Apply to Persons with Infectious Diseases?

In his book, *No Pity: People with Disabilities Forging a New Civil Rights Movement*, Joseph Shapiro notes that many people with "traditional," or physically apparent, disabilities were not anxious to be associated with HIV positive individuals. At the time the ADA was being forged and fought for, the AIDS crisis of the 1980s was widely publicized. Many people saw HIV/ AIDS as a "gay" disease and felt it was simply "their" problem. These differences in viewpoint were temporarily set aside for the sake of passing the ADA, but some people then, and now, wonder why people with infectious diseases like HIV are protected under the ADA.

To determine blame—or innocence—before protecting a disabled person's rights is at best an inefficient method of ensuring such protection under the law.

Disease-disabled people are subject to the same discriminations as physically disabled people, and this is a primary reason their protection under the ADA is so critical. One example of this is in the history of the American education system, where some children have been denied appropriate education and discriminated against due to their HIV, hepatitis B or hepatitis C status—the same discrimination has happened to some physically disabled persons when educators have assumed, based on the child's appearance, that he or she would be mentally unable to participate with the general student population.

There are those who would deny an infected person a job position or an education because they feel the infected person poses a risk to others around them. In their book, *The Americans with Disabilities Act Handbook*, editors Maureen Harrison and Steve Gilbert point out that while the ADA does acknowledge that some people with disabilities may pose a "direct threat" to others, "the decision to exclude cannot be based on merely 'an elevated risk of injury,'" nor may they be excluded simply because they are "regarded as having such an impairment." In addition, an infected person cannot be discriminated against merely because others *perceive* him/her to be a risk. When referring to the definition of disability, the ADA states that people protected by the ADA include people "known to have a relationship or association with" a disabled individual.

Therefore, the ADA also protects people who are associated with infected people (e.g., friends, volunteers, relatives).

Sections including infectious diseases as a disability under the ADA largely address HIV/AIDS, but the U.S. Department of Health and Human Services notes that physical or mental impairments as defined under the ADA include, *but are not limited to*, "contagious and noncontagious diseases such as tuberculosis and HIV disease (whether symptomatic or asymptomatic)." This means that infectious diseases not specifically mentioned, such as hepatitis B and C, may be covered under disability rights legislation.

How the ADA Determines Health Risks

Determining who is a health risk and under what circumstances he/she could transmit infection is extremely important, and the ADA is very clear about who plays the role of health risk arbiter.

A medical expert using up-to-date information must make this assessment—not an employer, a supervisor, a teacher, coach or a parent.

ADA regulations clearly state, "The determination that a person poses a direct threat to the health or safety of others may not be based on generalizations or stereotypes about the effects of a particular disability; it must be based on an individual assessment that considers the particular activity and the actual abilities and disabilities of the individual. The individual assessment must be based on reasonable judgment that relies on current medical evidence."

Civil Rights Protection for Disease-Disabled Students

Civil rights for infected students fall under the protection of many laws. For instance, the Americans with Disabilities Act (ADA), among others, requires all public and private schools and colleges to treat students and staff with infectious diseases as they would anyone else unless they pose a health risk that cannot be eliminated by a modification of procedures or by the provision of additional aids or services.

Section 504 of the Rehabilitation Act of 1973 prohibits discrimination based on disability by recipients of federal financial assistance—especially public schools.

The main difference between ADA and Section 504 is that Section 504 applies to the recipients of grants from the federal government and Title II of the ADA applies only to public entities. A school or college may be both a recipient of federal funds from the U.S. Department of Education and a public entity. In such cases, the institution is subject to both ADA and Section 504.

When it comes to education, ADA's objectives and language are very similar to Section 504. For this reason, both laws, as they relate to education, are administered by the Department of Education's Office for Civil Rights (OCR) and are considered essentially identical. Patterned after Section 504, the applicable provision of the ADA similarly states in Title II, 42 U.S.C. §12132:

"Subject to the provisions of this title, no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs or activities of a public entity or be subject to discrimination by any such entity."

Preventing Harassment Based on Infectious Disease in Schools and Colleges

In July 2000, the Department of Education's Office of Civil Rights wrote a letter to educators warning of their legal and educational duty to stop harassment of disabled students under Section 504 and the ADA.

"Disability harassment can have a profound impact on students, raise safety concerns and erode efforts to ensure that students with disabilities have equal access to the myriad benefits that an education offers. Indeed, harassment can seriously interfere with the ability of students with disabilities to receive the education critical to their advancement," wrote Assistant Secretary for Civil Rights Norma V. Cantu. "Teachers and administrators must take emphatic action to ensure that these students are able to learn in an atmosphere free from harassment."

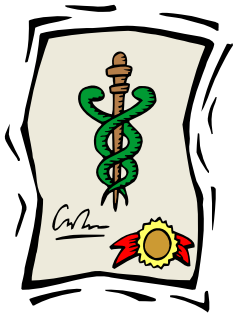
If a school fails to halt harassment, parents can initiate administrative due process procedures under Section 504 or the ADA to address the basic denial of a proper and free education, which

is guaranteed by federal law. Parents and organizations can also file complaints with the Department of Education's Office of Civil Rights. If a school fails to intervene, it risks civil and criminal action, depending on the severity of harassment, and the loss of federal funding.

The office suggests schools and colleges take the following steps to prevent and eliminate harassment:

- Create a campus environment that is aware of disability concerns and sensitive to disability harassment, weaving these issues into the curriculum or programs outside the classroom.
- Encourage parents, students, employees, and community members to discuss disability harassment and to report it when they become aware of it.
- Widely publicize anti-harassment statements and procedures for handling discrimination complaints. This information makes students and teachers aware of what constitutes harassment, that such conduct is prohibited, that the institution will not tolerate such behavior, and that effective action, including disciplinary action where appropriate, will be taken.
- Provide appropriate, up-to-date, and timely training so staff and students can recognize and handle potential harassment.
- Provide counseling to victims and harassers alike.
- Implement monitoring programs to follow up on resolved issues of disability harassment.
- Regularly assess and modify existing disability harassment policies and procedures to address any new issues.

The Office of Civil Rights offers technical assistance to schools, parents and disability advocacy organizations to ensure no student is harassed. For more information, contact the office at 800-USA-LEARN, 800-437-0833 (TTY) or 202-205-5507.



Can Schools Ask About a Student's Infection or Disease?

Given the clear laws that outlaw discrimination based on health issues, why do schools continue to ask if a child has a "chronic or infectious disease?"

Under the ADA, employers are prohibited from asking such questions of job applicants, yet schools and organizations routinely ask these questions of students and applicants. According to Dr. Harold Margolis, Director of the Centers for Disease Control and Prevention's (CDC) Division of Viral Hepatitis, disclosure is not necessary.

"The 2000 edition of the American Academy of Pediatrics Red Book states: 'routine use of these [standard] precautions avoids the necessity of identifying children known to be infected with HIV, HBV (hepatitis B virus) and HCV (hepatitis C virus) and acknowledges that unrecognized infection poses at least as much risk as the identified child.'

"Students infected with HIV, HBV or HCV do not need to be identified to school personnel, based on the assumption that school staff are using standard precautions when handling first-aid

or emergency situations," Dr. Margolis added. "Since HIV, HBV and HCV infected children and adolescents will not be identified, policies and procedures to manage potential exposures to blood or blood-containing materials should be established and implemented and parents should take an active role to ensure these are in place."

Dr. Margolis recommends that procedures be in place for any special health problems or medical conditions that a child might have requiring specific action. Examples of conditions needing procedures/actions might include allergies, asthma, diabetes, epilepsy and sickle cell anemia. Staff should know 1) what happens to the child during a crisis related to the condition, 2) how to prevent a crisis, 3) how to deal with a crisis, and 4) whether training is necessary in a particular emergency procedure. Again, all aid should be rendered using standard precautions.

Civil Rights Protection for Employees

(Source: The U.S. Equal Employment Opportunity Commission)

Titles I and V of the Americans with Disabilities Act prohibit discrimination on the basis of disability in all employment practices. Many states have their own state laws, similar to the ADA, that also bar discrimination based on infectious disease and provide legal channels for redress.

Who is protected under the ADA?

An individual with a disability under the ADA is a person who has a physical or mental impairment that substantially limits one or more major life activities, has a record of such an impairment, or is regarded as having such an impairment.

A qualified employee or applicant with a disability is someone who satisfies skill, experience, education, and other job-related requirements of the position held or desired, and who, with or without reasonable accommodation, can perform the essential functions of that position.

What is the "Reasonable Accommodation" that employers must make?

Reasonable accommodation may include, but is not limited to, making existing facilities used by employees readily accessible to and usable by persons with disabilities; job restructuring; modified work schedules; additional unpaid leave; reassignment to a vacant position; acquiring or modifying equipment or devices; adjusting or modifying examinations, training materials, or policies; and providing qualified readers or interpreters.

Reasonable accommodation may be necessary to apply for a job, to perform job functions, or to enjoy the benefits and privileges of employment that are enjoyed by people without disabilities. An employer is not required to lower production standards to make an accommodation. An employer generally is not obligated to provide personal use items such as eyeglasses or hearing aids.

What is considered undue hardship?

An employer is required to make a reasonable accommodation to a qualified individual with a disability unless doing so would impose an undue hardship on the operation of the employer's business. Undue hardship means an action that requires significant difficulty or expense when considered in relation to factors such as a business's size, financial resources, and the nature and structure of its operation.

What can employers ask and not ask prospective employees during interviews?

Before making an offer of employment, an employer may not ask job applicants about the

existence, nature, or severity of a disability. Applicants may be asked about their ability to perform job functions. A job offer may be conditioned on the results of a medical examination, but only if the examination is required for all entering employees in the same job category. Medical examinations of employees must be job-related and consistent with business necessity.

Who can file a charge of discrimination?

Any individual who believes that his/her employment rights have been violated may file a charge of discrimination with EEOC.

In addition, an individual, organization, or agency may file a charge on behalf of another person in order to protect the aggrieved person's identity.

How is a charge of discrimination filed?

A charge may be filed by mail or in person at the nearest EEOC office. Individuals may consult their local telephone directory (U.S. Government listing) or call 1-800-669-4000 (voice) or 1-800-669-6820 (TTY) to contact the nearest EEOC office for more information on specific procedures for filing a charge.

Individuals who need an accommodation in order to file a charge (*e.g.*, sign language interpreter, print materials in an accessible format) should inform the EEOC field office so appropriate arrangements can be made.

What information must be provided to file a charge?

The requirements to file a charge include: the complaining party's name, address, and telephone number and the name, address, and telephone number of the respondent employer, employment agency, or union that is alleged to have discriminated, number of employees (or union members), if known, a short description of the alleged violation (the event that caused the complaining party to believe that his/her rights were violated), and the date(s) of the alleged violation(s).

What are the time limits for filing a charge of discrimination?

All laws enforced by EEOC, except the Equal Pay Act, require filing a charge with EEOC before a private lawsuit may be filed in court. There are strict time limits within which charges must be filed:

- A charge must be filed with EEOC within 180 days from the date of the alleged violation, in order to protect the charging party's rights.
- This 180-day filing deadline is extended to 300 days if the charge also is covered by a state or local anti-discrimination law. For ADEA (the Age Discrimination in Employment Act of 1967) charges, only state laws extend the filing limit to 300 days.

To protect legal rights, it is always best to contact EEOC promptly when discrimination is suspected.

What agency handles a charge that is also covered by state or local law?

Many states and localities have anti-discrimination laws and agencies responsible for enforcing those laws. EEOC refers to these agencies as "Fair Employment Practices Agencies (FEPAs)." Through the use of "work sharing agreements," EEOC and the FEPAs avoid duplication of effort while at the same time ensuring that a charging party's rights are protected under both federal and state law.

What happens after a charge is filed with EEOC?

The employer is notified that the charge has been filed. From this point there are a number of ways a charge may be handled:

- A charge may be assigned for priority investigation if the initial facts appear to support a violation of law. When the evidence is less strong, the charge may be assigned for follow up investigation to determine whether it is likely that a violation has occurred.
- EEOC can seek to settle a charge at any stage of the investigation if the charging party and the employer express an interest in doing so. If settlement efforts are not successful, the investigation continues.
- In investigating a charge, EEOC may make written requests for information, interview people, review documents, and, as needed, visit the facility where the alleged discrimination occurred. When the investigation is complete, EEOC will discuss the evidence with the charging party or employer, as appropriate.
- The charge may be selected for EEOC's mediation program if both the charging party and the employer express an interest in this option. Mediation is offered as an alternative to a lengthy investigation.Participation in the mediation program is confidential, voluntary, and requires consent from both charging party and employer. If mediation is unsuccessful, the charge is returned for investigation.
- A charge may be dismissed at any point if, in the agency's best judgment, further investigation will not establish a violation of the law. A charge may be dismissed at the time it is filed, if an initial in-depth interview does not produce evidence to support the claim. When a charge is dismissed, a notice is issued in accordance with the law, giving the charging party 90 days in which to file a lawsuit on his/her own behalf.

How does EEOC resolve discrimination charges?

If the evidence obtained in an investigation does not establish that discrimination occurred, this will be explained to the charging party. A required notice is then issued, closing the case and giving the charging party 90 days in which to file a lawsuit on his or her own behalf.
If the evidence establishes that discrimination has occurred, the employer and the charging

party will be informed of this in a letter of determination that explains the finding. EEOC will then attempt conciliation with the employer to develop a remedy for the discrimination. If the case is successfully conciliated, or if a case has earlier been successfully mediated or settled, neither EEOC nor the charging party may go to court unless the conciliation, mediation, or settlement agreement is not honored.

If EEOC is unable to successfully conciliate the case, the agency will decide whether to bring suit in federal court. If EEOC decides not to sue, it will issue a notice closing the case and giving the charging party 90 days in which to file a lawsuit on his or her own behalf. In Title VII of the Civil Rights Act of 1964 and ADA cases against state or local governments, the Department of Justice takes these actions.

When can an individual file an employment discrimination lawsuit in court?

A charging party may file a lawsuit within 90 days after receiving a notice of a "right to sue" from EEOC, as stated above. Under Title VII and the ADA, a charging party also can request a notice of "right to sue" from EEOC 180 days after the charge was first filed with the Commission and may then bring suit within 90 days after receiving this notice. Under the ADEA, a suit may be filed at any time 60 days after filing a charge with EEOC, but not later than 90 days after EEOC gives notice that it has completed action on the charge.

Under the EPA (Equal Pay Act), a lawsuit must be filed within two years (three years for willful violations) of the discriminatory act, which in most cases is payment of a discriminatory lower wage.

What remedies are available when discrimination occurs?

The "relief" or remedies available for employment discrimination, whether caused by intentional acts or by practices that have a discriminatory effect, may include:

- Back pay.
- Hiring.
- Promotion.
- Reinstatement.
- Front pay.
- Reasonable accommodation.
- Other actions that will make an individual "whole" (in the condition he/she would have been but for the discrimination).

Remedies also may include payment of attorneys' fees, expert witness fees and court costs.

Under most EEOC-enforced laws, compensatory and punitive damages also may be available where intentional discrimination is found. Damages may be available to compensate for actual monetary losses, for future monetary losses, and for mental anguish and inconvenience. Punitive damages also may be available if an employer acted with malice or reckless

indifference. Punitive damages are not available against the federal, state or local governments.

In cases concerning reasonable accommodation under the ADA, compensatory or punitive damages may not be awarded to the charging party if an employer can demonstrate that "good faith" efforts were made to provide reasonable accommodation.

An employer may be required to post notices to all employees addressing the violations of a specific charge and advising them of their rights under the laws EEOC enforces and their right to be free from retaliation. Such notices must be accessible, as needed, to persons with visual or other disabilities that affect reading.

The employer may be required to take corrective or preventive actions to cure the source of the identified discrimination and minimize the chance of its recurrence, as well as discontinue the specific discriminatory practices involved in the case.

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