



Combating Violence & Abuse of People with Disabilities



A Call to Action

Nancy M. Fitzsimons

Foreword by Dick Sobsey



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Foreword

Maltreatment of people with disabilities takes many forms. It can explode in a moment of violence, or it can fester through decades of neglect. It can be the work of unrepentant thugs who take pleasure in inflicting pain, or well-respected policy makers who fail to take necessary action. Violence and abuse are as tangible in the crushing of dreams and the denial of humanity as in the spilling of blood and flowing of tears.

As a young man, back in 1968, I first faced the grim reality of institutional abuse and neglect. In the years that followed, I began to see some of the many other forms of violence and abuse that touched the lives of people with disabilities. Four decades older and what seems like centuries wearier, I look out on a world today that I would like to think looks at least marginally better and ask myself whether there has been any meaningful change and any lessons learned.

A few things have improved. First, fewer people with disabilities live out their lives in massive institutions that breed abuse. While moving from institutional to community care is not in itself a solution to the problem of abuse, it is an important step toward addressing the issue.

Second, there is a much greater public and professional recognition of the problem. Of course, there have been episodic exposés of abuse for well over a hundred years, but these previous efforts at raising public consciousness did not penetrate deeply into society or sustain themselves for extended periods of time.

Third, beyond a general recognition of the problem, there has been significant scholarly research and analysis, which has the potential to better direct our efforts to control the risk of abuse. To give just a few examples, Sullivan and Knutson's (2000) epidemiological studies provided a foundation to help us understand the relationship between child abuse and disability. In one of their studies with a large sample of children in the American midwest, 31% of children identified as having disabilities by the school had a history of reported maltreatment versus only 9% of children without disabilities (Sullivan & Knutson, 2000). Martin and colleagues (2006) found that women with disabilities were more than 4 times as likely as women without disabilities to have experienced sexual assault within the last year. In addition to research that clarifies the risks, other studies have helped to guide prevention efforts. Khemka, Hickson, and Reynolds (2005) demonstrated that women with intellectual disabilities can be taught decision-making skills that can be expected to reduce their risk for sexual exploitation and violence.

Fourth, the special concern about crimes against people with disabilities is increasingly recognized in mainstream criminology, law enforcement, and child protection. For example, the *Encyclopedia of Crime and Punishment* includes a section

on “Crimes Against Persons with Disabilities” written by Michael Rand (2006), Chief of Victimization Statistics at the U.S. Bureau of Justice Statistics. While Rand correctly points out that “the measurement of crime against people with disabilities is in its infancy” (p. 396), he recognizes that “there is strong evidence that having a disability increases one’s vulnerability to victimization” (p. 396) and calls for better methods of measuring these crimes. This recognition is critical to making any real progress. As long as recognition was limited to a few disability rights advocates, there was little prospect of making significant improvements.

Finally, as a result of the greater recognition of the problem, there have been significant developments in law, policy, and regulation that have made at least some headway in controlling risks. In 1994, The U.S. Congress amended the Hate Crime Statistics Act of 1990 (PL 101-275) to require the collection of information on hate or bias crimes committed against people with mental or physical disabilities, and in 1996 the first national statistics were collected (Federal Bureau of Investigation, 2004). Since then, more states have added disability to the list of protected categories under hate crime legislation. As of 2008, slightly more than 50% of states include people with disabilities as a protected class, and two additional states have pending legislation to add disability to current Acts.

With all of these positive developments, it might be tempting to feel like the world is a better place and that violence is on its way out. Sadly, there is no reason to believe that there has been any substantial progress in actually preventing violence against people with disabilities.

Recently, I watched Geraldo Rivera discussing rampant abuse and neglect in a large state institution. His 1972 exposé of Willowbrook State School led to widespread public outrage, but more than three decades later, his exposé of similar problems at Denton State School in Texas received a lot less attention. Have we just come to accept it? Hyde (2008), writing in the *Dallas Observer*, tells the story of Farat Chishty, whose son Haseeb was left paralyzed as a result of a near fatal attack, and the staff member who confessed to the beating that caused these injuries. Hyde’s account cites an Associated Press report that more than 800 employees of Texas State Schools have been suspended or fired for causing serious harm to residents in a 3-year period and that an investigation by the U.S. Justice Department in 2006 documented neglect, cover-up, and 17 deaths in 18 months at the Lubbock State School.

A second recent news story described a mother whose son was abused in a Connecticut group home (Goode, 2008). The story describes how Alice Stockton brought her suspicions of abuse of her son, Christopher, to the attention of authorities 2 years earlier and was told nothing could be done. Her 38-year-old son has autism and cannot speak to disclose the abuse. His mother left an audio recorder in her son’s room and recorded evidence of staff abuse. An employee pled “no contest” to a charge of negligent cruelty to a person and received a suspended 5-year sentence but was banned from working as a caregiver.

It is disheartening that such cases of abuse of vulnerable people continue to occur, but it is truly tragic that it is so often left for determined family members, like these two mothers, to confront the problem. The supervisors, managers, and regulators of these services are paid to protect against abuse and respond to any abuse that occurs. Many take this responsibility seriously but are overwhelmed by the

difficulties they face. Far too many lack the will or the inclination to meet this responsibility. In more than a few cases, those responsible for protecting vulnerable children and adults with disabilities actively cover up abuse and neglect.

Rarely has the failure of the system to protect vulnerable children and adults with disabilities been detailed more clearly than in the 258-page grand jury report handed down recently in Philadelphia on the death of Danieal Kelly (Tanfani, 2008). Danieal, a 14-year-old girl with cerebral palsy, starved to death during a prolonged period of neglect. According to the report, child protection workers assigned to Danieal's case did nothing to protect her from a slow and undignified death but did a great deal to protect the system with such actions as falsification of documents after she died. While the specific charges against individuals have yet to be proven in court, the grand jury investigation report as summarized alleges that a worker who was assigned to the case, who previously had been suspended on three occasions for poor performance, claimed he didn't know that the 14-year-old was entitled to go to school or that it was against the law for a parent not to provide necessary care for a child. It alleges that a supervisor, who admitted that she falsified records to make it seem that some of the maltreatment reports had been investigated and found to be unsubstantiated in Danieal's case, told the grand jury that such falsification of records was routine practice. It also alleges that a private agency contracted to oversee Danieal's care assigned a caseworker who made a few visits to the home but never met the child, and that he and other agency staff had families sign batches of visit records so that they could log numerous visits that never occurred.

The stories of Haseeb, Christopher, and Danieal were just three of the dozens of grim tales of abuse of people with disabilities that emerged in the news in a single 2-week period during the summer of 2008. There are thousands every year (e.g., Icard, 2008), but these published accounts are only the tiniest tip of the iceberg. Many people with disabilities do not have dedicated family members to bring their cases to light like Haseeb's and Christopher's mothers. Many dedicated family members, self-advocates, and advocates do make diligent attempts but are thwarted. Every indication suggests that most cover-ups are successful.

The sharp contrast between apparent steps forward and the continued plague of violence is difficult to interpret. Is it possible that things are somehow better than they appear? Are we deluding ourselves to think that there is any progress in the face of continued suffering? Is the situation hopeless?

Significant social changes rarely come quickly or easily. There has been some real progress made, but the path ahead is long and uncharted. We do not know how long a journey lies ahead, but we cannot stop here. We need to move forward and renew our efforts.

Combating Violence and Abuse of People with Disabilities is an important step forward on a shared journey toward a safer world for people with disabilities. The author and her contributors have done an excellent job of weaving together practical information, principles, and individual human experience. In organizing the book around four key principles, the author provides a useful framework for arranging information and developing practical individualized programs. By tying the book to her own experience with the Advocacy and Empowerment Project,

Nancy Fitzsimons provides rich description of how a program can be successfully implemented. Some readers may want to follow this model closely and others may extract the best parts to apply in their own contexts.

For some readers, Chapter 3 on models of disability and its relationship to violence and abuse will be the heart of this book. Without a working model of why violence occurs, attempts to address the issue are limited to superficial solutions at best. While this chapter is a favorite of mine, there is a lot more to this book than theory. Its focus is on practical approaches to personal safety, written for people with disabilities, their families and advocates, violence prevention and intervention workers, and people involved in providing services to people with disabilities.

Combating Violence and Abuse presents practical strategies for improving the personal safety of people with disabilities on many different levels. The author recognizes that we need to address systemic risk factors as well as help to empower individuals to resist abuse. That makes this book an important step forward.

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Preface

There is a growing body of research showing that people with disabilities are more likely to experience violence and abuse than are people without disabilities. Yet in my experience as a practicing social worker, and later as an academic, abuse of people with disabilities is too often a well-kept secret. People with disabilities often are marginalized in our society. Perhaps this is one reason why the abuse is not acknowledged or seen as a serious problem. My thinking about the problem of violence and abuse and people with disabilities was greatly affected by a conversation I had with a man while I was traveling to New Hampshire in the late 1990s to attend a conference on abuse of people with disabilities.

Author's Story

While talking with the man seated next to me on the airplane, I was asked about the purpose of my trip. I explained that I was attending a conference about abuse of people with disabilities. The man seemed kind of surprised by my answer. He asked me why anyone would want to hurt someone who is disabled. I went on to tell him what I knew about abuse of people with disabilities. I painted a pretty serious picture of the problem. I could tell that he was quite surprised by what I was telling him. He couldn't imagine why family members, friends, or anyone for that matter would hurt people who he thought were generally helpless and harmless.

What I learned from my conversation with a stranger on an airplane and from many other conversations, experiences, and reading the literature can be summarized as follows:

1. Most people have no idea how common and serious the problem of violence and abuse of people with disabilities is in our society—including the people who should know, such as police and prosecuting attorneys.
2. Negative attitudes, false beliefs, and stereotypes about people with disabilities perpetuate the problem. Think about the man on the airplane, who perceived people with disabilities to be “helpless” and “harmless.” These are examples of false beliefs and stereotypes about people with disabilities that contribute to the problem, rather than help solve the problem.
3. The saying “out of sight, out of mind” seems to apply. People with disabilities are the largest minority group in the United States, yet they often are excluded from mainstream society. Violence and abuse is an all-too-common experience for people with disabilities, yet the general public knows very little about the problem.

Over the last few decades progress has surely been made to address the problem, yet sadly, so much more needs to be done. It is my belief that individual and collective action must be taken to prevent violence toward and abuse of people with disabilities. Before going any farther, it is important to explain who this book is written for and who this book is about.

Target Audience

First, this book is written for and is about people with all types of disabilities—physical, sensory (vision or hearing), intellectual, and mental health. The focus is on adults with disabilities, not children. Although much of the information applies to children with disabilities, this book is written using the research and literature about adults with disabilities. The resources provided are adult focused. The ideas for combating violence and abuse are geared toward adults. This book addresses abuse of both men and women with disabilities. However, it is important to know that the majority of research and writing on this issue is about women with disabilities. So far, very little emphasis has been placed on understanding abuse of men with disabilities.

If you are a person with a disability reading this book, I know that you want to be in control of your life. You know the impact of abuse on your life. You may have had barriers to getting help and to living a life free from harm. I know the difficulty people with intellectual disabilities may have using this book. It is my hope that family members, teachers, social workers, and other professionals will use and adapt the materials to educate and empower the people with intellectual disabilities that they support. It is my belief that all people with disabilities, as empowered self-advocates, should be at the forefront of any action to combat violence and abuse in their own lives and in their communities.

This book is also written for all of the people who support or provide services to people with disabilities:

- Family members/partners/spouses
- Friends
- Professionals providing disability services (personal assistants, service coordinators, social workers, vocational rehabilitation counselors)
- Professionals providing victim assistance services (victim advocates, domestic violence advocates, sexual assault advocates, adult protection workers)
- Professionals working in the criminal and civil justice systems (police officers, victim advocates, attorneys, judges)

Professionals play a key role in preventing violence and abuse. When the abuse is a crime, police officers, prosecuting attorneys, and judges are key players in holding offenders accountable for their crimes. When victims need supports and services to develop a safety plan, to flee their abuser, or to get an order for protection, professionals working in victim and adult protection services play a crucial role. When victims need supports and services to increase their independence, disabil-

ity services professionals play an important part. In short, many professionals, along with family members and friends, need to take action.

Terminology

I have tried to approach writing this book as a conversation between me and you, the reader. You will notice that I refer to *you* throughout the book. This was done on purpose as a way for me to talk directly to you. On occasion I also use the word *I* when talking about something that I feel strongly about. Throughout the book you will notice that I cite the sources of the information. I have tried to balance citing sources (i.e., giving credit to others for their ideas and words) with readability. There are times when I am presenting information based on my own experiences: practice research, and academic study.

It was my goal to explain ideas and use words that I thought most people would understand. This was not always easy to do because some words and ideas are difficult to explain. Three approaches were used to make this book more “reader friendly”:

1. Words that are in **bold** are defined in the glossary at the end of the book.
2. Some words are defined in the text.
3. Alternative words or explanations are provided in parentheses after the word/idea; for example, “attorneys (also called *lawyers*).”

It is important for you to understand how I am using some of the key terms throughout this book. It was not easy selecting the terms that I thought would be accurate and would make the book more readable for a wide audience of readers.

- *Combat* means to fight or to struggle to achieve one’s goal. *Combat* also means to destroy something that is dangerous or harmful. *Combat* is a pretty powerful word. I debated about using this word. However, I believe that the problem of violence toward and abuse of people with disabilities is so serious, a strong word such as *combat* is justified.
- *People with disabilities* is used to refer to men and women with a wide variety of disabilities. I will identify a specific disability or gender when it is particularly important to the passage.
- *Victim* is used to refer to any person who is victimized by another person. A person is a victim because of the abusive actions of the abuser.
- *Abuse* is a broad term used to refer to all forms of violence and abuse, including physical assault, sexual assault, financial exploitation, neglect, and psychological abuse. The use of the term *abuse* should not be interpreted to minimize the seriousness of the offenses, many of which are crimes under federal and state laws.
- *Abuser* or *offender* is used to refer to any person who commits acts of violence or abuse. *Defendant* is used to refer to an abuser or offender who is charged with a crime in a criminal case or with wrongdoing in a civil lawsuit.

- *Professional* refers to anyone who gets paid to provide services to people with disabilities or to victims of violence and abuse. I will identify the type when I am referring to a specific group of service providers.

Care provider refers to family, friends, professionals, and others who provide paid or non-paid support and services to people with disabilities. I will identify the specific type of care provider when referring to one particular group; for example, personal assistants or parents.

- *Prevention* or *preventing* is used to refer to reducing (or minimizing) the risk for violence and abuse. The term is also used to refer to stopping the abuse from happening again once a person has been abused.

Overview of the Book

This book is about giving you the knowledge and skills needed to take action to combat violence toward and abuse of people with disabilities. Throughout the book you will find *newspaper headlines*, *personal stories*, *author stories*, and *direct quotes* to connect you to real people and their experiences. *Ask Yourself* questions will help you think more deeply about the topics covered in the book. *Learning Activities* will help you apply what you are learning.

Chapter 1: *Guiding Principles for Combating Violence and Abuse* lays out the guiding principles or values for taking action: empowerment, advocacy/self-advocacy, self-determination, strengths perspective, and collaboration.

Chapter 2: *The Relationship Between Disability and Abuse* focuses on understanding the connection between disability and violence and abuse. You will learn about the Social Model of Disability, theories of abuse of people with disabilities, and reasons for vulnerability.

Chapter 3: *Recognizing and Responding to Violence and Abuse* looks at the types and indicators of abuse, including examples of violence and abuse that are unique to people with disabilities. You will also learn what you should do if you suspect or know someone is being abused.

Chapter 4: *Systemic Barriers to Preventing Violence and Abuse* explores the societal and organizational barriers that perpetuate the violence and abuse and make it difficult to end abusive relationships and situations.

Chapter 5: *Personal Barriers to Preventing Violence and Abuse* focuses on the personal or individual barriers that make it difficult to end abusive relationships and situations. You will learn about how systemic barriers cause or exacerbate personal barriers. You will also learn about the “web of power and control.”

Chapter 6: *Understanding the System* provides an overview of victim services, vulnerable adult protection and advocacy services, the criminal justice system, and the civil justice system.

Chapter 7: *Empowering People with Disabilities to Prevent Violence and Abuse* focuses on ways to help you and the people you support prevent violence and abuse.

You will learn about assertiveness, interpersonal/intimate relationships, personal safety, and hiring and managing personal assistants.

Chapter 8: *Principles in Practice: The Advocacy and Empowerment Project* focuses on how the guiding principles for combating violence and abuse were applied to one specific university–community collaboration—the *Advocacy and Empowerment Project*. I was fortunate enough to take on the role of Project Director about halfway through the 3-year project.

Final Thoughts

As a social worker who has supported and collaborated with people with disabilities for more than 20 years, I know how important the principles of empowerment, self-advocacy, self-determination, strengths perspective, and collaboration are to people with disabilities. I have come to learn the difference between “talking the talk” and “walking the walk”—meaning actually upholding the principles in my practice. I have worked on several projects with self-advocates to combat violence and abuse of people with disabilities. This book represents some of the most important things about violence toward and abuse of people with disabilities that I have learned so far. I hope that as a result of reading this book you will be able to

- Prevent violence and abuse in your own life
- Empower people with disabilities that you know
- Educate others—family, friends, professionals, community leaders, legislators
- Change systems (disability services, victim services, criminal justice)

On December 16, 2006, the General Assembly of the United Nations adopted the Convention on the Rights of Persons with Disabilities (CRPD). One of the rights is the right to freedom from exploitation, violence, and abuse (United Nations, 2006). The United States has yet to sign the CRPD and ratify the treaty. Through individual and collective action, the CRPD will eventually be adopted in the United States. Through individual and collective action, you and I can break the silence and stop the violence toward and abuse of people with disabilities.

REFERENCE

United Nations. (2006). *CRPD in plain language*. Retrieved January 13, 2009, from <http://ratifynow.org/un-convention/crpd-in-plain-language/>

Acknowledgments

The original idea for the book came out of the *Advocacy and Empowerment Project, Taking Charge* curriculum at the Department of Disability and Human Development, University of Illinois at Chicago. Dr. Charles E. Drum and Dr. Christopher Keys were awarded a grant by the National Institute on Disability and Rehabilitation Research (NIDRR) (Grant #H133G970124) to develop a university–community collaboration model to address the problem of abuse of people with disabilities. The *Taking Charge: Responding to Abuse, Neglect and Exploitation* curriculum and 1-day workshop emerged from the collaboration. I became involved in the project as Principal Investigator and Project Director 1½ years into the project. I worked closely with Dr. Christopher Keys, Dr. Willi Horner-Johnson, and Michael Wonderlich on the completion of the project. While the book eventually took on a new direction, the following concepts from the *Taking Charge* curriculum were incorporated into the book: understanding violence and abuse from the social model of disability, continuum of abuse, internal and external barriers, web of power and control, and understanding the system.

Thank you to Dr. Christopher Keys at DePaul University and Drs. Willi Horner-Johnson and Charles E. Drum at Oregon Health & Science University for sharing their ideas, insight, and expertise. They each reviewed drafts of the manuscript and gave constructive feedback that pushed me to dig deeper into the literature and to think very carefully about the tone of the book and readability for my audience. Thank you to Drs. Willi Horner-Johnson and Charles E. Drum for helping write Chapter 8 about the *Advocacy and Empowerment Project*.

I need to acknowledge and thank all of the people with disabilities and professionals with whom I collaborated on the *Advocacy and Empowerment Project*; the *Disability Awareness for Law Enforcement Project* funded by the Administration on Developmental Disabilities; and the *Shadow Victims: Crimes Against People with Disabilities Project* funded by the Office of Violence Against Women. Through these projects I heard the stories of abuse and survival from many people with disabilities—some of which are included in the book. Thank you for sharing your stories, your insights, and your expertise.

Thank you to all of the researchers, practitioners, advocates, and self-advocates whose work both awes and inspires me. I am particularly indebted to Dick Sobsey, who wrote the first book I ever read about abuse of people with disabilities: *Violence and Abuse in the Lives of People with Disabilities: The End of Silent Acceptance?* I am honored and very appreciative that Dick Sobsey agreed to write the foreword to my book.

Finding the time to research and write this book would not have been possible without the support of my university. I received a Minnesota State University,

Mankato Teaching Scholar Award to draft the first six chapters of the book during the summer of 2006. During the spring of 2008, I was awarded a teaching release and received funding for a graduate assistant to help me finish writing the book from Dr. John Alessio, Dean of the College of Social and Behavioral Sciences. I wish to thank Dr. Alessio for the support he has shown me during the last 2 years.

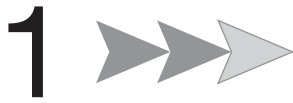
Thank you to my brother Jim Fitzsimons and sister-in-law Amy Fitzsimons for sharing their artistic and computer graphic talents by creating all (but one) of the figures in the book.

Paul H. Brookes Publishing Co. was the first publisher I contacted when I was looking for a company to publish this book. Rebecca Lazo, Acquisitions Editor, was interested and enthusiastic from the start. Her initial feedback on the first draft of the manuscript helped me redefine the direction of the book. Her ongoing feedback helped to achieve the goals of creating an informative book usable by a wide audience of readers. Thank you to Steve Plocher, Acquisitions Assistant, for his support and for answering all of my many questions throughout the development process. His patience is greatly appreciated. Thank you to all of the people at Paul H. Brookes Publishing Co. who made my first venture in authoring a book such a positive experience.

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Finally, I wish to thank my husband, Dr. Andrew Johnson, for his encouragement and support.

*For my social work mentor and dear friend
Paula Braghetta,
a tireless advocate for people with disabilities.
You are dearly missed by me
and by all those who were fortunate enough to know you.*



Guiding Principles for Combating Violence and Abuse

Newspaper stories give us a sense of what issues are considered important (at least by the writers and publishers of newspapers) and what people in our communities are talking about. Let's begin thinking about the guiding principles (or **values**) for combating violence and abuse by reading the summaries of three newspaper articles. Think about what all three stories have in common.

Their own voices; SPARC residents at meeting on self-advocacy

written by Dori Meinert, State Journal Register, Springfield, Illinois, September 22, 2005, p. 1

This newspaper article tells about the experiences of two men with developmental disabilities who traveled to Washington, D.C., to attend a national conference on self-advocacy for people with disabilities. The purpose of the conference is to encourage people with disabilities to become their own advocates. Brandon Von Liski, a self-advocate, shared his thoughts about self-advocacy:

I think it's hard for some people to speak up to staff. I think some people get nervous....I guess they're afraid the staff is going to say, "No, you can't do this or you can't do that." I think people should stick up for themselves because nobody else is going to do it for you. (p. 1)

Urging self-advocacy; Challenge daily barriers, expert tells disabled

*written by Dottie Aldrich, The Patriot News,
Harrisburg, Pennsylvania, September 6, 2006, p. W01*

This newspaper article tells about a meeting held by the **Center for Independent Living** in Central Pennsylvania to talk about programs to help people with disabilities live on their own and break down barriers in their communities. Pat Brockley, an independent living specialist, talked about the rights guaranteed under the **Americans with Disabilities Act** (ADA) of 1990 (PL 101-336). She also talked about the importance of self-advocacy, stating, “We need to teach people [to] be self-advocates. Things are not going to change unless people ask for it. Self-advocacy is what we’re trying to have people understand and how important it is.” (p. W01)

Crime victim proposes independence; Woman paralyzed in shooting at age 10 went on to be a leader

written by Barbara Ramirez,

Corpus Christi Caller-Times, Corpus Christi, Texas, April 20, 2007, p. B3

This newspaper article tells the story of Regina Blye, who was paralyzed at the age of 10. She was shot in the neck by a 13-year-old boy who had a crush on her and he said, “If I can’t have you, no one can” (p. B3). Ms. Blye was the keynote speaker at the Fourth Annual Opening Doors Conference: Serving Victims with Disabilities held by Crime Victim Services. Ms. Blye’s message for people with disabilities was “to be independent, take charge of their lives, but not to fear asking for assistance” (p. B3).

Before I explain why these three newspaper stories were selected



Ask Yourself...

What do these three stories have in common?

What is the main point that the person quoted in each of the stories was making?

Unlike many of the other newspaper stories you will read in this book, the first three articles selected are stories of hope and empowerment of people with disabilities. All three stories talk about the importance of people with disabilities speaking up and taking charge of their lives through self-advocacy. The last article is directly related to the topic of this book. Ms. Blye was a crime victim—she became disabled as a result of a shooting. Her message to the audience of people with and without disabilities reflects all of the guiding principles for combating violence and abuse presented in this book. Let’s begin by thinking about the idea of *guiding principles*.

DEFINING GUIDING PRINCIPLES

In order to combat violence and abuse of people with disabilities, you need to

- Understand the problem
- Be aware of the available resources
- Weigh the pros and cons of your options
- Develop a plan and put it into action

All of these areas will be discussed later in the book. A person's mind-set or way of thinking is just as important as what a person knows. You may be asking yourself *why* a person's way of thinking matters; it matters because a person's way of thinking has an effect on how he or she will approach combating violence and abuse of people with disabilities.



Ask Yourself...

What words would I use to describe the right mind-set or way of thinking needed to combat violence and abuse of people with disabilities?

A person's way of thinking is influenced by values. Values refer to the ideals or principles that are very important to a person, such as freedom, independence, equality, and family. In this book the term **guiding principles** is used to refer to the values that need to be put into action to combat violence and abuse. The guiding principles are **empowerment, advocacy/self-advocacy, self-determination, strengths perspective, and collaboration**. Let's look at each of the guiding principles and apply them to combating violence and abuse.

Empowerment

You are probably familiar with the term *empowerment*.



Ask Yourself...

How do I define empowerment?

What does it mean to be empowered?

How can I support the empowerment of people with disabilities?

Empowerment has many different meanings. It is difficult to write one brief definition that fully explains what the term *empowerment* means. Let's look at some of the different ways we can think about empowerment.

Empowerment is a value or a principle that guides how professionals and family members support and work with people with disabilities (Zimmerman & Warschausky, 1998). An empowerment approach emphasizes *wellness* rather than *illness* and *strengths and competency* rather than *deficits or limitations*. In social work, **empowerment practice** is defined as "the process of helping individuals, families, groups, and communities to increase their personal, interpersonal, socioeconomic, and political strength and develop influence toward improving their circumstances" (Barker, 2003, p. 142). Family members and professionals uphold the principle of empowerment when they collaborate (work together or in partnership) with people with disabilities to help them become as independent as possible, develop skills to break down barriers, and create inclusive communities (see Tip Box 1.1).

Empowerment is also a process of increasing power so that individuals and groups can take action to improve their lives (Gilson, Bricout, & Baskind, 1998; Gordon, 1995; Saleebey, 2000; Zimmerman & Warschausky, 1998). In order for people with disabilities, individually or collectively, to have control over their lives,

Tips for engaging in empowerment practice

- Listen to and learn from people with disabilities.
- Try to understand and then respect the choices made by people with disabilities.
- Focus on strengths rather than limitations.
- Seek solutions rather than focus on problems.
- Focus on skill building rather than deficit reduction.
- Engage in collaborative partnerships rather than using professional control.

Sources: Collins and Valentine (2003), Gilson et al. (1998).

TIP BOX 1.1

they need to be aware of the barriers in their communities that limit equal opportunity. People need the knowledge and skills to make changes in their lives and in their communities. In addition, people need supports and opportunities to practice skills in making change. Through the empowerment process, people begin to feel empowered (Hagner & Marrone, 1995). They begin to believe in their own individual and collective power to take control of their lives and to make the changes needed to create inclusive communities.

Empowerment is also an outcome, meaning the outcome of using an empowerment approach and the empowerment process is to become empowered or achieve power (Saleebey, 2000; Zimmerman & Warschausky, 1998).

Empowerment of people with disabilities began with three movements: the **Independent Living Movement** of people with physical disabilities, the **Self-Help Movement** of mental health consumers, and the **People First Movement** of people with intellectual disabilities (formerly referred to as *mental retardation* and sometimes called *developmental disability*) (Dybwad, 1996; Gordon, 1995; Hagner & Marrone, 1995). In each of these movements, people with disabilities were working to make sure they had the same opportunities and control over their lives as people without disabilities. They were also trying to radically change the service delivery systems to be responsive to their needs. People with disabilities are perhaps the least powerful minority group in our society. Yet, through empowerment, individually and collectively, people with disabilities have been able to obtain greater control over and improvement of their lives (Gordon, 1995). People with disabilities have also made a difference in broader issues that affect their communities, states, and the nation.

It is my belief that empowerment is the most important guiding principle for combating violence and abuse of people with disabilities. People with disabilities will achieve greater empowerment when all of the other principles are practiced. Think back to what Regina Blye said to the people attending the Opening Doors

Conference. Her message for people with disabilities was “to be independent, take charge of their lives, but not to fear asking for assistance” (Ramirez, 2007, April 20, p. B3). I believe she was talking about the need for people with disabilities to become empowered in order to “take charge of their lives” (Ramirez, 2007, April 20, p. B3). As you may already know, many people with disabilities who are being abused are afraid to ask for help. They do not believe that they will actually be helped. However, people with disabilities need “not fear asking for assistance” (Ramirez, 2007, April 20, p. B3) when family members, friends, and professionals uphold the principle of empowerment.

Advocacy and Self-Advocacy

You are probably familiar with the terms *advocate* and *self-advocate*.



Ask Yourself...

What is the difference between an advocate and a self-advocate?

Why are advocacy and self-advocacy guiding principles for combating violence and abuse?

The main difference between advocacy and self-advocacy concerns who is doing the advocating. An advocate speaks and acts on behalf of others. A self-advocate speaks and acts on his or her own behalf. Both advocates and self-advocates are needed to combat violence and abuse of people with disabilities.

Advocacy Advocacy is “the process of doing something for or speaking on behalf of some person or cause” (Stroman, 2003, p. 46). There are many types of advocacy. **Case advocacy** refers to “actions by professionals on behalf of clients or client groups to obtain needed services, resources, or entitlements or to ensure clients’ rights are upheld” (Ezell, 2001, p. 27). Another type of advocacy is **system advocacy** (sometimes called class or cause advocacy), defined as “actions taken to effect changes in policies and practices affecting all persons in a certain group or class” (Ezell, 2001, p. 27). If you are a family member, friend, or professional, you may engage in case advocacy or system advocacy on behalf of and in collaboration with self-advocates—the people with disabilities whom you know.

Self-Advocacy Self-advocacy is defined as “a process in which an individual or a group of people speak or act on their own behalf to obtain needed services, resources, and entitlements or to ensure their rights are upheld” (Ezell, 2001, p. 27). Self-advocates affiliated with **Self Advocates Becoming Empowered (SABE)** define self-advocacy as

Giv[ing] a person with a disability a chance [to] speak up for themselves and others. By letting individuals tell others how they feel about issues that affect their lives, they can educate the public about persons with disabilities and how they can be included in all aspects of community life. (Levitz, 2005, para. 4)

Self-advocacy is the *action* part of empowerment (Miller & Keys, 1996; Zimmerman & Warschausky, 1998). It is through self-advocacy that the Disability Rights Movement has been able to achieve its goals.

Self-advocacy first gained importance in the early 1960s among people with physical disabilities as part of the Independent Living Movement (Stroman, 2003). In 1982 The National Council on Independent Living was formed as an association of Centers for Independent Living (CILs). There are now CILs serving every community throughout the United States. Self-advocacy for people with intellectual disabilities began in the 1960s in Sweden and by the mid-1970s in the United States grew into the People First Movement (Dybwad, 1996; Stroman, 2003). The first People First Conference was held in Oregon in 1974. The phrase *people first* came from one member of the movement who said, “We are tired of being seen first as handicapped or retarded or disabled. We want to be seen as people first” (Stroman, 2003, p. 47). In 1991, SABE was formed as the national coalition of all state and local self-advocacy organizations for people with intellectual disabilities. There are now more than 500 People First chapters in the United States and 43 in other countries around the world.

What all types of advocacy have in common is a focus on change—in particular change from the status quo (the way things are now). The sources of many of the problems that people with disabilities experience are societal (organizational, community, environmental), requiring system advocacy. Political action, community organizing, and public education campaigns are all strategies used in systems advocacy.

Combating violence and abuse of people with disabilities requires taking action through advocacy and self-advocacy. Family members, friends, and professionals can collaborate with people with disabilities to make and put into practice policies that meet the legal, emotional, and physical needs of people with disabilities who are abused. Family members, friends, and professionals can help people with disabilities learn self-advocacy skills that promote self-determination and result in empowerment. While family members, friends, and professionals are important allies, it is people with disabilities as self-advocates who should be at the center of any effort to combat violence and abuse.

Self-Determination

If you are a person with disabilities or a **care provider** who supports someone with a disability, you know the term *self-determination*. Self-determination has been a goal of the Disability Rights Movement since its beginning in the 1960s. The Center on Self-Determination (n.d.) defines **self-determination** as “the ability for people to control their lives, to reach the goals they have set, and to take part fully in the world around them” (para. 4). Reread the definitions of self-advocacy.



Ask Yourself...

What do I think is the difference between self-advocacy and self-determination?

Why is self-determination included as a guiding principle?

Self-advocacy is about action. It is through self-advocacy that you are able to be self-determining. I see this as the main difference between the two terms—the action part of self-advocacy.

Self-determination is included as a guiding principle more for the family members, friends, and professionals reading this book than it is for people with disabilities. This is because I believe that advocates should put the self-determination of people with disabilities first, not advocate for what they want or for what they think people with disabilities should want. The vast majority of people with disabilities have the ability to make and/or take part in making decisions about their own lives. As a family member, friend, or professional you can support people with disabilities by helping them think through their options and the consequences of selecting each option. Some people with disabilities may have difficulty or be unable to make their own decisions. When you need to make a decision on behalf of another person, it is helpful to learn as much as possible about the person. Remember that negative attitudes, false beliefs, and stereotypes about people with disabilities can cloud your judgment and influence your decisions and the decisions of others (see Tip Box 1.2).

Applying the principle of self-determination is very important when working with people with disabilities who have been abused. Victims may not always act in ways that professionals and others think is in their best interest. However, as you will discover in Chapter 4, Systemic Barriers, and Chapter 5, Personal Barriers, the barriers for all victims, but especially for victims with disabilities, are powerful obstacles to getting out of abusive relationships and situations. Supporting the self-determination of victims requires recognizing the power of the barriers and clearly explaining available resources and options. It also means discussing the pros and cons of options and to the greatest degree possible supporting individuals to act in what they believe is their own best interest at that moment in time.

Tips for making decisions on behalf of others

Learn about the person's

- Likes and dislikes
- Cultural heritage (history, background)
- Religious beliefs
- Lifestyle preferences
- Life experiences

Learn about the

- Preferences of people in similar situations
- Community norms (the standards or common practices of people in the person's community)

TIP BOX 1.2

Strengths Perspective

Everyone has strengths. Strengths are assets (positive qualities), talents, skills, and abilities. Strengths are what a person is good at doing. Take a moment to think about your strengths.



Ask Yourself...

What am I good at doing?

What are my assets (positive qualities)?

What are my talents?

You will recall that an empowerment approach focuses on strengths, not limitations. The concept of strengths is another one of the guiding principles that is directed more to the family members, friends, and professionals reading this book than it is to people with disabilities. Practicing from a **strengths perspective** means that everything you do will help people with disabilities discover and improve their strengths in order to achieve their goals (Saleebey, 2000). As a family member, friend, or professional, you can support the empowerment of people with disabilities by identifying and building on strengths. Practicing from a strengths perspective means asking what a person can do, rather than dwelling on what a person cannot do (see Tip Box 1.3).

Employing a strengths perspective is very important when working with people with disabilities who have been abused, due to the harmful impact of the abuse on victims. Self-blame, low self-esteem, and learned helplessness are some of the common feelings that can occur as a result of abuse. These feelings and others will be discussed in Chapter 5, Personal Barriers. It is important to remember that even in hard times people have the ability to rise above obstacles and become even

Tips for promoting strengths

- Every person has strengths.
- Trauma and abuse may be harmful but may also provide opportunity for growth.
- Be aware of negative attitudes, beliefs, and stereotypes that you have about people with disabilities.
- Have high expectations. Every person has the ability to grow and change.
- Take each person's goals and wishes seriously.
- Collaborate, rather than dictate (give orders or tell people what to do).

Source: Saleebey (2000).

stronger (Saleebey, 2000). The very fact that a victim has survived abuse is proof of individual strength. **Survivor's pride** is a term used to refer to the growth and dignity (self-respect or pride) that can come from overcoming obstacles (Saleebey, 2000). Using a strengths perspective can help individuals move from being a victim to becoming a survivor. Using a strengths perspective can help people with disabilities discover or rediscover their strengths and become empowered.

Collaboration

The last guiding principle is **collaboration**, which means working together or working in partnership.



Ask Yourself...

Have I ever been a part of a collaboration where people with and without disabilities worked together as equal partners?

If I have been part of a collaboration with people with and without disabilities, what words would I use to describe the collaboration?

Earlier in this chapter you learned about system advocacy—actions taken to change policies and practices that affect all people in a certain group. As you read this book you will learn about many problems with the systems that are supposed to offer support and services to people with disabilities who have been abused. Changing systems to meet the needs of people with disabilities requires collective (group) action. This is why collaboration is one of the guiding principles. A collaborative approach—bringing together people with all types of disabilities, their family members and friends, and professionals from disability services; victim assistance; the vulnerable adult advocacy and protection system; and the criminal justice system—is a powerful approach to combating violence and abuse.

Interdisciplinary Collaboration *Interdisciplinary* refers to two or more disciplines (or professions such as education, nursing, social work, and psychology). **Interdisciplinary collaboration** refers to people who are from different professional disciplines working together as a team to create a plan for and deliver services that meet the needs of client systems (individuals, agencies, and communities) in order to achieve agreed-upon goals. Professionals from different disciplines have benefited from interdisciplinary collaboration in a number of areas, including

- Training in child protection services (Glaser & Williams, 1995)
- Services to students with special needs (Associated Colleges of Central Kansas, 2000)
- Early intervention with children with disabilities (Roberts-DeGennaro, 1996)
- Services for women with disabilities (Milberger et al., 2003)
- Domestic violence services for people with intellectual disabilities (Carlson, 1998)
- Health care for female victims of domestic violence (Shields, Baer, Leininger, Marlow, & DeKeyser, 1998)

Participants in interdisciplinary collaboration have reported a better understanding of the various roles of other disciplines. Interdisciplinary collaboration also results in improved **teamwork** and collaboration in the delivery of services and in positive outcomes for service recipients. One major limitation is the lack of involvement of people with disabilities in the interdisciplinary collaboration. Let's look at a few projects that *have* successfully included people with disabilities in the collaboration.

Collaboration with People with Disabilities People with disabilities have been included in collaborative projects as learners, educators, counselors, and partners. The following are three examples of projects that have included people with disabilities as equal partners. In Chapter 8 you will learn about a fourth project: the Advocacy and Empowerment Project.

- People with disabilities and their families were part of a coalition-building project on aging and developmental disabilities (Keys & Factor, 2001). The project was undertaken to deal with the deficits in the service delivery system for people with developmental disabilities at middle age and beyond. Coalitions made up of people with disabilities, families, professionals who work in elder services and disability services were formed. One of the goals of the project was to empower people with disabilities and their families through their participation as coalition members.
- Partners in Policymaking started in 1987 to teach people with disabilities and their families the knowledge and skills they needed to be involved in policy making at the local, state, and national levels. One evaluation of Partners in Policymaking found that people with disabilities who participated in the training reported an increased sense of empowerment and an increased view of themselves as self-determining individuals (Cunconan-Lahr & Brotherson, 1996). Partners in Policymaking has been implemented throughout the United States and internationally with more than 15,000 Partners having graduated from the program (Minnesota Governor's Council on Developmental Disabilities, 2007).
- A peer counseling training program for women with disabilities offered in a self-help organization was effective in meeting the needs of women with disabilities seeking supports (Saxton, 1981). The peer counselors developed marketable skills and gained greater self-confidence and a more positive self-concept as a result of helping others. As a result of their interaction with the peer counselors, the women with disabilities reported no longer feeling alone. Both the peer counselors and the service recipients gained a greater acceptance of themselves as women with disabilities.

In all of these projects, people with disabilities collaborated as equal partners or participants with professionals. A collaborative approach is the logical choice when your goal is to uphold the principles of empowerment, advocacy/self-advocacy, self-determination, and strengths as you undertake your efforts to combat violence and abuse of people with disabilities.

FINAL THOUGHTS

I hope that you see that *you* are part of the solution. You are beginning to have some ideas about what you can do in collaboration with others to combat violence and abuse. You know that whatever actions are taken should promote the empowerment, self-advocacy, self-determination, and strengths of people with disabilities. If you are a person with a disability, your voice and your involvement are crucial to any change effort. If you are a family member, friend, or professional, you know that you must listen to and learn from people with disabilities and work as partners to change systems. By the time you finish this book, you will have the information and take-action mind-set to combat violence and abuse of people with disabilities in your own life and in your community.

RESOURCES

Web Sites

Center on Self-Determination, Oregon Health Sciences University, <http://www.ohsu.edu/oidd/CSD/>
 National Empowerment Center, <http://www.power2u.org>
 Partners in Policymaking, The Minnesota Governor's Council on Developmental Disabilities, <http://www.partnersinpolicymaking.com>
 Self Advocates Becoming Empowered, <http://www.sabeusa.org>
 The Disability Rights and Independent Living Movement, University of California at Berkeley, <http://bancroft.berkeley.edu/collections/drilm/index.html>
 The National Council on Independent Living, <http://www.ncil.org>
 The National Mental Health Consumers' Self-Help Clearinghouse, <http://www.mhselfhelp.org>

DVD/Video/Training Tools

Advocacy Empowerment Wheel, available on the National Center on Domestic and Sexual Violence web site, <http://www.ncdsv.org/images/AdvocacyEmpowermentwheelNOSHADIN-NCDSV.pdf>
Declaration of Independence (DVD), Blue Tower Training, 1-866-258-8266, <http://bluetowertraining.com>
My Choice, Your Decision (Video with handbook), Blue Tower Training, 1-866-258-8266, <http://bluetowertraining.com>

2 ➡➡➡

The Relationship Between Disability and Abuse

Warnings on abuse of the disabled ignored

*written by Yvette Cabrera,
Orange County Register, Santa Ana, California, February 8, 2007, p. 1*

In this newspaper story it was reported that two men with intellectual disabilities were sexually assaulted in the restroom of a vocational academy. The executive director of a disability resource and advocacy group stated in response to the crime

We are so used to using categorical, stereotypic, devaluing, dehumanizing language in everyday speech when it comes to people with disabilities that it doesn't feel like hate. Here we are today, people with disabilities are being victimized daily, routinely and people aren't getting that. It's not just a crime of opportunity, it's motivated by hate. (p. 1)

Leslie Morrison, supervising attorney for the investigations unit of Protection and Advocacy, Inc., a state disability advocacy agency investigating the vocational academy, had issued a report more than three years prior to this incident that outlined the problems with the system. Based on what Cabrera learned while researching the story, she concluded that "Morrison's findings are astounding, but what's even more incredible is that here we are more than three years later and the system remains unchanged" (p. 1).

Perhaps you are wondering why this newspaper story was chosen to begin the chapter. Before I explain,



Ask Yourself...

Why is it that 3 years after the protection and advocacy agency issued a report about the problem of abuse of people with disabilities, nothing had seemingly been done to correct the problem?

Does the lack of action to change the system reflect that people with disabilities are undervalued in our society?

The newspaper story highlights a serious problem—violence and abuse of people with disabilities. The story raises some important questions about why abuse is tolerated and how people with disabilities fit into our society. Is nothing being done to fix the problem because the people who are being abused do not really matter much in our society? The story suggests that people with disabilities are treated as if they are second-class citizens. This status in society puts people with disabilities at a disadvantage in all aspects of life—including making them vulnerable to violence and abuse.

OVERVIEW OF THE ISSUE

In order to understand the relationship between disability and abuse, we first need to look at the concept of *disability*. How many people have disabilities? What does the term *disability* mean? What are the different ways to understand the experience of disability in our society? As we explore these issues it is important that you think about your own understanding of disability. Next we will look at the theories that are used to explain abuse of people with disabilities. Why are people with disabilities particularly vulnerable to abuse? Finally, we will look at the relationship between disability and abuse from the Social Model of Disability. The Social Model provides the best framework to engage in your efforts to combat violence and abuse of people with disabilities.

DISABILITY POPULATION ESTIMATES

It is estimated that 10% of the world's population—approximately 650 million people—have a disability (World Health Organization [WHO], 2008a) and that 80% of these people live in low-income countries with limited access to health and rehabilitation services (WHO, 2008b). WHO reports that the number of people with disabilities around the world is increasing due to population growth, aging, chronic health conditions, injuries, violence, birth defects, AIDS, environmental problems, malnutrition, and other causes often related to poverty (2008b).

In the United States it is estimated that 41 million noninstitutionalized people over the age of 5 years or 15% of the population have one or more disabilities (Rehabilitation Research and Training Center on Disability Demographic and Statistics [StatsRRTC], 2007). The estimates used are based on the U.S. Census Bureau's 2006 *American Community Survey* (ACS) data. All of the disability data comes from the 2006 *Disability Status Report, United States* (StatsRRTC, 2007).

Disability is commonly associated with age, meaning that as people get older they are more likely to have a disability (see Figure 2.1). Women have a slightly higher rate of disability than men. It is estimated that 15.6% of females ages 5 and older have a disability and 14.4% of males have a disability (see Figure 2.2). Disability rates also vary by race. Native Americans reported the highest rate of disability at 21.7% of people age 5 and older. Asians reported the lowest rate of disability at 6.3% (see Figure 2.3).

The ACS asks people to report on the types of disability. Six types of disability are identified in the ACS: physical, sensory, mental, self-care, go-outside-home (refers to going outside the home alone to shop or visit a doctor's office), and

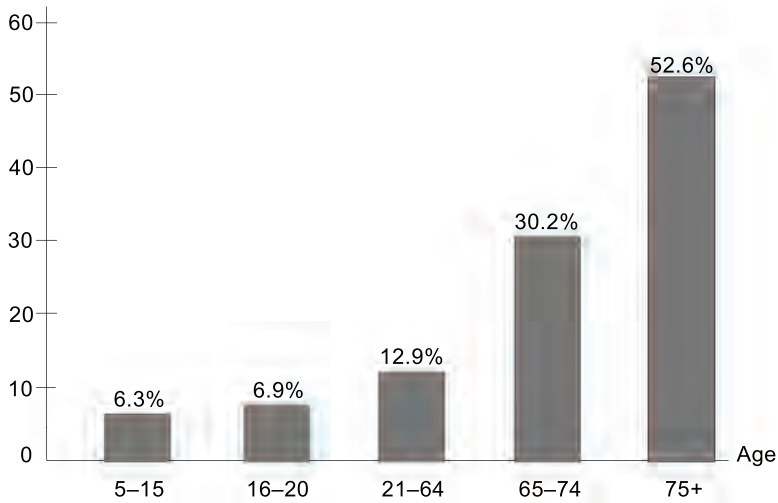


Figure 2.1. The percentage of noninstitutionalized people ages 5 and older with a disability, by age, in the United States in 2006. (Adapted from Rehabilitation Research and Training Center on Disability Demographics and Statistics [StatsRRTC]. [2007]. *2006 Disability Status Report* [p. 3]. Ithaca, NY: Cornell University. Adapted with permission.)

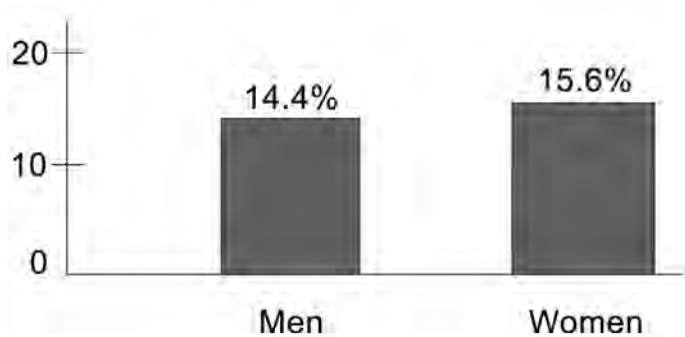


Figure 2.2. The percentage of noninstitutionalized people ages 5 and older with a disability, by gender, in the United States in 2006. (Adapted from Rehabilitation Research and Training Center on Disability Demographics and Statistics [StatsRRTC]. [2007]. *2006 Disability Status Report* [p. 18]. Ithaca, NY: Cornell University. Adapted with permission.)

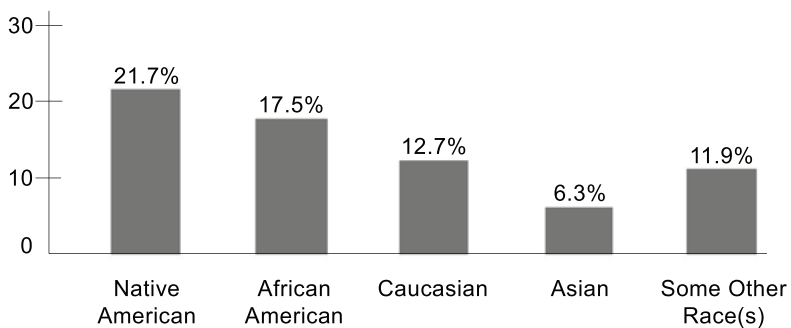


Figure 2.3. The percentage of noninstitutionalized working-age people (ages 21-64) with a disability, by race, in the United States in 2006. (Adapted from Rehabilitation Research and Training Center on Disability Demographics and Statistics [StatsRRTC]. [2007]. *2006 Disability Status Report* [pp. 20-21]. Ithaca, NY: Cornell University. Adapted with permission.)

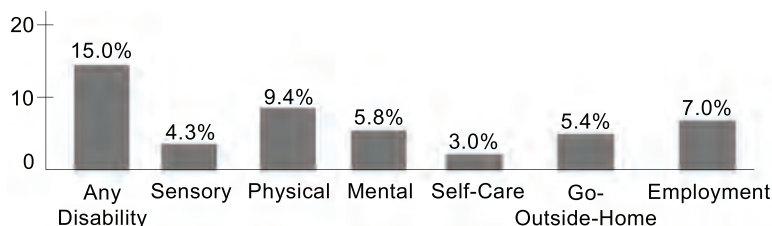


Figure 2.4. The percentage of noninstitutionalized people ages 5 and older with a disability, by disability category, in the United States in 2006. (Adapted from Rehabilitation Research and Training Center on Disability Demographics and Statistics [StatsRRTC]. [2007]. *2006 Disability Status Report* [pp. 6–7]. Ithaca, NY: Cornell University. Adapted with permission.)

employment (refers to a physical, mental, or emotional condition lasting more than 6 months that made it difficult to work at a job or business). Survey participants were asked to respond affirmatively to all of the categories of disability that applied. Physical disability is the most common type of disability in the United States at 9.4%. The least common type of disability is self-care at 3.0% (see Figure 2.4).

You may come across different disability estimates. The U.S. Census Bureau has a few different ways for collecting disability data. For more information about how disability data are collected, visit the U.S. Census Bureau web site at www.census.gov and click on *D* under *Subjects A to Z*. Then look for *Disability Data*.

DISABILITY TERMINOLOGY

Throughout history the words used to refer to people with disabilities have changed. The words once commonly used include such negative terms as *imbecile*, *moron*, *gimp*, *deaf and dumb*, *idiot*, *palsy*, and *cripple*. You know that some people still use insulting words to refer to people with disabilities. Fortunately these very negative words are far less acceptable to the general public than they once were. And they are certainly not acceptable to people with disabilities. The language has changed as our understanding of disability has changed. People with disabilities through their own self-advocacy were to a great extent responsible for the changes. **People First language**, coming from the Self-Advocacy Movement, has largely, although not completely, been accepted by the disability community as the preferred language to use when referring to people with disabilities (see Table 2.1). People first language recognizes the *person* first and then the disability (Snow, 2005).

The word *handicapped* was once commonly used. Using the *International Classification of Impairments, Disabilities, and Handicaps (ICIDH)*, the World Health Organization (WHO) defines **handicap** the following way:

In the context of health experience a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for the individual. (WHO, 1980, p. 183)

The *ICIDH* has been renamed and is now called the *International Classification of Functioning, Disability, and Health (ICF)*. The word *handicap* is no longer used by WHO. The word **impairment** is used by WHO and is defined as “problems in body function or structure such as significant deviation or loss” (WHO, 2001, p. 12).

Table 2.1. Examples of people first language

Say:	Instead of:
People with disabilities	The handicapped or disabled
He has a cognitive disability/diagnosis.	He's mentally retarded.
She has autism (or a diagnosis of...)	She's autistic.
He has Down syndrome (or a diagnosis of...)	He's Down's; he's a mongoloid.
She has a learning disability (diagnosis).	She's learning disabled.
He has a physical disability.	He's a quadriplegic/is crippled.
She's of short stature/she's a little person.	She's a dwarf/midget.
He has a mental health condition/diagnosis.	He's emotionally disturbed/mentally ill.
She uses a wheelchair/mobility chair.	She's confined to/is wheelchair bound.
He receives special education services.	He's in special education.
She has a developmental delay.	She's developmentally delayed.
Children without disabilities.	Normal or healthy kids.
Communicates with her eyes/device/etc.	Is nonverbal.
Customer	Client, consumer, recipient, etc.
Congenital disability	Birth defect
Brain injury	Brain damaged
Accessible parking, hotel room, etc.	Handicapped parking, hotel room, etc.
She needs...or she uses...	She has a problem with...she has special needs...

From Snow, K. (2007). *Examples of people first language*, from Disabilityisnatural.com; reprinted with permission.

Disability is a more complex word to define. The WHO uses the *ICF* definition of disability. Disability is defined as “the outcome or result of a complex relationship between an individual’s health condition and personal factors, and of the external factors that represent the circumstances in which the individual lives” (WHO, 2001, p. 17).

The Americans with Disabilities Act (ADA; PL 101-336) uses a broad definition of disability. An individual with a disability is

A person who has a physical or mental impairment that substantially limits one or more major life activities

A person who has a history or record of such an impairment

A person who is perceived by others as having such an impairment (U.S. Department of Justice, 2005, p. 1)

See Table 2.2 for examples of disability under the ADA.

Refer to the *Americans with Disabilities Act Questions and Answers* listed under Resources at the end of this chapter to learn more about the ADA. The U.S. federal government has other definitions of disability used to determine eligibility for benefits and services. Each state also has its own definition of disability.

Final Thoughts About Disability Terminology

You are probably familiar with the rhyme “sticks and stones may break my bones but words will never hurt me” (English proverb). I disagree—words can and do hurt people. If you are a person with a disability, you have probably been called

Table 2.2. Examples of disability under the ADA

Part One: A person who has a physical or mental impairment
• Impairments that substantially limit major life activities: seeing, hearing, speaking, walking, breathing, performing manual tasks, learning, caring for oneself, and working.   • Conditions such as: epilepsy, paralysis, HIV infection, AIDS, a substantial hearing or visual impairment, intellectual disability.   • Minor, nonchronic conditions of short duration, such as a broken limb or sprain, generally would not be covered.
Part Two: A person who has a history or record of impairment.
• A person who has recovered from cancer or a mental health condition who is treated by others as if they had a disability based on past history.
Part Three: A person seen by others as having an impairment.
• A person with a severe facial disfigurement who is denied employment because an employer is afraid of the negative reactions of others.

From U.S. Department of Justice. (2002, May). *Americans with Disabilities Act: Questions and answers*. Washington, DC: U.S. Department of Justice, Civil Rights Division; adapted by permission.

hurtful names and described by other people using very negative words. Here are a few key points to remember about word choices:

- Use People First language—recognize the person first, then the disability.
- Avoid using words that are negative—meaning if you would not want to be referred to by a certain word, do not use it to describe another person.
- Do not use *handicapped* to refer to a person with a disability.

Let’s move on to examining the models of disability.

MODELS OF DISABILITY

Two broad models for understanding disability are the Individual Model and the Social Model. It is important to understand the Social Model in order to understand the problem of violence and abuse of people with disabilities. However, first you need to understand the Individual Model and some of the problems with this model.

Individual Model of Disability

The **Individual Model of Disability** locates the problem of disability within the individual (Oliver, 1996). Problems are seen as coming from the physical, sensory (e.g., sight, smell, hearing, taste, touch), or mental limitations that are caused by the impairment. Most of the older ways of thinking about disability focused on the individual as both the cause of disability and the target of intervention. The problem with the Individual Model is that disability is viewed as an individual problem requiring the services of professionals to change, cure, or fix the person (see Table 2.3). There is little, if any, recognition of the role that society (the environment) plays in creating and maintaining disability.



Ask Yourself...

How much does the Individual Model of Disability reflect my experience as a person with a disability? As a family member or friend? As a professional?

As a person with a disability, do most people that I meet think that there is something wrong with me? That I need to be fixed?

Table 2.3. Individual model of disability perspectives

Moral Model: Views disability as a punishment for wrongdoing or sin
Medical Model: Views disability as a defect or sickness that must be treated or cured through medical intervention
Rehabilitation Model: Views disability as a limitation in functional ability that requires intervention by rehabilitation and other professionals

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Source: Rothman (2003).

Social Model of Disability

The **Social Model of Disability** was introduced in the 1960s and focuses on the role of society (the environment) in creating and maintaining disability (Oliver, 1996). The Social Model locates the majority of challenges experienced by people with disabilities within society. According to Oliver, “it is not individual limitations, of whatever kind, which are the cause of the problem but society’s failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken [into account] in its social organization” (p. 32). The Social Model does not deny that some limitations are the result of individual impairment, some illnesses have disabling outcomes, and that many people with disabilities experience illness at some point in their lives (Oliver, 1996). The problem is that the medical community tries to eliminate or fix the disability rather than treat the illness. The Social Model focuses on changing attitudes and environmental barriers created by society, rather than changing the individual.



Ask Yourself...

How much does the Social Model of Disability reflect my understanding and experience as a person with a disability? As a family member or friend? As a professional?

How much easier would my life be if society better met the needs of all people with disabilities?

How much easier would the lives of people with disabilities be if society better met the needs of all people with disabilities?

Final Thoughts About the Social Model of Disability

As you read this book you will notice that current thinking about the problem of violence and abuse of people with disabilities is greatly influenced by the Social Model of Disability.

THEORIES OF VIOLENCE AND ABUSE OF PEOPLE WITH DISABILITIES

Several theories have been proposed to explain violence and abuse of people with disabilities. We are going to focus on three main theories:

- Dependency-Stress Model
- Power and Control Model
- Integrated Ecological Theory of Abuse

As you read about these models or theories, keep in mind that they are possible explanations; there has not been enough research into the causes of abuse of people with disabilities to come to any clear conclusions.

Dependency-Stress Model

Before examining the Dependency-Stress Model,



Ask Yourself...

Have I heard people excuse abusing a person with a disability because of stress?

Have I heard people with disabilities minimize harmful behavior toward them by saying that the person is under a lot of stress right now?

The **Dependency-Stress Model** (also referred to as *caregiver* or *care provider stress*) is one of the most commonly used and controversial explanations for abuse of vulnerable populations, including children with disabilities (Rodriguez & Murphy, 1997; Sobsey, 1994), adults with disabilities (Sobsey, 1994), and elderly people (Anetzberger, 2000; Brandl, 2000; Brandl & Raymond, 2005). In this model, the main reason care providers engage in abusive behavior is because they are under stress due to the demands of caregiving. When the demands of caregiving outweigh (are greater than) the coping abilities of care providers, care providers lash out to temporarily relieve the stress.

One criticism of the Dependency-Stress Model is that it blames the victim for the abusive actions of the **offender** (Brandl, 2000; Sobsey, 1994). First, the model cannot possibly explain sexual assault of people with disabilities. How can stress be a plausible explanation for sexual assault? Although it is true that some care providers are under stress and may lack necessary supports and resources, stress is an unacceptable excuse for abusive behavior. Everyone experiences stress. We all have a choice in how we deal with the stress in our lives. Another criticism is that a belief in the care provider stress theory leads to the abuse being dealt with as a social service issue rather than as a crime (Brandl, 2000; Sobsey, 1994). According to Brandl (2000), “Many abusers only examine their behavior once they have been arrested—a message that their behavior is not just inappropriate but also illegal” (p. 43). There is general agreement that care provider stress is an unacceptable and far too simple explanation for abusive behavior (Anetzberger, 2000; Brandl & Raymond, 2005; Rodriguez & Murphy, 1997; Sobsey, 1994).

Power and Control Model

Before examining the Power and Control Model, think about your own sense of personal power and control over your life.



Ask Yourself...

Who makes the majority of decisions about my life?

How much control do I have over how I live my life?

How much control do my friends and acquaintances with disabilities have over their lives?

The **Power and Control Model** is the main theory used to explain domestic and sexual violence (National Center for Victims of Crime [NCVC], 2008a; NCVC, 2008b). Domestic and sexual violence is typically about power and control. According to the NCVC (2008a), “The abuser wants to dominate the victim and wants all the power in the relationship—and uses violence in order to establish and maintain authority and power” (para. 4). The Power and Control Model has been more recently used to explain **domestic violence** (sometimes referred to as *domestic abuse*) of people in later life—*elder abuse* (Brandl, 2000; Brandl & Raymond, 2005). The Domestic Abuse Intervention Project in Duluth, Minnesota, developed the Domestic and Sexual Violence Power and Control Wheel. The items in the slices of the wheel are tactics that are used on a regular basis against female victims. The actions listed in the outer ring, physical and sexual abuse, are more extreme and less frequently used methods for male abusers to control their partners (Domestic Abuse Intervention Project, n.d.; see Figure 2.5).

Abuse of People with Disabilities Caregiver Power and Control Model

The **Abuse of People with Disabilities Caregiver Power and Control Model** (referred to as the Disability Abuse Model), based on the Power and Control Model, was adapted by the Wisconsin Coalition Against Domestic Violence (n.d.a) to explain violence and abuse of people with disabilities. Using the Disability Abuse Model, power is used by care providers to obtain control over people with disabilities. Power and control issues are seen in relationships with spouses, partners, and family members (Calderbank, 2000; Cramer, Gilson, & DePoy, 2003; Guidry Tyiska, 1998; Mays, 2006; Milberger et al., 2003), personal assistants (Oktay & Tompkins, 2004; Saxton et al., 2001), and in institutionalized settings (Crossmaker, 1991). The tactics in the Abuse of People with Disabilities Caregiver Power and Control Wheel in Figure 2.6 have been adapted from the Domestic and Sexual Violence Power and Control Wheel to better reflect the experiences of people with disabilities. For example,

- Caregiver privilege includes denying the right to privacy, not allowing people to use their abilities to the fullest, and making unilateral (one-sided) decisions.
- Withholding, misusing, or delaying needed supports includes care providers refusing to use or allow the use of communication devices and purposely destroying or not fixing adaptive equipment.

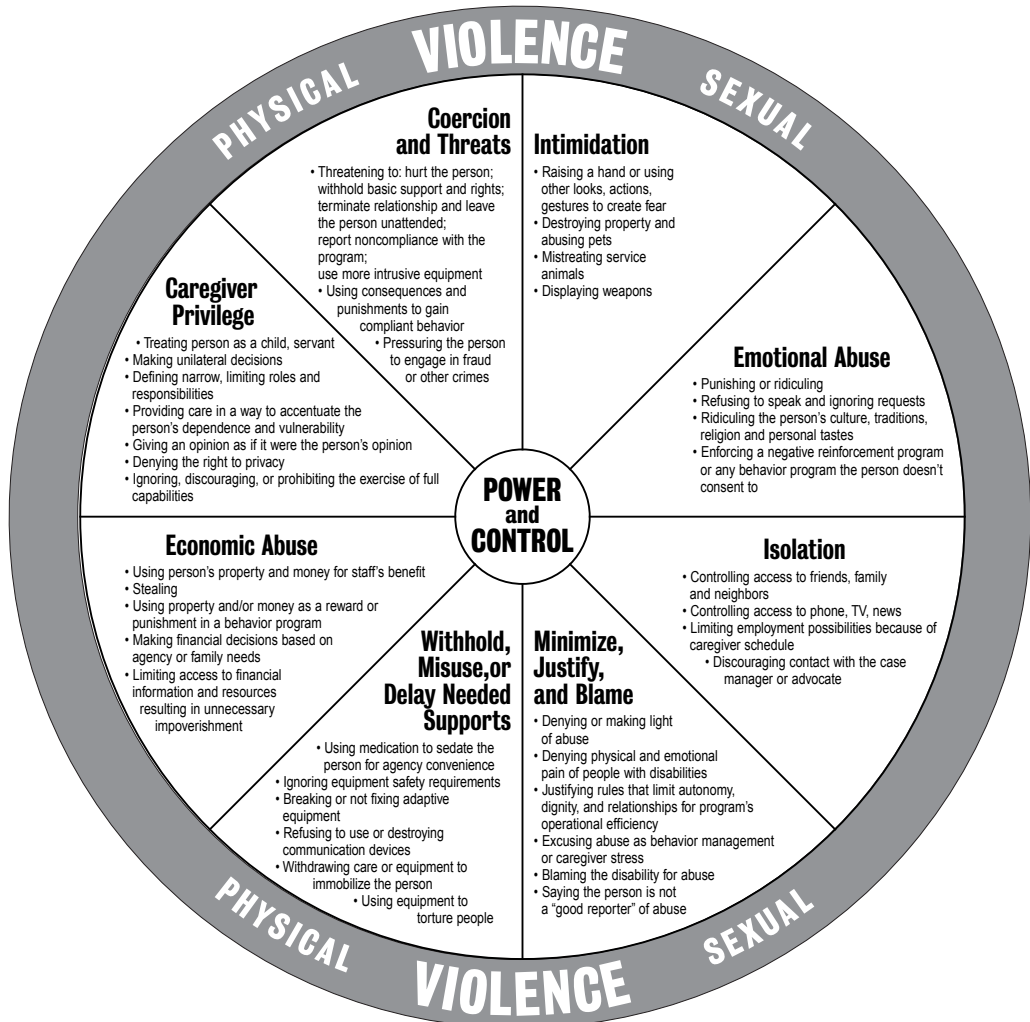
The Disability Abuse Model is pretty easy to understand. In Chapter 7 you learn about how you can use the Disability Abuse Model to examine your own relationships or the relationships of the people with disabilities you support.



Copyright © 2008, Domestic Abuse Intervention Project, 202 E. Superior St., Duluth, MN; reprinted by permission. In *Combating Violence and Abuse of People with Disabilities: A Call to Action* by Nancy M. Fitzsimons (2009, Paul H. Brookes Publishing Co.)

Figure 2.5. The Domestic and Sexual Violence Power and Control Wheel was developed to explain violence perpetrated by men against women in intimate (spousal/partner) relationships.

The Disability Abuse Model is similar to the Social Model of Disability in that it recognizes that forces beyond the individual have a negative impact on people with disabilities. This model also highlights the importance of one of our guiding principles—empowerment. If violence and abuse is understood as an issue of loss of power and control then it is all the more important to make sure that any effort to address the problem supports the empowerment of people with disabilities. Let's use the Power and Control Model in a learning activity to help you recognize care provider power and control tactics.



Copyright © 2008, Wisconsin Coalition Against Domestic Violence, 307 S. Paterson St., Suite 1, Madison, WI; reprinted by permission. In *Combating Violence and Abuse of People with Disabilities: A Call to Action* by Nancy M. Fitzsimons (2009, Paul H. Brookes Publishing Co.)

Figure 2.6. The Abuse of People with Disabilities Caregiver Power and Control Wheel was adapted from the Domestic and Sexual Violence Power and Control Wheel developed by the Domestic Violence Intervention Project (Duluth, Minnesota) to explain abuse of people with disabilities.

LEARNING ACTIVITY

Care Provider Power and Control Tactics

Read April's story. Think about the power and control tactics that apply.

April and Sean have been married for less than 2 years. Shortly after the birth of their son, April, a woman who is deaf, began having serious mental health problems. She was very depressed and unable to care for herself or her baby.

Sean believed that April needed to breast-feed their baby. Sean told April that if she did not properly feed the baby he would leave her, go to court, and have her declared an unfit mother. When April failed to follow Sean's orders, he tied her to a chair and forced her to nurse the baby. He refused to let her use the telephone or computer to talk with family and friends. Despite April's many requests for help, Sean claimed she was faking her illness and refused to take her to the doctor to get help. Sean restricted April's access to money and would not let her drive. He repeatedly told April that she was an unfit mother and a bad wife. April's mother eventually came to the home demanding to see her daughter. April told her mother about the abuse. Her mother immediately reported the domestic violence to the police, helped April get an **Order for Protection**, and helped her get services to treat her depression and heal from the domestic violence. Sean was arrested and convicted of committing domestic abuse.

Power and control tactics that apply to April's story include

- Perpetrating physical violence
- Making unilateral decisions
- Limiting access to financial resources
- Controlling access to friends, family, and neighbors
- Making light of the abuse
- Ridiculing
- Using punishment to gain compliant behavior
- Threatening to terminate the relationship
- Controlling access to the telephone and computer

April's story is one example of domestic violence by a male partner against a woman with disabilities. April's husband used his power to control all aspects of her life. Fortunately for April, her mother recognized that there was a problem and got involved.

As you think about April's story, it is important to look at whether the cycle of domestic violence experienced by women without disabilities is the same for women with disabilities. The **Walker Cycle Theory of Violence** has been used to explain the phases of abusive episodes perpetrated against women by their partners (Walker, 2000). The three distinct phases of the violence are the tension-building phase, the abusive episode, and the honeymoon or loving-contrition phase. For women with disabilities, the third phase of domestic violence may not apply (Copel, 2006). Women with disabilities have reported that after the violent episode there was a period of separation that lasted as long as the male partner wanted. There was no honeymoon phase in which the abuser apologized and showed remorse (guilt or regret). Eventually a superficially normal relationship resumed and the woman never knew when the next abusive episode would occur. Be aware that the typical cycle of domestic violence may not apply to April and other women with disabilities.

LEARNING ACTIVITY

 Care Provider Power and Control Tactics

Read Keisha's story. Think about the power and control tactics that apply.

Keisha (not her real name) is a 37-year-old woman who has cerebral palsy. She has severe physical and intellectual disabilities. She is fed through a feeding tube due to her difficulty swallowing. She lives in a group home with several other people with intellectual disabilities. One evening a paid care provider at the home heard what sounded like soft crying and screaming coming from Keisha's room. When the care provider went into the room she found that the majority of Keisha's nightgown had been stuffed in her mouth. The care provider reported the abuse to her supervisor and the police were called. During questioning by the police the abuser confessed that she put the nightgown in the victim's mouth because Keisha was "making noises that bothered her and she did not want to hear them" (Treleven, 2004, p. B1).

Power and control tactics that apply to Keisha's story include

- Using punishment to gain compliant behavior
- Ignoring requests
- Enforcing an unauthorized behavior management program
- Excusing abuse as behavior management

Some people with disabilities—most commonly people with **cognitive** disabilities such as intellectual disabilities, dementia, or severe mental health conditions—may present challenging behaviors that require intervention by professionals. In most cases a trained *behavior analyst*, typically someone with a graduate-level psychology degree, will work with an interdisciplinary team, including family members and the person with a disability, to develop a **behavior management program** to teach and reinforce wanted behaviors and inhibit unwanted behaviors. Most behavior management programs today focus on learning the reasons for the behaviors, teaching adaptive alternative behaviors, and modifying the environment—referred to as *positive behavioral supports* (Carr, Horner, & Turnbull, 1999). Signatures of approval are obtained from all of the people involved in creating, implementing, and monitoring the authorized behavior management program, including legal guardians and the people presenting the challenging behaviors.

Keisha's story is a good example of the power of care providers. In this case, the care provider used *punishment*, a controversial form of behavior management, to obtain compliance. Behavior analysts avoid or minimally use punishment because of the potential for causing harm and because positive reinforcement is much more effective (Carr et al., 1999). Most likely the care provider began by telling Keisha to be quiet. When Keisha did not comply, the care provider stuffed a nightgown in Keisha's mouth to force her to be quiet. It is remotely possible that the care provider thought that she was teaching Keisha to follow directions rather than abusing her. Many acts of violence and abuse are committed against people with disabilities under the excuse of behavior management. However, given the very violent and life-threatening nature of the care provider's actions, it appears

that Keisha was being punished for not complying with the care providers command to be quiet. Be aware that people with disabilities experience violence and abuse through authorized and unauthorized behavior management techniques labeled and sanctioned as behavior management.

Integrated Ecological Theory of Abuse

The **Integrated Ecological Theory of Abuse** (referred to as the Integrated Ecological Theory) was proposed by Dick Sobsey (1994) in his book *Violence and Abuse in the Lives of People with Disabilities: The End of Silent Acceptance?* The Integrated Ecological Theory of Abuse provides a comprehensive explanation of violence and abuse of people with disabilities. A similar model has been proposed to explain elder abuse (Anetzberger, 2000). The Integrated Ecological Theory draws from several theories: General Systems Theory, Ecological Model, Counter-Control Model, and Social Learning Theory (see Table 2.4). At first glance the theory might appear complicated. Here is what you need to know to better understand the theory:

- At the center of the Integrated Ecological Theory is human interaction—people interact with other people.
- Interaction between human beings can become abusive when one person in the relationship has more power than the other. When the more powerful person chooses to use his or her power, the weaker person has no way to use power to stop the abuse.
- People with disabilities are vulnerable to abuse as a result of their impairments *and* because of the disempowering actions of care providers and the broader society.
- Abusive behavior that is reinforced will more likely be engaged in by people who observe the abuse. People who observe abusive behavior that is punished are less likely to engage in abusive behavior.
- People with disabilities are vulnerable to violence and abuse when the environments where they live, work, learn, and play reinforce abusive behavior and fail to reinforce nonabusive behavior.

Table 2.4. Theories used in the Integrated Ecological Theory of Abuse

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General Systems Theory was first used in the field of biology and later applied to social systems to explain how people and societies run and relate to one another (Lesser & Pope, 2007).

Ecological Model was first used in the field of child development to explain the interactive nature of the parent–child relationship within the larger community and culture. This model has been applied to many aspects of family relationships, including child abuse. The *ecological perspective* expanded the Ecological Model to help understand people and their environment in a wide array of situations. The focus is on the interactions that occur between people and their environment that influence one another (Barker, 2003, p. 136; Lesser & Pope, 2007).

Counter-Control Model focused on how people react to each other by reinforcing behavior that is wanted and punishing behavior that is not desirable (Sobsey, 1994). A healthy relationship between people is created when each person has equal power in the relationship and each can exert an equal amount of counter-control.

Social Learning Theory focused on how modeled behavior (behavior that can be observed) influences our own behavior (Sobsey, 1994). Behavior that is reinforced is more likely to be engaged in by others observing the behavior. Behavior that is punished is less likely to be engaged in by others observing the behavior.

Table 2.5. Integrated Ecological Theory of Abuse: Systems and characteristics

Potential victim	Potential offender	Environment	Culture
Impaired physical defenses	Need for control	Emphasizes control	Devalues victims
Impaired communication	Authoritarian	Attracts abusers	Objectifies victims
Lacks critical information	Low self-esteem	Isolated from society (physical and/or social isolation)	Teaches compliance
Learned helplessness	Displaced aggression	Provides awarded models of aggression	Emphasizes vulnerabilities
Learned compliance	Exposed to abusive models	Covers up allegations	Reinforces aggression
Underdeveloped sense of personal space	Little attachment to victim	Has many care providers	Denies problems
Dependency	Devaluing attitudes	Has transient care providers	Discourages attachment Discourages solutions
Desire to please or be accepted	Impulsive behavior	Dehumanizes potential victims	
Few alternatives to exploitation		Eliminates nonabusers Clusters risk Discourages attachment	

From Sobsey, D. (1994). *Violence and abuse in the lives of people with disabilities: The end of silent acceptance?* Baltimore: Paul H. Brookes Publishing Co.; adapted by permission.

The Integrated Ecological Theory focuses on the interaction between four systems: 1) characteristics of the potential victim, 2) characteristics of the potential offender, 3) characteristics of the immediate environment, and 4) characteristics of the broader society or culture (Sobsey, 1994). This theory applies to family environments and service system environments (see Table 2.5). Each of the four systems influences the others. The greater the number of characteristics in place, the more likely it becomes that abuse will occur and be tolerated. As you look at the characteristics of potential victims, keep in mind that many of these characteristics are caused or at least strongly influenced by the environment. Also keep in mind that an overemphasis on the characteristics of the potential victim could unintentionally lead to blaming the victim.

When using the Integrated Ecological Model to examine the potential for abuse in a family (e.g., domestic) or service system environment, consider the environment *and* the family members or employees, or potential offenders. For example, environments that emphasize control, cover up reports of abuse, and discharge employees who are not abusive will more likely attract and keep employees who have a need for control, engage in impulsive behavior, and undervalue people with disabilities. Also, consider the characteristics of people with disabilities. If people have impaired physical defenses and/or impaired communication, and have learned compliance, then the risk for abuse is great. It is the characteristics of the people with disabilities in combination with the characteristics of the family members or employees *and* the service provider organization (environment) that creates an enormous power imbalance in favor of the care providers. This power imbalance can result in a dangerous situation for people with disabilities. The situation is made worse if the broader society or culture undervalues people with disabilities and denies that a problem exists. In the next section, you will have

the opportunity to apply the Integrated Ecological Theory in a learning activity examining vulnerability.

Final Thoughts About Theories of Violence and Abuse

You've read a lot of information about possible explanations for violence and abuse of people with disabilities. Let's review the main points to remember:

- Care provider stress is often given as a reason for violence and abuse. While some care providers may feel stressed, stress is not an acceptable excuse for abusive behavior.
- Abuse can be understood as an issue of power and control. Care providers use power to gain control over people with disabilities. Prevention should emphasize empowerment of people with disabilities.
- The Integrated Ecological Theory looks at the interaction between the person with a disability, the care provider, the immediate environment, and the larger society. This theory recognizes the importance of looking at issues of care provider power and control *and* looking at how the environment reinforces (or does not reinforce) abuse.

VULNERABILITY TO VIOLENCE AND ABUSE

Before reading on, think about your own level of vulnerability.



Ask Yourself...

Do I have any characteristics, personal or environmental, that make me vulnerable to violence and abuse?

What strengths and supports do I have that help protect me from violence and abuse?

The term **vulnerable adult** refers to “a person who is being mistreated or is in danger of mistreatment and who, due to age and/or disability, is unable to protect himself or herself” (National Center on Elder Abuse [NCEA], 2005, para. 3). The legal definition of vulnerable adult varies from state to state. Not all people with disabilities see themselves as vulnerable adults. Do not assume that all people with disabilities are vulnerable adults or that all people who are elderly are vulnerable adults.

However, there are many reasons why people with disabilities as a group are vulnerable to violence and abuse. Most of the reasons come from the lack of power people with disabilities have in our society and the fact that their lives are often controlled by others (Andrews & Veronen, 1993; Calderbank, 2000; Crossmaker, 1991; Saxton, 1981; Sobsey, 1994). Women with disabilities are particularly vulnerable due to their devalued status as both women and individuals with disabilities (Chenowith, 1997; Cramer et al., 2003; Gill, 1997; Gilson, DePoy, & Cramer, 2001b; Mays, 2006). People from minority racial/ethnic groups and people who are lesbian, gay, bisexual, or transgender (LGBT) have additional vulnerability due to their devalued status in society (Cook-Daniels, 2007b; DeMonnin & Fun, 2005; Gill, 1997).

Here are some of the most commonly reported reasons for vulnerability to violence and abuse:

- Dependence on others for long-term care
- Lack of economic independence
- Stereotypes and negative attitudes that undervalue people with disabilities
- Less risk of discovery of abuse as perceived by offenders
- Failure to be believed when a report is made
- Lack of participation in abuse awareness and personal safety programs
- Less education about sexuality and healthy intimate relationships
- Fewer opportunities to engage in healthy interpersonal relationships
- Social isolation
- Overprotection
- Communication barriers
- Physical barriers to accessing supports and services
- Greater challenges in taking risk-reducing precautions or resisting abuse

You will look at these in greater detail in the chapters about systemic and personal barriers. Now that you have read the reasons for increased vulnerability,



Ask Yourself...

- *How many of the reasons are caused by a person's impairment?*
- *How many of the reasons are directly or indirectly caused by the environment?*

It seems pretty clear that most of the increased vulnerability has some connection to the environment where you and the people with disabilities you support live, work, learn, and play. A lot of the vulnerability is due to the belief that people with disabilities are helpless, incapable of making informed choices, unable to protect themselves, and not able to be self-advocates. Everyone has strengths. Everyone has weaknesses. Everyone has vulnerability to violence and abuse. When you use the *People First* way of thinking, you will recognize that each person with a disability is a one-of-a-kind human being—each with his or her own strengths, weaknesses, and vulnerabilities. This next learning activity will help you to enhance your skills in assessing strengths and vulnerabilities.

LEARNING ACTIVITY



Assessing Vulnerability

Read each of the examples. Refer back to the Integrated Ecological Model of Abuse earlier in this chapter as you think about each person's vulnerability. Place an X on the line to indicate the degree of vulnerability for each person. Think about your reasons for each of the ratings.

Jacob

Jacob is a 27-year-old man who is legally blind. He is a college graduate who works full time in human resources. He has a guide dog. He takes public transportation every day to go to work and most other places that are not within walking distance. He has some vision that allows him to see shades of light and dark. He lives in an apartment with a male roommate who is a close friend from college. Jacob's parents and sister also live in the same city. His family sees him two to three times a month. He is independent in meeting most of his daily living needs. His roommate and family provide support and assistance when needed.

Minimal Vulnerability

Moderate Vulnerability

Extreme Vulnerability

Thoughts About Jacob's Vulnerability

Jacob's vulnerability is probably on the lower end of the scale, or minimally vulnerable. He lives in his own home with a roommate of his choosing who is a close friend. He does not rely on any service providers for his care, removing some problematic environmental factors and increasing the control he has over his own life. He appears to be very self-reliant, reducing his potential as a victim. He is college educated and is employed full time, which increases the likelihood that he is financially independent. He works in human resources and may be familiar with the laws protecting people from discrimination, sexual harassment, and other laws about human rights. He has impaired physical defenses due to his blindness. However his guide dog may serve as a protective factor. The regular but not too frequent family contact may be a sign of a good relationship and could be a protective factor in the event that the relationship with his roommate becomes abusive.

Gabriel

Gabriel is a 22-year-old man with a severe intellectual disability and deafness. He lives several miles outside of a small rural town with his parents and three younger brothers. Their closest neighbor is three quarters of a mile away. Gabriel received special education services until the age of 21. He recently started going to a sheltered work program in town. He communicates by pointing at pictures and using a small number of signs. Transportation to and from the sheltered work program is provided by a private bus service. Gabriel is the first person picked up and the last person dropped off on the 36-mile round-trip each day. He requires assistance with most of his daily living care needs, including toileting, bathing, and dressing.

Minimal Vulnerability

Moderate Vulnerability

Extreme Vulnerability

Thoughts About Gabriel's Vulnerability

Gabriel's vulnerability is very high. Gabriel has most of the characteristics that make him a potential victim. Gabriel has a history of receiving special services and currently receives them. He spends most of his time in three environments, his home, the sheltered workshop, and the bus. His home is very isolated from the rest of society, increasing the chances that abuse by a family member would go undiscovered. He is alone for part of the long ride to and from the workshop, increasing the chances that he could be abused by the bus driver. Sheltered workshops are segregated settings that often cluster people with challenging behaviors that may include physical and sexual aggression and people with more severe disabilities who function less independently, thereby posing another potential risk factor for abuse. A potential protective factor is that the employees at the sheltered workshop, the bus driver, and the family could each monitor the care provided by the others, increasing the likelihood that abuse would be discovered and reported to the authorities. However, rural communities often place a high value on family privacy and lack of interference from governmental agencies. If this cultural norm applies, authorities may be reluctant to get involved if a report is made. On the other hand, people living in small towns often know everyone else's business, and if people chose to get involved this could serve as a protective factor.

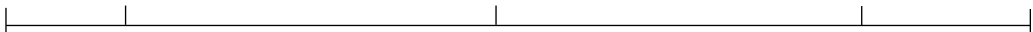
Maria

Maria is a 44-year-old woman with cerebral palsy (a condition that affects motor movement). She does not have an intellectual impairment. She has great difficulty communicating verbally. She uses a computer with a head pointer to communicate in writing. Maria is unable to walk and has limited use of her arms. She uses a power wheelchair. For the past three years Maria has lived in her own apartment with the support of the same live-in personal assistant (PA). The local Center for Independent Living (CIL) assists Maria in hiring and managing the personal assistant. Prior to moving into her own apartment, Maria lived in a nursing home. She also lived in a state-run institution from ages 11 to 22. She never attended school, but was taught to read by her mother. Maria depends on her PA for all of her daily living needs, including recharging the battery on her power wheelchair, putting on her head pointer to use her computer, and connecting her computer to the telephone. Her 69-year-old mother visits her three to four times per week. Maria also has two sisters; both live out of town and visit four to five times per year. She communicates with her sisters by e-mail every day.

Minimal Vulnerability

Moderate Vulnerability

Extreme Vulnerability



Thoughts About Maria's Vulnerability

Maria's vulnerability would be moderate to high. Given her history of institutionalization, she has most likely experienced abuse herself or has witnessed abuse of others. She may have many of the characteristics that would make her a potential victim, such as learned helplessness, learned compliance, and an underdeveloped sense of personal space. However, her current living situation does afford her some protective factors. She is involved with her local CIL. Through the supports, services, and information the CIL provides she may know about her rights and the resources available to protect her. Maria lives in her own home, which increases the likelihood that she has control over her environment. She has a stable live-in PA and receives support from the CIL in overseeing the care provided. Maria has regular contact, both in person and by e-mail, with family members, thus increasing the likelihood that abuse by the live-in PA would be discovered. In turn, the PA may observe or become aware of abuse by a family member and be of assistance to Maria. Her high degree of dependency and impaired physical defenses increase her vulnerability to abuse. However, while her verbal communication is severely impaired, she is able to communicate in writing using the computer. I do not mean to underestimate Maria's vulnerability. However, it is important to recognize the strengths present for Maria—strengths that are absent in Gabriel's situation.

FINAL THOUGHTS

It should be pretty clear that most vulnerability has little to do with individual impairment. It is true that impairment can affect individuals' abilities to protect and defend themselves. Difficulties with communication can make it harder to report abuse. Certain impairments do make it difficult for people to notice subtle signs that their safety is at risk. However, vulnerability has a whole lot more to do with the people, situations, and environments that you and other people with disabilities encounter. It is the environmental factors emphasized in the Social Model of Disability—attitudes, policies, and practices—that play the most significant role in the vulnerability to violence and abuse. When you use the Social Model of Disability to combat violence and abuse of people with disabilities you will focus less on fixing the individual and more on fixing the environment.

RESOURCES

Web Sites

ADA Home Page, <http://www.ada.gov>

American Association of People with Disabilities, <http://www.aapd-dc.org>

Disability Is Natural, <http://www.disabilityisnatural.com>

Disability Statistics: Online Resource for Disability Statistics, Cornell University, <http://www.ilr.cornell.edu/edi/DisabilityStatistics>

U.S. Census Bureau, Disability Data, <http://www.census.gov>

Suggested Readings

- Rehabilitation and Research Training Center on Disability Demographics and Statistics. (2006). *2006 Disability Status Report United States*, <http://www.DisabilityStatistics.org>
- Snow, K. (2008). *A Few Words About People First Language*, <http://www.disabilityisnatural.com/>
- U.S. Department of Justice. (2002, May). *Americans with Disabilities Act Questions and Answers*, <http://www.ada.gov>
- U.S. Department of Justice. (2005, September). *A Guide to Disability Rights Laws*, September 2005, <http://www.ada.gov>

Power and Control Wheels

The National Center on Domestic and Sexual Violence has links to a variety of power and control wheels; http://www.ncdsv.org/publications_wheel.html

- Abuse in Later Life Wheel
- Advocacy Empowerment Wheel
- Deaf Power and Control Wheel
- Equality Wheel for People with Disabilities
- Immigrant Power and Control Wheel
- Lesbian/Gay Power and Control Wheel

3

Recognizing and Responding to Violence and Abuse

Woman is charged in disabled husband's death

written by Heather Ratcliffe,

St. Louis Post-Dispatch, St. Louis, Missouri, June 21, 2006, p. B10

In this newspaper story it was reported that a St. Louis County woman was accused of recklessly causing her husband's death by failing to feed him or get him proper health care. Police said he was very thin and lying dead in dirty conditions when officers arrived at his home to assist on a call for an ambulance. The victim, who had a diagnosis of multiple sclerosis and had been bedridden for many years, was thought to have died that day. Driver's license records listed the man's height at 5 feet 9 inches and his weight as 220 pounds. He weighed 70 pounds when he died. The St. Louis County medical examiner's office determined the cause of death was a sepsis (blood) infection made worse by his lack of food.

The man in the story did not die from problems due to multiple sclerosis. Rather he died in his own home as a result of neglect at the hands of his care provider—his wife. Police and paramedics arriving at the home likely observed many signs of neglect leading to the criminal charge of recklessly causing death. This story is one where the neglect is quite obvious; however, cases of neglect are not always so obvious.

As you think about the problem of violence and abuse,



Ask Yourself...

Am I more concerned about being abused by someone I know or by a stranger?

Is home the safest place to be?

Would I recognize if I or someone I know was being abused?

What would be signs that I or someone I know was being abused?

OVERVIEW OF THE ISSUE

Everyone is at some risk of becoming a victim of violence and abuse. However, the body of research indicates that people with disabilities are at increased risk compared to people without disabilities (Ammerman & Baladerian, 1993; Brownridge, 2006; Dawkins, 1996; Hassouneh-Phillips & Curry, 2002; Horner-Johnson & Drum, 2006; Martin, Ray, Sotres-Alvarez, Kupper, Moracco, Dickens, et al., 2006; McCabe & Cummins, 1996; Sobsey, 1994; Sullivan & Knutson, 2000; Verdugo, Bermejo, & Fuertes, 1995). Yet many people, including you, may not be aware of this fact. We are beginning to gain a better understanding of who perpetrates the violence and abuse and under what circumstances. Not unlike the general population, people with disabilities are more likely to be abused by someone they know rather than a complete stranger. The most common setting for the abuse is in the home.

While this may be hard to believe, some people are not aware that how they are being treated is abuse. A woman with an intellectual disability said,

From the time I was very young my stepfather abused me. I didn't know what was happening until I became involved in [name of a disability group] and we had some sessions on sex and relationships. By this time I was 16 and he was still abusing me....I kept running away from home; it was the only thing I could do....I should have been told about things earlier, I have rights to know and should have been told. (Cattalani's 1993 study, as cited in Chenowith, 1997, p. 33)

If all you have ever known is hurtful words, threats, physical violence, and other harmful treatment from family members and others, these behaviors may seem normal. In some cases, abuse becomes common behavior. When this happens the behavior is no longer seen as abusive. It is dangerous to assume that everyone understands what physical assault, neglect, sexual assault, financial exploitation, and psychological abuse are.

SIZE OF THE PROBLEM

Research consistently shows that violence and abuse of people with disabilities is a widespread problem. Unfortunately, there are no national data available to better measure the rates of abuse of people with disabilities. The government has two methods for collecting national crime statistics. The U.S. Federal Bureau of Investigation (U.S. FBI) runs the Uniform Crime Report (UCR) Program (U.S. FBI, n.d.b). The FBI is responsible for collecting, analyzing, and publishing crime statistics collected from nearly 17,000 law enforcement agencies from across the United States. Unfortunately, individuals are not asked whether or not they have disabilities when a crime is reported. The UCR is not helpful in determining rates of crimes committed against people with disabilities. One notable exception is in the reporting of **hate crimes**.

In 1994 Congress amended the Hate Crimes Statistics Act (HCSA; PL 103-322A) to require the Federal Bureau of Investigation (FBI) reporting of hate crimes committed against people with disabilities. Hate in and of itself is not a crime. Rather, "a hate crime is a traditional offense like murder, arson, or vandalism with an added element of bias" (U.S. Federal Bureau of Investigation [FBI], n.d.a, para. 2).

The most recent UCR indicated that 1% of all single-bias incidents (motivated by the same bias) and 1% of all multiple-bias incidents (motivated by different biases) were motivated by disability bias (U.S. FBI, 2007). A total of 94 reported hate crimes were committed based on disability bias, with 74 offenses classified as anti-mental disability and 20 offenses classified as anti-physical disability (U.S. FBI, 2007).

The second source of crime data is the National Crime Victimization Survey (NCVS) (U.S. Bureau of Justice Statistics [U.S. BJS], 2007). The NCVS is the primary source of information on criminal victimization in the United States. Data are collected from a nationally representative sample of nearly 77,200 households representing nearly 134,000 people. The survey asks about the frequency and characteristics of crime and about the impact on the victim. Again, people who participate in the survey are not asked whether they have any disabilities. To address the lack of crime victimization data on people with disabilities, Congress passed the Crime Victims with Disabilities Awareness Act (PL 105-301) in 1998. The law requires that the Bureau of Justice Statistics (BJS) ask questions about disability status when conducting the NCVS (Petersilia, Foote, & Crowell, 2001). In response, BJS has added questions to the survey asking people who have been victimized by crime whether they have any disabilities. BJS expects to issue its first reports on crimes against people with disabilities in early 2009 (M. Rand, personal communication, August 13, 2008).

The size of the problem is not a total mystery. There have been many smaller studies since the 1990s that as a group tell a very compelling story. Some of the research is older and most is based on small samples of people. In the following pages, a few of these studies are discussed to highlight the problem. It is important to be careful about applying the findings to all people with disabilities. The studies do not represent a full review of all the research in this area, but will give you some sense of the scope of the problem.

Abuse of People with Disabilities

Some research looks at abuse of people with an array of disabilities (not just one particular type like physical disability or intellectual disability) and with both men and women included in the studies.

- Sobsey and Doe (1991) reviewed 162 reports of sexual assault involving people with disabilities. Results showed that 79.6% were sexually assaulted more than once, with the largest group (49.6%) reporting sexual assault on many (10 or more) occasions. Offenders were predominately male (90.8%). The researchers concluded that the abuse was severe, frequent, and chronic, often resulting in significant harm to the victim, and rarely reported to the police.
- Oktay and Tompkins (2004) surveyed 84 adults with disabilities who received personal assistance with activities of daily living. Personal assistance was provided by family members, informal care providers and agency care providers. Forty percent of the survey participants had only one care provider, 50% had two care providers, and 10% had three or more care providers. Results showed that 30% had been abused by their current primary care provider (the person

who provided the majority of care). In addition, 61% reported abuse by another care provider. Male care providers were more likely to abuse than female care providers. The most common forms of abuse by primary care providers were verbal abuse, physical assault, and financial abuse. The most common forms of abuse by other care providers were verbal abuse, neglect, and theft (a type of financial exploitation).

Abuse of Adults with Intellectual Disabilities

A lot of the research on abuse of people with intellectual disabilities focuses on sexual assault.

- Furey (1994) examined 461 reported cases of sexual assault of adults with intellectual disabilities. Results showed that 37% of the cases were confirmed by the investigating authority. The majority of victims were women (72%). The majority of offenders were men (88%). Most sexual assault (77%) occurred in the victim's home, whether that was an institutional setting or in the community. The majority of victims (92%) knew the offender.
- Furey and Niesen (1994) examined 171 confirmed cases of sexual assault of adults with intellectual disabilities. Researchers found that when the offender was another adult with an intellectual disability, men were at almost as much risk as women. The majority of offenders were men (94%). Most sexual assault (82%) occurred in the victim's home, whether that was an institutional setting or in the community.

A recent comprehensive review of published research between 1995 and 2005 provides important insight into the problem of abuse of people with intellectual disabilities (Horner-Johnson & Drum, 2006). Based on Horner-Johnson and Drum's analysis of many studies, there is evidence to support the belief that abuse is more common among people with intellectual disabilities than people without disabilities. In addition, abuse may be higher for people with intellectual disabilities than for people with other types of disabilities.

Abuse of Women with Disabilities

Many studies have focused on the abuse of women with disabilities. Once again, a few studies were selected to help you understand what this subgroup faces.

- Young, Nosek, Howland, Chanpong, and Rintala (1997) asked 860 women, 439 with physical disabilities and 421 without a disability, if they had ever experienced physical, sexual, or emotional abuse. Sixty-two percent of women with a disability and 62% of women without a disability each reported some type of abuse in their lifetime. Husbands or live-in partners were the most common perpetrators of emotional abuse and physical assault for both groups; male strangers were the most common perpetrators of sexual assault for both groups of women. Women with physical disabilities were more likely to be abused by paid care providers and were more likely to experience abuse for longer periods of time than women without disabilities.

- Milberger et al. (2003) examined the risk factors for abuse of 177 women with physical disabilities. More than half, or 56% of the women, had been abused during their lifetime. Of the women who reported abuse, 89% were abused on multiple occasions and 48% by multiple abusers. The most common abuser was a male partner (80%). In addition, 31% reported abuse by another family member. Only 33% of the women who had been abused sought help for their abuse.
- Hassouneh-Phillips and Curry (2002) conducted a comprehensive review of the literature on abuse of women with disabilities. They concluded that “women with disabilities experience abuse at similar or higher rates than women in the general population” (p. 96). Abuse most often occurred in the homes of victims. Male partners were the most common offenders. However, women with disabilities also experience abuse by family members, friends, paid care providers, transportation employees, and health care workers. Women with disabilities are also subject to disability-specific abuse, such as damage or removal of assistive devices.
- Brownridge (2006) used a representative sample of 7,027 women living in a marital or common-law union to examine the risk for partner violence. Researchers found that the women with disabilities had a 40% greater odds of domestic violence in the preceding 5 years than the women without disabilities. The women with disabilities were more likely to have been subjected to severe violence.
- Martin et al. (2006) used a representative sample of 5,326 women to find out if disability status was associated with their risk of being assaulted during the past year. Twenty-six percent of their sample reported having a disability. Researchers found that women with and without disabilities were equally likely to have experienced physical assault. However, the women with disabilities were 4 times more likely to have experienced sexual assault.

Abuse of Men with Disabilities

Little research has been conducted looking at abuse of men with disabilities. One study found that men with intellectual disabilities were as likely to experience sexual assault as women with intellectual disabilities (Brown, Stein, & Turk, 1995). Another study found that men with intellectual disabilities were particularly vulnerable to peer-on-peer sexual assault in institutional settings (Furey & Niesen, 1994). In a recent study focusing solely on men with disabilities, the men reported experiencing all types of abuse: physical assault, emotional abuse, financial exploitation, sexual assault, and neglect (Saxton et al., 2006). One of the most significant findings of the Saxton study was that disclosure of abuse was very difficult for men with disabilities, with the “male ethic” of “not squealing or complaining” commonly reported (p. 9). Clearly, much more research needs to be done on violence toward and abuse of men with disabilities.

Final Thoughts About the Size of the Problem

The research shows that violence and abuse is a serious problem for people with disabilities. The data, though limited, suggest that people with disabilities are more likely to be abused than people without disabilities. There will be a much clearer

picture of the rates of abuse once we have National Crime Victimization Survey data on crimes against people with disabilities.

OFFENDERS

Most violent crime victims are victimized by someone they know (Catalano, 2004), whether they have a disability or not. The most common perpetrators of disability abuse are people known to the victims, particularly spouses, partners, family members, and paid care providers (Abramson, 2005; Carlson, 1998; Hassouneh-Phillips & Curry, 2002; Milberger et al., 2003; Oktay & Tompkins, 2004; Powers et al., 2002; Young et al., 1997). Unlike people without disabilities, people with disabilities have the added vulnerability to abuse by paid care providers and others connected to them because of their disability. People with intellectual disabilities are also at risk of peer-on-peer abuse, often in institutional and other group care settings (Brown & Turk, 1994; Crossmaker, 1991; Furey & Niesen, 1994; McCarthy & Thompson, 1996). Offenders are far more likely to be men than women.

SETTINGS

The most likely location for abuse to occur is where people with disabilities live (Brown & Turk, 1994; Furey, 1994; Milberger et al., 2003; Hassouneh-Phillips & Curry, 2002; Powers et al., 2002; Saxton et al., 2001). Exposés raised awareness of the widespread abuses in institutional settings. Geraldo Rivera's exposé *Willowbrook: The Last Disgrace* (Primo & Berman, 1972) and Blatt and Kaplan's 1974 photographic essay *Christmas in Purgatory* depicted the horrors of life in institutions. Opponents of institutions believe that the dehumanizing environment of residential settings housing lots of people provide the power imbalances, space, and circumstances for all kinds of abuses to occur (Cambridge, 1999; Crossmaker, 1991). It is not only a matter of the size of the residence. The degree to which people with disabilities are isolated and have few opportunities to mix with other people outside their own home contributes to the vulnerability (Cambridge, 1999; McCarthy & Thompson, 1996). Abuse also takes place in health care, rehabilitation, educational, vocational, and other settings where people receive services (Gilson, Cramer, & DePoy, 2001a; Sobsey, 1994).

CONTINUUM FROM SUBTLE TO OBVIOUS

Abuse takes many forms. Some of the abuse is quite **subtle** (Calcraft, 2007; Calderbank, 2000; MacFarlane, 1994; Saxton et al., 2001). In other words, the behavior is difficult to see or identify as abuse (see Table 3.1).



Ask Yourself...

*Have I ever experienced **subtle abuse**?*

Have I ever been treated in a way that I thought might be abuse but I questioned my own judgment?

Have I ever been told that how I or someone I know was treated was not abuse even though I thought it was?

Table 3.1. Examples of subtle abuse of people with disabilities

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Ignoring a person when they ask for help
Making a person beg for help
Providing help in a way that makes the person feel like a burden or feel guilty
Intentionally making a person wait for help
Refusing to recharge the battery of a person's wheelchair
Providing physical care in a way that is unnecessarily rough or careless
Refusing to provide help until the person agrees to lend money
Purposely unplugging or turning off adaptive equipment

If you answered *yes* to the questions asked then maybe the way you or someone you know was treated was subtle abuse. Read about a woman with a physical disability who faced subtle abuse:

If they're [personal assistants are] feeling angry for some reason...at you or whatever, they might set you down in your chair a little harder than normal. Or... position you in a little rougher way. And you sit there, thinking, "Now, did he mean to do that?" It's really hard to distinguish. It makes you question yourself a lot. (Saxton et al., 2001, p. 404)

This story is one of many examples of how subtle abuse can leave victims wondering if they really were abused or if what they experienced was intentional or accidental.

One man with a disability described how subtle neglect becomes accepted behavior: "It's neglect, passive aggressive behaviors, control, not listening, deliberately not following directions....You may not be aware of it. And if you've lived with it for years and years, it may go right over your head" (Saxton et al., 2006, p. 7).

Other forms of abuse are quite obvious—the behavior is easy to see and recognize as abuse. **Obvious abuse** includes physical acts such as hitting, kicking, shoving, and burning, forced sexual contact, and threats of physical harm or forced sexual contact. Even though the abuse is obvious, it is still possible that in some situations a **culture of abuse** can exist and the behaviors may not be seen as abusive or be challenged.

Abuse may occur on a **continuum from subtle to obvious** (Fitzsimons-Cova, Drum, Keys, Wonderlich, & Horner-Johnson, 2000). Offenders may begin by engaging in subtle forms of abuse. Little by little, and sometimes not so gradually, the abusive behavior becomes obvious and very harmful (see Figure 3.1). One study of women with physical disabilities found that the progression from subtle to obvious abuse did not apply (Copel, 2006). For most of the women in the study the abuse by their spouses/partners began after they became disabled. The women steadily experienced severe and multiple forms of abuse until they were able to end the relationships.

TYPES AND INDICATORS OF ABUSE

There are five main types of abuse: **physical assault, neglect, financial exploitation, sexual assault, and psychological abuse**. In this book, I will use general definitions for each type. They are not the definitions that are used in the criminal

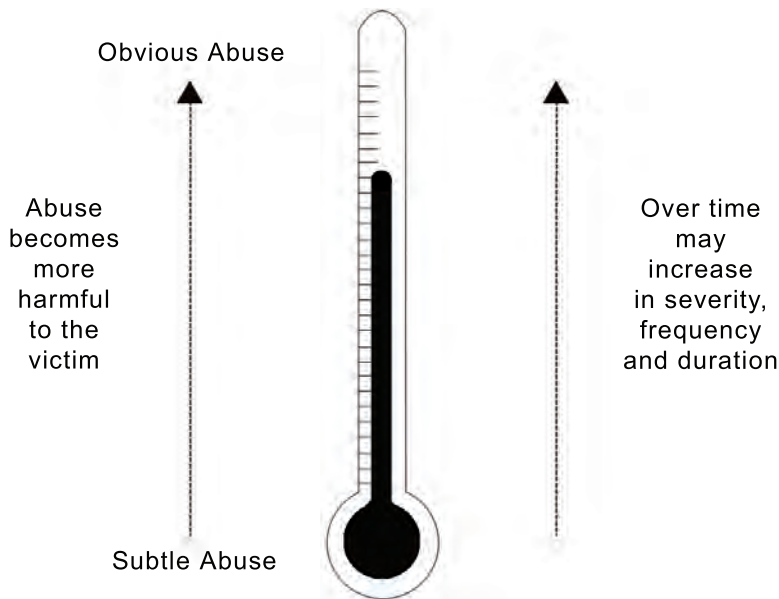


Figure 3.1. Abuse varies in intensity and can escalate along a continuum from subtle to obvious abuse. (From Fitzsimons-Cova, N., Drum, C., Keys, C., Wonderlich, M., & Horner-Johnson, W. [2000]. *Taking charge: Responding to abuse, neglect, and financial exploitation*. Chicago: Institute on Disability and Human Development, Department of Disability and Human Development, University of Illinois at Chicago. Adapted with permission.)

justice system or the vulnerable adult advocacy and protective system in your state or community. As you read about the forms of abuse, keep in mind that for some people abuse is the original cause of disability. For other people with disabilities the abuse causes increased impairment.

The **indicators** or warning signs of abuse are clues that something is happening in the life of the person that should be looked into. Some indicators are obvious signs of abuse. Other indicators are subtle, requiring careful observation. In some situations abuse may not be occurring at all. It is important to think about the person and any health or behavioral issues they have. Some people may get injured more easily due to health reasons or aging. For example, some medications and some health conditions like hemophilia (when blood clots slowly) can cause easy bruising. Some people may engage in self-injurious behaviors that cause injuries that look like abuse. Even if you discover that a person has a health or behavioral issue that might be the cause of the injury, it is still important to investigate to rule out abuse as the cause. It is important to put aside any biases that you might have that care providers would not abuse a person with a disability that they support.

Physical Assault

Abuse at group home alleged; A former worker is accused of beating a disabled resident in South Florida
written by Brian Haas, Orlando Sentinel, Orlando, Florida, December 15, 2006, p. B7

Table 3.2. Indicators of physical assault

Old and new bruises
Bilateral bruises on upper arms
Clustered bruises on trunk (i.e., chest, stomach, back)
Imprint injuries (e.g., marks shaped like fingers, thumbs, hands, belts, sticks, rulers)
Bite marks
Bleeding
Marks left by a gag or some form of restraint
Broken bones, sprains, fractures, dislocations
Punctures, cuts, welts
Eye injuries (e.g., black eye, detached retina)
Missing teeth
Internal injuries
Burns (especially inflicted by cigarettes, matches, ropes, irons)
Spotty balding from pulling hair
Unexplained scars or significant scarring
Untreated injuries

Sources: Baladerian (1997), Baladerian (1998), Cook and Kinstad (1999), Sobsey (1994).

In this newspaper story it was reported that a care provider at a residence for people with intellectual disabilities got mad because a man that he was supposed to be caring for misbehaved. The offender responded by punching and kicking the man and then dragged the man into his room by his hair and started breaking his possessions. The offender grabbed a DVD player and beat the man with it. The offender then physically assaulted the man with a bowling pin.

This story is almost too horrible to believe. Yet it is true. The man with an intellectual disability was a victim of a serious physical assault by someone who was supposed to be providing care.

Physical assault (sometimes called physical abuse) includes physical acts that are not accidental that cause pain, injury, or other physical suffering or harm. Physical assault includes hitting, shoving, slapping, kicking, pinching, burning, and physical restraint. Take a look at the indicators of physical assault (see Table 3.2). The indicators listed are not unique to people with disabilities. The problem for people with disabilities is that the indicators may not be recognized as abuse, even when the signs of physical assault seem pretty clear. Failure to recognize physical assault is particularly problematic for people who have impaired communication or cognitive abilities. The abuser may claim that the person with a disability caused their own injury through self-abuse or self-injurious behavior. The abuser may claim that the injury was an accident. The abuser may make up a story about how the injury occurred.

Physical assault may be occurring when

- The explanation for how the injury occurred does not make sense
- The explanation for how the injury occurred is not supported by medical findings
- Medical care is delayed or not obtained at all by a care provider

- The person is described by others as accident prone
- The injury is blamed on self-abuse and the person has no history of self-abuse
- The injury is blamed on self-abuse and the injury does not match the person's typical pattern or type of self-abuse
- There are multiple injuries at various stages of healing
- There are injuries on the body in places where it is unlikely for injuries to occur—for example, bruising on the back, stomach, or inner thigh

Restraint and seclusion, while not only done to people with disabilities, are serious forms of physical assault perpetrated against people with disabilities. The U.S. Office of Inspector General (OIG) refers to **restraint** as “methods of restricting a person’s freedom of movement” (U.S. Department of Health and Human Services [U.S. DHHS], 2000, p. 4). There are three types of restraint: **chemical restraint**, **physical restraint**, and **mechanical restraint**. **Seclusion** is “involuntarily confining a person alone in a room from which the person is physically prevented from leaving” (U.S. DHHS, 2000, p. 4). According to the OIG, the use of restraint and seclusion may be appropriate in some situations, such as in emergency situations when less restrictive interventions have failed to ensure the safety of the person with disabilities and others. The use of restraint and seclusion is inappropriate and abusive when it is used on a regular basis or as a “means of coercion, discipline, convenience, or retaliation by staff” (U.S. DHHS, 2000, p. 5) or other care providers. Restraint and seclusion should only be used under rare circumstances. The harmful consequences of frequent and inappropriate use of restraint and seclusion include “physical and psychological harm, loss of dignity, violations of civil rights, and even death” (Sundram, 2005a, p. 6-17).

Neglect

Refer back to the newspaper story, *Woman Is Charged in Disabled Husband’s Death*, at the beginning of the chapter.



Ask Yourself...

Was the man’s death caused by a failure to provide care (intentional neglect)?

Was the man’s death caused by care that was provided poorly (unintentional neglect)?

Did the man’s wife lack the knowledge, skills, and resources to properly care for her husband?

Neglect is much more complicated than it may first appear. In the case of the man in the newspaper story, since his wife was charged with recklessly causing death it is likely that the authorities determined that the neglect was intentional—his wife purposely failed to provide care.

Neglect is the failure to fulfill one’s responsibility to help; provide reasonable care; fulfill basic physical, medical, and emotional needs; or protect another person. Neglect results in harm or a risk of harm. Neglect can be intentional or unintentional, which can be the result of lack of training or an overworked care

provider (BITS Fraud Reduction Steering Committee, 2005). Neglect can be a failure to provide care or a poor quality of care (Oktay & Tompkins, 2004). Similar to physical assault, neglect is often difficult to hide. You can detect neglect by

- Talking with a person about the care they receive
- Observing the entire home and the conditions that the person with a disability lives in
- Observing the physical appearance of the person with a disability and other people living in the home
- Observing the treatment provided by family and other care providers

In some situations you may discover that the neglect is pervasive, meaning everyone living in the home lives in a neglectful environment or neglectful physical state.

Neglect can be divided into two broad types: 1) neglect of the person with a disability and his or her environment and 2) lack of services and supports. Review the indicators of neglect in Table 3.3. The more that people with disabilities depend on others, the greater their risk for neglect. One man with a disability described his experience with unintentional neglect or poor quality of care: “An attendant dropped me because he really wasn’t paying attention, and I broke my leg in the

Table 3.3. Indicators of neglect

Neglect of the person and environment
Malnutrition (e.g., underfeeding, poor quality of food)
Dehydration (lack of fluids)
A smell of urine or feces on the person
Poor grooming (e.g., overgrown fingernails and toenails; uncut, matted, or unclean hair; unshaven facial hair; body crevices caked with dirt)
Poor skin condition or skin breakdown (e.g., rash, bedsores, open wounds)
Infestations (e.g., fleas, lice, roaches, rodents)
Clutter, filth, or bad smell in the home
Improper sleeping, cooking, or bathing accommodations
Home in need of repair to maintain health and safety (e.g., broken windows, exposed wiring, leaky roof)
A lack of heat, plumbing (including running water), electricity, refrigeration, ventilation, or light
Too many animals or animals lacking care and resulting in a health hazard
Lack of services and supports
Special dietary (food) needs not met
Failure to provide medication as prescribed
Medical, dental, nursing, physical therapy, or other therapeutic care not provided
Adaptive aids are not available or properly cared for (e.g., eyeglasses, hearing aids, communication devices, wheelchairs)
Lack of proper supervision
Improper use of restraint
A person unable to care for self is left unattended for a long period of time
Inappropriate care providers are used (e.g., too young, impaired by substance abuse)
Withholding of care or delaying care
A lack of regular and timely help with daily living needs
Refusing to provide care in the way preferred by the person with a disability

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Sources: Baladerian (1997), Baladerian (1998), Cramer et al. (2003), Cook and Kinstad (1999), Gilson et al. (2001a), Sobsey (1994).

fall. Whether or not it's considered abuse, it's harmful....a lack of focus or attention can result in severe physical damage" (Saxton et al., 2006, p. 6).

Many of the indicators of neglect focus on physical care. Neglect can also include failing to support the social and emotional needs of people with disabilities. This type of neglect is unique to people with disabilities. One woman with a disability described the harmful impact of social and emotional neglect as follows:

Many people with physical disabilities or emotional and mental disabilities have been kept just as isolated and just as much away from communications and connections as people who are deaf or hard of hearing, and that's...[because] their caregivers or their significant others or [other] people in their lives are controlling and don't provide for connection. (Gilson et al., 2001a, p. 230)

As you have learned, neglect is a very serious and complex problem for people with disabilities. You read about one extreme example of intentional neglect that resulted in a man's death. It is the most severe examples of neglect that make the newspaper headlines. However, it is equally important to be aware of the less harmful or nonlethal forms of neglect. Poor quality of care due to lack of resources, awareness, or skills and social and emotional isolation are perhaps the most common forms of neglect experienced by people with disabilities and are the easiest to resolve.

Financial Exploitation

Jose's Story

Jose is legally blind and is physically disabled as the result of stroke. He lives in an assisted living facility. Jose's son Ramone was given power of attorney when he moved into the facility. Jose had assets and income of about \$100,000 dollars. Over a year and a half Ramone paid the assisted living facility expenses of about \$45,000 dollars with Jose's money but usually made payments late. Ramone stole and spent about \$25,000 dollars before Jose noticed the missing funds. Once the theft was discovered, Jose withdrew Ramone's power of attorney and gave it to his niece, Karina. Karina discovered that Jose was \$6,000 dollars behind on his assisted living account. Karina encouraged Jose to report Ramone's handling of his finances to the police. Ramone was charged and convicted of financial exploitation of a vulnerable adult.

Jose's story of financial exploitation is one of thousands that occur each year to people with disabilities. A 2001 study conducted by the National Association of Adult Protective Service Administrators (NAAPSA) reported 38,015 documented reports of financial exploitation of the elderly and vulnerable adults (BITS Fraud Reduction Steering Committee, 2005). It is believed that only 1 in 14 cases get reported, meaning that the number of yearly cases of financial exploitation could be as high as 850,000.

Financial exploitation (sometimes called financial abuse) is the improper or illegal use of another person's money, property, and other assets (material goods)

without informed consent or when consent is obtained by bullying or fraud. Financial exploitation can be grouped into two broad types (BITS Fraud Reduction Steering Committee, 2005):

- Theft of income, which is the most common form of financial abuse
- Theft of assets, which is “more extensive and typically involves abuse associated with power of attorney, real estate transactions, identity theft, or tax manipulation” (p. 53)

Financial exploitation not only affects people who have lots of money, property, or other assets. People with disabilities who have very little money and assets can be victims of financial exploitation. For example, people with disabilities who receive government cash benefits, such as Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI), may be financially exploited by family members and other care providers (see Table 3.4).

One form of financial exploitation unique to people with disabilities who rely on care providers, especially paid care providers, is extortion—meaning care providers “demanded or requested money, items, or favors in exchange for continuing their duties” (Oktay & Tompkins, 2004, p. 183). Rather than outright stealing, care providers may ask for money or so-called loans that never get paid back, or they may ask to borrow vehicles. The following statements call attention to the lose–lose circumstances for people with disabilities.

One person with a disability explained that he loaned his PA money “because I need her to help me.” Another said “because I would have had no care if I didn’t.” One person agreed to supplement the personal assistant’s pay after the agency cut wages “because I was afraid she would leave.” (Oktay & Tompkins, 2004, p. 183)

As you can see, the situation is either “lose your care provider” or “lose your money.” Some people end up believing that their only real option is to put up with financial exploitation.

Table 3.4. Indicators of financial exploitation

Withholding money
Taking money without consent or by means of threat
Illogical explanations about how money is managed
Lack of legal records about who is responsible for managing the person’s money and assets
Lack of documentation about how money is spent or assets are invested
Unexplained disappearance of money or valuable possessions
Sudden changes or unusual activity in bank account or banking practices
Basic needs not being met when money appears adequate (e.g., clothing, shelter, food, medication)
Lack of money early in the month when disability or other types of government benefits are paid
Payment to a care provider is too much or too often
Person has to ask or beg for his or her money
Person is prevented from getting or keeping a job
Person is not permitted to know about or have access to his or her own money or family money

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Sources: Baladerian (1997), Baladerian (1998), BITS (2005), Cook and Kinstad (1999), and Sobsey (1994).

Sexual Assault

Kyle's Story

Kyle has epilepsy as well as a form of cerebral palsy that is severe and affects his entire body. He needs assistance with all daily activities. Kyle's new care provider is a young man named Jeff. Kyle's family found Jeff by placing an advertisement in the local newspaper. During the interview with Jeff, the family asked him many questions about his experience caring for a person with a physical disability. However, they did not ask any questions about criminal behaviors, charges, or convictions or obtain a criminal background check. After a few weeks, the family began to notice changes in Kyle's behavior. Kyle was usually happy and smiled a lot, but this no longer was the case. When Kyle's family questioned him, he communicated that nothing was wrong. Jeff was always around during the questioning. Kyle had weekly sessions with his physical therapist. The physical therapist, like his family, saw changes in Kyle's behavior. Kyle became somewhat resistant and defensive during the therapy. The physical therapist asked Kyle if he was not feeling well or if something was bothering him. Kyle indicated that he was fine. Eventually Kyle's family took him to see his doctor to find out if something was physically wrong with Kyle. The doctor got permission from Kyle and his guardian to do a thorough physical examination. He discovered signs of sexual penetration of Kyle's buttocks. The doctor reported his suspicion of sexual assault to the police. The police and APS investigated. The authorities discovered that Jeff had previously been suspected of sexually assaulting another man with a disability; however, no charges were ever filed. The prosecuting attorney charged Jeff with sexual assault. Jeff was convicted of sexual assault and sentenced to 6 years in prison.

I would like to report that Kyle's experience of sexual assault is an isolated example. You have read about the scope of the problem, so you already know that this is far from the truth. Sexual assault is a problem for both men and women with disabilities—although less is known about sexual assault of men with disabilities.

Sexual assault (sometimes called sexual abuse) is forcing or bullying another person to engage in or observe sexual acts (see Table 3.5):

- **Hands-off behavior** is sexual assault that does not involve the abuser physically touching another person for sexual or other pleasure.
- **Hands-on behavior** is sexual assault that involves the abuser physically touching another person for sexual or other pleasure.
- **Harmful genital practice** is unwanted, intrusive, and/or painful procedures in caring for a person's genitals or rectum (Ramsey-Klawnsnik, 1993; Ramsey-Klawnsnik, 2003).

The third type of sexual assault, harmful genital practice, was first described by Ramsey-Klawnsnik in her work with elder abuse victims. She has also witnessed harmful genital practice of people with severe physical and intellectual

Table 3.5. Examples of hands-off and hands-on sexual assault

Hands-off sexual assault
Exhibitionism (exposing private body parts to others)
Voyeurism (watching others for sexual pleasure)
Forcing a person to view pornographic material
Making demeaning (negative) remarks about a person's body
Calling a person names (e.g., slut, whore)
Berating a person about his or her sexual history
Sexual harassment
Threatening hands-on sexual assault
Hands-on sexual assault
Forcing a person to kiss
Unwanted touching of another person's breasts, genitals, or buttocks
Forced penetration of a person's vagina or rectum with a penis, finger, or any object

Sources: Ramsey-Klawnsnik (1993) and Ramsey-Klawnsnik (2003).

disabilities. At a training attended by the author, Ramsey-Klawnsnik described how care providers engaged in unnecessary and very painful practices of cleaning rectal and genital areas of the body in the name of proper hygiene. Even when confronted by authorities about their abusive behaviors, some care providers continued to insist that the painful cleansing was necessary.

Unlike physical assault and neglect, sexual assault is often hidden and difficult to detect. Take a look at the indicators of sexual assault in Table 3.6. Compared with people without disabilities, sexual assault of people with disabilities is often chronic, repeated, and occurs over a longer period of time. Some victims may test the waters by hinting about the abuse to see how others will react. Hinting, rather than making a direct statement of sexual assault, is called a **coded disclosure** (Ramsey-Klawnsnik, 1993). Men, unlike women who have been sexually assaulted, are less likely to own their experience and talk about the abuse (Brown & Turk, 1994, Saxton et al., 2006).

One of the key signs of sexual assault is behavioral change, meaning that the victim starts to behave in ways that are not typical. For example, individuals that are usually outgoing and friendly suddenly become withdrawn and keep to

Table 3.6. Indicators of sexual assault

A direct or coded disclosure of sexual assault
Torn or missing clothing
Genital or urinary pain, infection, soreness, or scarring
Injury to a person's genitals, rectum, mouth, or breasts (e.g., bleeding, bruising, injury, infection, scarring, redness, pain, irritation), particularly red flags such as human bite marks, rope marks, and burn marks
Signs of forced restraint (e.g., rope marks, finger imprints)
A person who is not known to be sexually active or unable to consent to sexual relations gets a sexually transmitted disease or becomes pregnant
Frequent physical illness with no clear cause (e.g., stomachache, sore throat, vomiting)
Intense fear response to a specific person or to people in general
Nightmares, night terrors, sleep problems
Self-destructive behavior or thoughts of suicide

Sources: Cook & Kinstad, 1999; Mansell & Sobsey, 2001; Sobsey, 1994

themselves. Pay attention to changes in behavior. Remember that people who are afraid to report the abuse or who find verbal communication difficult will find ways to let you know that something is wrong, even if they are not fully aware or intentionally telling you something is wrong.

People with disabilities who need help with personal care like bathing, dressing, and toileting experience some unique vulnerability to sexual assault. One problem is the difficulty in creating and maintaining **personal boundaries** with care providers. You will learn more about personal boundaries in the chapter on preventing violence and abuse. According to Saxton et al. (2001), “the line between appropriate touching as an essential part of the job of a [care provider] and inappropriate touching, which could lead to unwanted or [confusing] sexual contact, [is] not always clear” (p. 401). One woman with a disability talked about her experience with blurred intimate care boundaries: “You have someone doing intimate work for you...so they give you a little massage—is that OK or not OK?...they’re always undressing you. That’s how...things get gray. Things get strange” (Saxton et al., 2001, p. 401).

Another woman with a disability said,

When she got that washcloth between my legs and I need her to really wash it good because I’ve been having yeast infections. How does a woman make sure that when her vulva is being cleaned, it is not being rubbed too much? Or too hard? (Saxton et al., 2001, p. 401)

Obvious sexual assault may occur when people with disabilities are coerced (bullied or threatened) into engaging in unwanted sexual activity by care providers as a trade-off for receiving care. When you or people you support depend on others for personal care, a power imbalance that favors the care provider occurs. Let’s look at this issue for a particularly vulnerable group—people with intellectual disabilities.

Jane Doe’s Story

Jane Doe is a 24-year-old African American woman who has a moderate intellectual disability. She lives at home with her parents. She attended special education classes until the age of 21. Since that time she has worked in a sheltered workshop. One day Jane went with her mother to visit her uncle in the hospital. A security guard (let’s call him Calvin) saw Jane talking to herself and recognized that she had an intellectual disability. Calvin arranged for Jane’s mother to go to the treatment area to see the uncle, leaving Jane unattended in the emergency room. Calvin then started talking with Jane. He asked Jane if she would like something to drink. He asked and got permission from Jane’s mother to get her daughter some orange juice. Calvin told Jane that her mom said it was okay to go with him to get something to drink. He led Jane to the basement of the hospital where he sexually assaulted her. Jane returned to the emergency room. Her mother noticed that she looked untidy and commented on her appearance. Jane refused to tell her mother what happened until they were in the car heading home. Her mother immediately stopped a police officer. They returned to the hospital and confronted the security guard. At first Calvin denied that he sexually assaulted Jane.

Semen was found on the floor and at the site of the assault. Calvin then claimed that the sex was consensual. Calvin pled guilty to the crime of sexual assault of a person with diminished intelligence and was sentenced to 8 years' probation with the first 2 years under house arrest (Burgess, 2005, p. 912).

Before I share my thought about Jane Doe's story,



Ask Yourself...

What are the reasons that Jane Doe was more vulnerable to sexual assault?

Why are people with intellectual disabilities particularly vulnerable to sexual assault?

Calvin the security guard probably thought that Jane would be a very easy victim. In some ways she was. She was easily recognized as having a disability. She was willingly led away to an isolated area. What Calvin did not count on was that Jane would report the assault and that she would be believed by her mother and the police.

As you already know, people with intellectual disabilities are at great risk for sexual assault. Reasons for the increased vulnerability include

- Lack of knowledge about sex and intimate relationships
- Being seen as powerless by abusers
- Being more easily influenced by pressure, threat, or coercion (bullying)
- Limited communication skills
- A desire to be in a romantic relationship even if the relationship is abusive
- Not being believed when reporting abuse (Brown & Turk, 1994; Carlson, 1998; Furey, 1994; Sobsey & Mansell, 1990)

These reasons are not necessarily unique to people with intellectual disabilities. However, they are particularly problematic for people with intellectual disabilities and other people who have impaired thinking (such as people with dementia and severe mental health conditions).

Let's examine the issue of consent as it is applied to people with intellectual disabilities. You may recall that in Jane Doe's story, Calvin, the abuser, tried to claim that the sex was consensual. There is no evidence that the sex was consensual. And even if it was consensual, giving permission or agreeing to have sex is not enough. People must be able to give *informed consent* or must have **competence to consent**. Three elements must be present to establish legal competence to consent:

1. Knowledge of the important aspects of a decision and their risks and attendant benefits
2. Intelligence, reason, or understanding, which shows that the knowledge is comprehended and applied in a manner consistent with a person's values or beliefs

3. Voluntariness, meaning that the person is not subjected to coercion and understands that he or she has a choice and the ability to say *yes* or *no* (Sundram, 2005c, p. 95)

Sexual assault can occur even when people are willing participants if they are not able to give informed consent or are not legally competent to consent. Issues of power and control must be considered. The relationship is sexually abusive when offenders are in positions of authority, making it unlikely that the person could resist even if he or she wanted to (see Table 3.7).

In order to recognize sexual assault of people with intellectual disabilities it is important to pay close attention to verbal and nonverbal signs (Baladerian, 1997; Mansell & Sobsey, 2001). You already know the importance of paying attention to changes in behavior. Read June Doe’s story of sexual assault and pay attention to the verbal and nonverbal signs that June was being sexually assaulted (see Table 3.8).

June Doe’s Story

June is a 37-year-old woman who has a moderate intellectual disability. June has lived in several institutions for people with intellectual disabilities. Her family has always been involved in her life. During one home visit, June made reference to sexual assault while watching her mother make bread. June spontaneously referred to the dough looking like a specific staff member’s buttocks and genitals. Several months later, June said to her sister who was pregnant that she was also going to have a baby. She said that a specific “staff person was her boyfriend, called her his queen bee, cared for her, and brought her ice cream.” June described that her boyfriend would “take off her belt and pull her pants down and push her against the wall.” June reenacted the sexual positions on the floor by lying face down or bending over like a dog. She said “you have to cooperate and be quiet and keep it a secret.” June told her sister that she did not want to go back to the home because “you get babies there” (Burgess, 2005, p. 913).

While June never said she was being sexually assaulted, she was clearly communicating, both verbally and nonverbally, that she was being sexually assaulted

Table 3.7. Determining competence to engage in sexual activity

The following are factors used by the courts in determining competence to consent:
A person’s mental age versus chronological age
Intelligence as measured by an IQ score and level of intellectual disability
Functional abilities (e.g., ability to read, write, hold a job, travel alone, manage money)
Receipt of disability services (e.g., special education, living at a home for people with intellectual disabilities)
Actual knowledge of the sex act and its possible consequences (e.g., sexually transmitted diseases, pregnancy)
An ability to resist coercion by people in positions of authority

Source: Sundram (2005c, p. 9-7).

Table 3.8. Additional indicators of sexual assault of people with intellectual disabilities

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Acting out the abuse
Sexual aggression towards others (e.g., sex talk, grabbing or touching genitals, buttocks, or breasts)
Problematic sexual behaviors (e.g., putting harmful objects into genitals, self-exposure, masturbation causing injury)
Nonsexualized self-abusive behaviors (e.g., head-banging, self-biting, cutting)
Verbal abuse toward others
Running away
Physical aggression toward others
Elective mutism (i.e., refusing to speak)
Nightmares, night terrors
Verbal comments that suggest being threatened or told to keep quiet (e.g., “Don’t tell; I’ll kill you”)
Evidence of an unusually secretive “special” relationship with another person, particularly one involving bribery, trickery, or coercion
Regression to childlike behavior (e.g., urinating or defecating on self)
Loss of independent living skills

Note: These indicators do not apply only to people with intellectual disabilities; rather, they are indicators often seen in people with intellectual disabilities who have been sexually assaulted.
Sources: Baladerian (1997, 1998), Mansell and Sobsey (2001).

by a staff member at the institution. Perhaps you are asking: “What did June’s sister do to protect June?” “How long did the sexual assault go on?” or “What happened to the abuser?” June’s sister and parents did report the abuse to administrators at the institution. The first suspicion of abuse occurred in 1980. The first and all additional reports made to administrators at the institution were ignored. In 1993 officials from the institution finally acknowledged that June had been sexually assaulted by the suspected staff member. The offender confessed to sexually assaulting June and 15 other female residents at the institution (Burgess, 2005). In this day and age one would hope that it would be impossible for sexual assault to go on for an extended period of time, especially when the indicators of sexual assault were so obvious. You will revisit June Doe’s story in the chapters about barriers to preventing abuse.

Psychological Abuse

The final type of abuse is psychological or emotional abuse. This type of abuse is presented last because other forms of abuse (sexual assault, physical assault, financial exploitation, neglect) often occur along with psychological abuse. One woman with a physical disability described the psychological abuse by her husband that escalated into physical and sexual violence:

He used all kinds of nasty, bad language. He said evil things. He was like a rabid animal. When I talked back, he became enraged and beat me usually with his fists, but sometimes with whatever he could get his hands on. He broke a lamp on my back once. He threw things all the time when he was mad. He raped me. (Copel, 2006, p. 120)

Copel (2006) found that the common experience among the women with physical disabilities in her study was that the abusive episodes “began with verbal

abuse, with the words becoming ‘meaner and nastier,’ and [ended] with episodes of violence” (p. 119).

Read Bonnie’s story of psychological abuse. As you read,



Ask Yourself...

What is the connection between psychological abuse and power and control?

What tactics did Bonnie’s husband use to maintain power and control over Bonnie?

Bonnie’s Story

Bonnie is a 50-year-old woman who has a brain injury caused by a car accident when she was 22 years old. Her injury resulted in a physical disability. She uses a wheelchair because she is paralyzed on the left side of her body. Bonnie is assisted in most of her daily activities by a PA, Ann, and by her husband. One evening Bonnie and her husband got into a very heated argument, and Bonnie told her husband she wanted a divorce. Her husband stated that he would kill himself before he ever consented to a divorce. He then removed the battery from Bonnie’s wheelchair and removed the telephones. When Bonnie told her husband that she needed to use her wheelchair to get to the bathroom, he told her he’d take her to the bathroom when he was good and ready. The next day when Ann arrived at Bonnie’s home for work she was unable to get inside. After extensive knocking on the front door and several telephone calls, Ann went around to the back of the house and let herself in the home through the back door. Ann saw that Bonnie was sitting in her wheelchair in soiled clothing and was visibly upset. Bonnie told Ann about the abuse by her husband the night before and shared that he is frequently abusive to her. Bonnie told Ann that she had never told anyone about the abuse because she feared for her life. A loaded shotgun was kept under the bed. Ann helped Bonnie report the abuse to the police and to Adult Protection Services (APS). Bonnie was assisted in getting an **Order for Protection**. Her husband was convicted of felony terrorist threats, felony possession of a short-barreled shotgun, gross misdemeanor obstruction of the legal process, and misdemeanor disorderly conduct.

Psychological or emotional abuse includes acts, physical or verbal, intended to hurt a person’s feelings, harm a person emotionally, or to humiliate, demean, intimidate, produce harm, or threaten harm (see Table 3.9). As you review the forms of psychological abuse you will notice that many of the examples are included in the *Abuse of People with Disabilities Caregiver Power and Control Wheel* (see Figure 2.6). In Bonnie’s situation, her husband was clearly engaging in psychological abuse to maintain power and control over his wife. The power and control exerted by an abuser can make a person unable or unwilling to report the abuse. When Bonnie finally told Ann about the abuse, it was only after Ann asked and after the psychological abuse and other abuse had been going on for a while. Not wanting to report may even occur when the person is asked direct questions by police or others

Table 3.9. Forms of psychological abuse

Calling names, swearing, screaming, making fun of, humiliating, or putting another person down
Criticizing a person's thoughts, feelings, opinions, beliefs, or actions
Forcing a person to perform degrading acts or engage in illegal behaviors
Threatening physical violence
Threatening to take away or get sole custody of children
Destroying personal property
Making a person afraid by using looks, actions, or gestures (e.g., waving a fist in a person's face)
Displaying weapons with the intent to scare
Threatening to leave or commit suicide
Threatening to have a person institutionalized
Threatening to harm pets or children
Threatening to take away adaptive aids

Sources: Baladerian (1998), Cook and Kinstad (1999), Sobsey (1994).

concerned about the victim's welfare. A key sign of psychological abuse is change in a person's demeanor (behavior, appearance) when the offender is around. Watch for changes in demeanor or signs of fear, resentment, or overcompliance. These behaviors may indicate that the person is being abused and may point to the offender(s).

Care- and Disability-Related Abuse

Some abuse against people with disabilities does not easily fit into the traditional categories. According to Hassouneh-Phillips (2005), "care- and disability-related forms of abuse are specific to people with disabilities" (p. 74). You may have experienced some of the abusive treatment listed in Table 3.10. Let's read what several people had to say about care- and disability-related abuse.

An acquaintance of a woman with a disability talked about how the woman's mother tried to control every aspect of her daughter's life:

Her mother was intrusive in every aspect of her life down to the time of day she went to the bathroom, and she made her use a scooter indoors although she could have used

Table 3.10. Examples of care- and disability-related abuse

Overmedicating or withholding medication to obtain compliance
Taking over, damaging, destroying, or taking away assistive devices or threatening to do so
Withholding care, refusing to provide care in the way preferred, taking over care, threatening removal of care
Leaving work early or not coming to work on time but still getting full payment
Depriving or invading a person's privacy
Depriving a person of independence (autonomy)
Establishing unwanted and unnecessary control over a person's life
Gossiping
Blaming a person for his or her disability
Criticizing or becoming angry because a person is not "appropriately" grateful for care
Making negative comments about the disability

Sources: Cramer et al. (2003), Hassouneh-Phillips (2005), Saxton et al. (2006), Saxton et al. (2001).

a wheelchair or walker, and when she ran into the wall, her mother would scold her very terribly and even in front of me.... and I thought if she did that in front of me, what is she doing when I'm not here. (Cramer et al., 2003, p. 192)

One woman with a physical disability shared the problems she has with care providers' invading her privacy and gossiping about her to others:

They started talking [to each other] about HIV, as if it didn't matter if the next person knows. If you come to take care of me, take care of me. If I want to tell [someone] I've got HIV...that's my business, not the attendant's. (Saxton et al., 2001, p. 401)

Finally, a woman with a physical disability talked about how her care provider refused to listen to her and threatened to walk out:

He worked for a couple of hours and then, you know, he would have a 10-minute break. So he didn't want to listen to my rules. He was constantly saying "well hire somebody else, I can leave right now." He'd say, "Keep it up, keep it up, I'll leave," you know, so what do you do when you're stuck in bed and they say, "Oh I can leave right now"? You feel like somebody's holding a gun at you, you've got to shut up. (Hassouneh-Phillips, 2005, p. 75)

Now that you are familiar with the types of care- and disability-related types of abuse,



Ask Yourself...

Have I ever experienced care- or disability-related abuse?

Have I ever unknowingly perpetrated care- or disability-related abuse against people with disabilities whom I support?

You should now have a pretty good understanding of the types and indicators of violence toward and abuse of people with disabilities. Let's apply what you have learned in a learning activity.

LEARNING ACTIVITY

Recognizing Abuse



Read Henry's Story. Think about the possible indicators of abuse.

Henry is a 52-year-old man who is legally blind. He became blind later in his life due to a disease of the eyes. He lives in his own home. Henry recently had hip replacement surgery. After a short stay at a rehabilitation facility, Henry returned home. He has a home health aid/chore worker named Cheryl who visits him four times a week to assist with personal care and housekeeping tasks. One day Cheryl noticed that a spare guest bedroom had been used and that there was barely any food in the refrigerator. When Cheryl was emptying the kitchen wastebasket she found an empty liquor bottle, beer cans, and cigar butts. Cheryl thought this was strange, but didn't say anything to Henry. Later, when Cheryl was helping Henry with his bath she noticed bruises on his upper arms. When Cheryl asked Henry about the bruises, he said, "you know me; I bruise easy." Later in the day, Cheryl

asked Henry if he would like to go grocery shopping. Henry said, “I think I can wait until I get my next disability check in a couple of weeks.” Cheryl asked, “Are you sure? There doesn’t seem to be much food in the house.” Henry then explained that he was a little short of money because his son recently lost his job and needed money. Henry’s son arrived at the home while Cheryl was finishing doing the laundry. He got angry that Cheryl was there. He called Henry a “blind idiot” and yelled at him for letting strangers in the house. Henry appeared frightened and told Cheryl “You’ve done enough for today. Why don’t you go home early?” Henry’s son stormed downstairs, stating he was going to get a beer and watch television. Cheryl asked Henry if everything was all right. Henry assured Cheryl that he was fine and that his son was under a lot of stress. Cheryl told Henry to call her at any time if he needed help. Cheryl reported her concerns to her supervisor at the Home Health Agency. (Adapted from *Vulnerable Adult Law and Practice Case Studies* with permission from the Minnesota Department of Human Services, Adult Protection Services.)



Ask Yourself...

What are the indicators or signs that Henry is possibly being abused by his son?

What types of abuse do you suspect Henry may be experiencing?

Thoughts About Henry’s Story

There is good reason to suspect that Henry is being abused by his son. The indicators of abuse are

- Bilateral bruises on Henry’s upper arms, perhaps caused by being forcefully grabbed by someone
- Unlikely explanation by Henry for how he got the bruises
- Sudden change in the availability of food in the house
- Lack of money by the middle of the month even though he had received a disability check less than 2 weeks prior
- Henry appearing frightened when his son was around
- The son calling his father names and yelling at him, humiliating him in front of the home health worker
- Henry excusing his son’s behavior and attributing it to stress

The types of abuses that I suspect are physical abuse, financial exploitation, and psychological abuse. Based on Henry’s reaction when his son was around and the son’s behavior toward his father, the son is the likely abuser.

Final Thoughts About Types and Indicators of Abuse

It is important to be able to recognize abuse when it is occurring to you or to someone you know. As you now know, there are many forms of subtle abuse that can become common, everyday occurrences. Subtle abuse can also leave people wondering “Was I just abused?” or “Did he mean to do that?” You now know that some

behaviors that may not be harmful to people without disabilities are abusive when perpetrated against people with disabilities. Finally, you are now aware (or more aware) of care- and disability-related abuse and the harmful impact that these forms of abuse have on people with disabilities. Now that you can recognize abuse, let's examine what you should do if you suspect or know someone is being abused.

RESPONDING TO VIOLENCE AND ABUSE



Ask Yourself ...

If I was being abused, what would help me choose to report the abuse?

If I told someone about the abuse, how would I want the person to respond?

Victims of violence and abuse need others to be patient, understanding, non-judgmental, and noncontrolling in order to help them deal with the abuse, regain a feeling of control over their lives, and feel a sense of empowerment. Victims of abuse are under emotional distress; therefore it can be difficult for them to decide who to tell, who to trust, and what to do. You may be the first person that a victim tells about the abuse. How you respond can make all the difference in the world to the person. First and foremost, believe what the person is telling you. Unless you are a police officer or an APS worker, it is not your place to determine the facts of the situation. Immediately call 911 if the person is still in danger. If needed, access emergency medical services.

Remember that some victims may make a coded disclosure—they may indirectly tell you that they were abused. If you suspect that someone is being abused or is hinting about being abused, find out more. Use a nonthreatening approach to decrease the chances that the person will shut down and stop talking to you. Ask questions that will help you learn more about the person's day-to-day life. Ask about people they spend time with, places they go, what makes them happy, and what makes them feel scared, sad, and hurt. Use words that are familiar to the person.

McFarlane et al. (2001) developed a simple four-question instruction called the Abuse Assessment Screen–Disability (AAS-D; see Figure 3.2) to screen for abuse toward women with physical disabilities in a medical clinic setting. The screening tool asks two abuse-related and two disability-related abuse questions. According to McFarlane et al., interview questionnaires are a better way to detect abuse than depending on self-report of abuse. This abuse screening tool is simple and easy to administer. The AAS-D could be adapted to meet the needs of other populations of people with disabilities.

Meeting the Three Major Needs of Victims

According to the Office for Victims of Crime (U.S. OVC, 2001) every victim has three major needs: to feel safe, to express their emotions, and to know what comes next. You can help meet the needs of victims by

- Being patient and allowing the person time to tell his or her story
- Listening without judgment or shock

1. Within the last year, have you been hit, slapped, kicked, pushed, shoved, or otherwise physically hurt by someone?				
			YES	NO
If YES, who? (Circle all that apply)				
Intimate partner	Care provider	Health professional	Family member	Other
Please describe: _____				
2. Within the last year, has anyone forced you to have sexual activities?				
			YES	NO
If YES, who? (Circle all that apply)				
Intimate partner	Care provider	Health professional	Family member	Other
Please describe: _____				
3. Within the last year, has anyone prevented you from using a wheelchair, cane, respirator, or other assistive devices?				
			YES	NO
If YES, who? (Circle all that apply)				
Intimate partner	Care provider	Health professional	Family member	Other
Please describe: _____				
4. Within the last year, has anyone you depend on refused to help you with an important personal need, such as taking your medicine, getting to the bathroom, getting out of bed, bathing, getting dressed, or getting food or drink?				
			YES	NO
If YES, who? (Circle all that apply)				
Intimate partner	Care provider	Health professional	Family member	Other
Please describe: _____				

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Figure 3.2. The Abuse Assessment Screen-Disability (AAS-D) was developed to screen abuse of women with physical disabilities in medical clinic settings. (From McFarlane, J., Hughes, R.B., Nosek, M.A., Groff, J.Y., Swedlend, N., & Mullen, P.D. [2001]. Abuse assessment screen-disability [AAS-D]: Measuring frequency, type and perpetrator of abuse toward women with physical disabilities. *Journal of Women's Health & Gender-Based Medicine*, 10[9], 862. Reprinted with permission.)

- Speaking and behaving in an accepting and nonjudgmental manner
- Conveying **empathy** (see Table 3.11)
- Agreeing that the behavior is abusive
- Supporting the person in how he or she is feeling (Cook & Kinstad, 1999; U.S. OVC, 2001)

There is no typical reaction to being abused. Responses may range from what seems like no emotion to great emotion. Some people may show emotions that

Table 3.11. Examples of empathy statements

I am sorry this is happening to you.

You don't deserve to be abused.

It took a lot of courage for you to tell me.

It's not your fault.

Table 3.12.   Examples of minimizing statements

It wasn't really that bad.
I shouldn't have made him so mad.
She wouldn't ever hurt me. She was just upset.
He only gets this way when he drinks.
I should have known better than to give her my ATM PIN number.

---

do not seem to match the situation, such as smiling or laughing when describing the abuse. Some people may make light of or deny the extent of the abuse (see Table 3.12). Be prepared for any reaction.

Empowering Victims of Abuse

Unless a person is considered a vulnerable adult or has a legal guardian, what happens after the person tells you about the abuse is up to the person with a disability. If there are no laws mandating that a report be made to the proper authorities, then the decision to involve the police is up to the victim. If you are involved as a trusted family member, friend, or professional, you can help the person think through what their next steps might be. You can help the person understand what comes next by talking through the options. Help the person weigh the pros and cons of calling the police, leaving the abuser, seeking victim assistance services, and other options that might apply in his or her situation.

**Special Considerations For People
Who Are Considered Vulnerable Adults**

Sometimes a disclosure of abuse must be reported to APS. If you or an individual whom you support is considered a vulnerable adult in your state, anyone who is a mandated reporter will need to report the abuse. In Chapter 7, Understanding the System, you will learn more about the vulnerable adult advocacy and protection system. If you or an individual that you support has a legal guardian, the guardian will need to be notified. If you are a person with a disability and you are being abused, ask about the law in your state and find out if and why a report must be made. If you support someone who is a vulnerable adult, explain to the person *who* must be notified and *why*. Remember that one of the three needs of victims is to know what comes next.

Having no control over involving the police or APS is a very disempowering feeling. As a person with a disability, you can decrease your own feelings of disempowerment by knowing your rights and insisting that you need to be kept informed of what is happening with your case. You should also be involved and offered choices when there are decisions to be made about your life. If you are supporting a person with a disability who has been abused, engage in practices that keep the person informed and help them feel empowered (see Tip Box 3.1).

Tips for empowering vulnerable adults

- Ask how you can help
- Provide information about their rights
- Keep them in the information loop
- Involve them in making decisions about their life
- Offer options when they have choices to make

TIP BOX 3.1**FINAL THOUGHTS**

One of the parts of the empowerment process is getting the information needed to make a change. It is impossible to prevent violence and abuse if you do not understand the problem. It is impossible to stop abuse if you do not know that how you are being treated is abuse or if you do not know the indicators or warning signs that someone is being abused. Information about recognizing abuse should be made readily available through education and outreach to people with disabilities, care providers, and the broader community. In particular people with disabilities need to know: “How I am being treated is abuse,” “I’m not the only one,” “This could be happening to someone I know right now,” “The way I am being treated is wrong,” and “There are laws to protect me from abuse.” Recognizing the problem is the first step toward taking individual and collective action to combat violence and abuse.

RESOURCES**Web Sites**

Abused Deaf Women’s Advocacy Services, <http://www.adwas.org>
Disability, Abuse and Personal Rights Project, <http://disability-abuse.com>
National Clearinghouse on Abuse in Later Life, <http://www.ncall.us>
National Center on Domestic and Sexual Violence, <http://www.ncdsv.org>
National Center on Victims of Crime, <http://www.ncvc.org>
Office for Victims of Crime, <http://www.ojp.usdoj.gov/ovc>
SafePlace, <http://www.safeplace.org>

Suggested Reading

National Research Council. (2001). *Crime victims with developmental disabilities: Report of a workshop*. Committee on Law and Justice. In J. Petersilia, J. Foote, & N.A. Crowell (Eds.), Commission on Behavioral and Social Sciences and Education. Washington, DC: National Academies Press.

Office for Victims of Crime. (2001, December). *First response to victims of crime: A handbook for law enforcement officers on how to approach and help elderly victims, victims of sexual assault, child victims, victims of domestic violence, victims of alcohol-related driving crashes, survivors of homicide victims*. Retrieved August 13, 2008, from <http://www.ojp.usdoj.gov/ovc/publications/infores/firstrep/2001/welcome.html>

Office for Victims of Crime. (2002, October). *First response to victims of crime who have disabilities: A handbook for law enforcement officers on how to approach and help crime victims who have Alzheimer's disease, mental illness, mental retardation, or who are blind or visually impaired, deaf or hard of hearing*. Retrieved August 13, 2008, from <http://www.ojp.usdoj.gov/ovc/publications/infores/firstrep/2002/welcome.html>

Curricula and Videos

- Fitzsimons, N.M., & Wilkins, T.L. (2005). *Shadow victims: Crimes against people with disabilities* [Online curriculum]. Minneapolis, MN: Law Enforcement Resource Center, http://www.lerc.com/Products/product_multi.html, 1-800-279-9884.
- Fitzsimons, N.M. (2005). *Shadow victims: Crimes against people with disabilities* [Workbook]. Minneapolis, MN: Law Enforcement Resource Center, http://www.lerc.com/Products/product_multi.html, 1-800-279-9884.
- Hingsburger, D., & Diverse City Press. (n.d.). *NO! How!!!* [video]. Blue Tower Training, <http://bluetowertraining.com> or 1-866-258-8266.
- Hughes, C.M., & Abramson, W.H. (2000). *Stop the violence, break the silence: A training guide*. Austin, TX: SafePlace Institute. <http://www.safeplace.org>, 512-385-5181 or 512-482-0691 (TTY).
- Justice Institute of British Columbia. (n.d.). *Charting new waters: Responding to violence against women with disabilities. Video and facilitators' guide*. British Columbia, Canada: Author. 604-525-5422
- Mercurio, R.G. (2000). *Meet us where we are* [Video]. Boston: Fanlight Productions. <http://www.fanlight.com>, 1-800-937-4113.
- SafePlace Institute. (n.d.) *Responding to violent crimes against persons with disabilities: A manual for law enforcement, prosecutors and court personnel*. Austin, TX: SafePlace Institute, <http://www.safeplace.org>, 512-385-5181 or 512-482-0691 (TTY).
- SafePlace Institute. (2002). *Disability, violence and survival* [DVD/VHS]. Austin, TX: SafePlace Institute. <http://www.safeplace.org>, 512-385-5181 or 512-482-0691 (TTY).
- Video Action Fund. (2000). *Serving crime victims with disabilities*. Boston: Fanlight Productions, <http://www.fanlight.com>, 1-800-937-4113.
- Wisconsin Coalition Against Sexual Assault. (1998). *Widening the circle: Sexual assault/abuse and people with disabilities and the elderly (Manual and Video)*. www.wcasa.org, 608-257-1516 (voice/TTY).
- Young Adult Institute: National Institute for People with Disabilities Network. (n.d.) *Is this abuse?: An essential training program for all direct care staff working in the field of developmental disabilities* [DVD]. New York: Young Adult Institute (YAI), <http://www.yai.org>, 1-212-273-6517.

4

Systemic Barriers to Preventing Violence and Abuse

Many violence shelters lack access for disabled

written by George Watson,

Chicago Tribune, Chicago, Illinois, February 28, 2001, p. 7

In this newspaper story it was reported that few domestic violence shelters can accommodate women with disabilities. The story highlights the experience of two sisters with physical and developmental disabilities who were physically assaulted and psychologically tormented by their mother and sexually assaulted by their father. The women reported that it took years to find a shelter. Their experience is not unique. Of the over 2,000 shelters in the United States, the majority of them were inaccessible to people with disabilities. A coordinator for Vermont's Shelters acknowledged the problem and stated, "It's a huge challenge" (p. 7). The coordinator went on to say, "Part of the problem has been that the shelters that have been developed were planned by women who don't have disabilities" (p. 7). The President of Barrier Free Living, an independent living center, reported that of the 1,300 shelter beds in New York City, only two could accommodate a woman using a wheelchair.

In a more recent newspaper story published in the Los Angeles Times, two women with disabilities shared the difficulty they had trying to access shelter services and getting help from service providers who actually understood their disabilities (Daniels, 2004). The problems identified in the newspaper stories are not unique to domestic violence shelters. The systemic barriers—organizational and societal—for people with disabilities who are abused are widespread. This story was selected to help you to begin to think about your experiences and understanding of systemic barriers.



Ask Yourself...

Can I relate to the experiences of the women in the newspaper story?

Have I been denied access to services or received second-rate services because I have a disability?

Have people that I support been denied access to services because they have a disability or received second-rate services because they have a disability?

OVERVIEW OF THE ISSUE

All of the information that you have read so far is very important to help you prevent and stop violence and abuse. Knowing the environments and situations where abuse is more likely to occur will help you in your efforts to prevent abuse from happening. In order to stop unwanted behavior early, it is important to pay attention to those gray areas where it is not quite clear if the behavior of others is abuse. Recognizing abuse when it occurs to you or someone with disabilities whom you support is the first step in preventing future abuse. It is equally important to understand the barriers that people with disabilities experience on a daily basis, especially those barriers that make it difficult for people with disabilities to prevent violence and abuse.

Systemic barriers are organizational and societal obstacles that perpetuate violence to and abuse of people with disabilities and make it difficult to end abusive relationships and situations (Barile, 2002; Fitzsimons-Cova et al., 2000). Systemic barriers exist in the environments in which people with disabilities live, work, learn, and play. The systemic barriers add to the increased vulnerability to violence and abuse experienced by people with disabilities. You will recall that the Social Model of Disability helps us understand that it is social and environmental barriers that create the most problems for people with disabilities. It is very important to be aware of the systemic barriers in order to avoid blaming victims who stay in abusive situations or to avoid suggesting easy solutions to a complex problem. If you are a person with a disability, hopefully you find it helpful knowing that your experiences are not unique and that you are not the source of the problem.

The systemic barriers are grouped into five categories:

- Physical barriers
- Economic barriers
- Communication barriers
- Service system barriers
- Attitudinal barriers

As you read about the systemic barriers, you or someone you support may have encountered a barrier that is not mentioned. Not every possible type of systemic barrier is being discussed. You may also notice that there is some overlap between the different categories of barriers. It is not possible to create totally separate categories. The different types of barriers are really interconnected—they are all related to one another. Let's start with looking at physical barriers.

PHYSICAL BARRIERS

Texas courts ignore disabled-access laws

*written by James C. Harrington,
San Antonio Express-News, San Antonio, Texas, December 6, 1996, p. 9B*

This newspaper story is about the accessibility of court buildings and courtrooms in Texas. In order to determine how accessible the Texas courts were, the Texas Civil Rights Project conducted a random survey of 111 courthouses in 74 counties in Texas and sent a written survey to all 2,555 state judges. According to Harrington, legal director of the Texas Civil Rights Project, “virtually no court building or courtroom is completely accessible to individuals with disabilities” (p. 9B). The problems inside the courtrooms included inaccessible jury boxes, counsel tables, and witness stands; lack of appropriate public seating for people with disabilities; and no accommodations for people who are blind or deaf. Harrington equated the lack of accessibility to a failure of the courts “to practice the democratic ideal of equal access to justice” (p. 9B).

This newspaper story was written 6 years after the Americans with Disabilities Act (ADA; PL 101-336) required that people with disabilities have equal access to all government services, including federal and state courthouses. Essentially, the ADA requires that all physical barriers to access be removed. Equal access to the court system is important for people with disabilities who have been crime victims. Perhaps you are thinking that this story represents how things were in the past or only in one particular state.



Ask Yourself...

Have physical barriers ever stopped me or someone I support from entering a public building or fully participating in the community?

Physical barriers are architectural and structural barriers that physically prevent people from taking part in all aspects of community life. Institutionalization and segregation are the most extreme forms of physical barriers. In the United States, the ADA was passed in 1990 (PL 101-336) to provide equal opportunity for people with disabilities in accessing government services, public accommodations, private businesses, and transportation (U.S. Department of Justice [DOJ], 2005). The ADA is one of many federal laws protecting the rights of people with disabilities (see Table 4.1).

Although major efforts have been made to get rid of architectural and structural barriers, these barriers still exist and can prevent people with disabilities from accessing community-based supports and services. Lack of accessible domestic violence shelters and other victim services is a barrier for people with disabilities (although the literature seems to only refer to women with disabilities) (Baladerian, 2005; Cramer et al., 2003; Milberger et al., 2003; Nosek, Howland, & Young, 1997; Saxton et al., 2001). The lack of affordable and accessible housing, including transition housing, is another problem for people with disabilities trying to leave abusive situations (Gilson et al., 2001a). Problems with the access to the courts remains a

Table 4.1. Federal laws protecting the rights of people with disabilities

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Americans with Disabilities Act (ADA) of 1990 (PL 101-336): Prohibits discrimination based on disability in employment, state and local government, public accommodation, commercial facilities, transportation, and telecommunications.
Telecommunications Act of 1996 (PL 104-104): Requires manufacturers of telecommunications equipment and telecommunication service providers to ensure that equipment and services are accessible to people with disabilities.
Fair Housing Amendments Act of 1988 (PL 100-403): Amended the law to include people with disabilities as a protected class under the Fair Housing Act. Prohibits housing discrimination on the basis of disability, race, color, religion, familial status, and national origin.
Air Carrier Access Act of 1986 (PL 99-435): Prohibits domestic and foreign air carriers from discriminating against qualified individuals with physical or mental impairments.
Voting Accessibility for the Elderly and Handicapped Act of 1984 (PL 98-435): Requires that polling places be physically accessible to people with disabilities for federal elections.
National Voter Registration Act (NVRA) of 1993 (PL 103-31): Commonly referred to as the <i>Motor Voter Act</i> . Requires all offices of state-funded programs that are primarily engaged in providing services to people with disabilities to provide all program applicants with voter registration forms, to assist them in completing the forms, and to transmit completed forms to the appropriate state official.
Civil Rights of Institutionalized Persons Act (CRIPA) of 1997 (PL 104-150): Provides federal oversight and protections for people confined to state and local government institutions, including institutions for people with developmental or psychiatric disabilities, to ensure health and safety of residents of institutions.
Individuals with Disabilities Education Act (IDEA) of 1990 (PL 101-476): Requires public schools to provide children with disabilities with a free appropriate education in the least restrictive environment appropriate to their individual needs.
Rehabilitation Act of 1973 (PL 93-112): Prohibits discrimination on the basis of disability in all federal agencies, in federal employment, and in all federal programs receiving federal dollars.
Architectural Barriers Act of 1968 (PL 90-480): Requires that all federal buildings and buildings built with federal dollars meet federal standards for physical accessibility.

Source: Definitions taken from U.S. Department of Justice (2005). <http://www.ada.gov/cguide.htm>

problem today, even though the ADA was passed in 1990. A status report from the U.S. Department of Justice (2007) on enforcing the ADA reported on three court access-related cases dealing with physical accessibility. Physical barriers, perhaps the easiest type of systemic barrier to eliminate, continue to be a major obstacle for people with disabilities.

ECONOMIC BARRIERS

Chance encounters; Job hunters with disabilities crave an opportunity

*written by Shandra Martinez, Grand Rapids Press,
Grand Rapids, Michigan, November 25, 2007, p. F1*

Imagine that you filled out 200 job applications, with only 3 resulting in a callback. This is the experience of Jon, a 23-year-old man with a hearing impairment. In the newspaper article, Jon said that “one of the interviews was an obvious waste of time. The interviewer’s lack of interest was evident: averted eyes, nervous nods, and limp handshake” (p. F1). Yolanda, a 34-year-old woman with cerebral palsy reported, “I do get called for interviews, but I don’t get called back. A lot of people, they generally form an opinion without giving the person with the disability a chance” (p. F1).

Perhaps you can relate to Jon and Yolanda's struggle to get a job. The most recent data from the U.S. Census Bureau is that only 37.7% of working-age people (ages 21–64) with disabilities are employed (StatsRRTC, 2007). For working-age people without disabilities the percent employed is 79.7%. Clearly, there is a dramatic employment gap between people with and without disabilities. Getting an education and having a job, particularly a job that pays a livable wage, is important for anyone to achieve financial independence and security.



Ask Yourself...

What barriers to financial independence and security have I experienced?

What barriers to financial independence and security have people with disabilities whom I know experienced?

Economic barriers (also called *financial barriers*) are obstacles people with disabilities experience in education and employment that limit their ability to become financially independent and secure. The Americans with Disabilities Act (ADA) of 1990 (PL 101-336) makes discrimination in employment and in education against the law (U.S. Department of Justice, 2005). The ADA helps to make sure that people with disabilities have the opportunity to become financially self-sufficient. Unfortunately, this goal has yet to be achieved, particularly for people with more severe physical, sensory, and intellectual disabilities (StatsRRTC, 2007) and women with disabilities (Collins & Valentine, 2003).

Let's examine what is known about the employment, income, and education status of people with disabilities in the United States. The data on economic barriers comes from the 2006 American Community Survey (ACS) collected by the U.S. Census Bureau and reported in the *2006 Disability Status Report United States* (StatsRRTC, 2007).

Employment

You already know that less than 40% of working-age people with disabilities are employed. People with a sensory disability were the most likely to be employed (47.5%). When we look at full-time/full-year employment, the picture for people with disabilities looks even worse. Only 21.7% of working-age people with disabilities are employed full-time/full-year. For working-age people without disabilities the percent employed full-time/full-year is 56.6%. See Figure 4.1 for a breakdown of employment by disability type.

Earnings/Income/Poverty

People with disabilities who work full-time/full-year earn on average \$30,000 a year, which is \$7,000 less than the average wage earnings of people without disabilities. The difference in household income is even greater. The average household income of working-age people with disabilities was \$36,300.00. For working-age people without disabilities that average household income was \$65,000.00. Based on the data on worker earnings and household income you will not be surprised to read that people with disabilities are more likely to be poor than people without

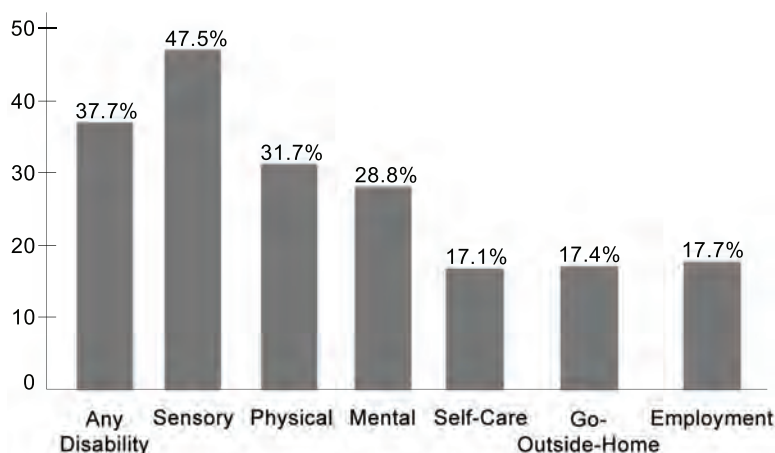


Figure 4.1. The percentage of noninstitutionalized people, working-age (ages 21–64), who are employed either part-time or full-time by disability category in the United States in 2006. (From Rehabilitation Research and Training Center on Disability Demographics and Statistics [StatsRRTC]. [2007]. *2006 disability status report* [pp. 22–23]. Ithaca, NY: Cornell University. Adapted with permission.)

disabilities. One quarter (25.3%) of all working-age people with disabilities live in poverty. This poverty rate is almost three times the rate for working-age people without disabilities (9.2%). People with a mental disability (32.5%) are the most likely to be poor. Figure 4.2 shows the prevalence of poverty by disability type.

Level of education has a direct impact on achieving financial independence and security. People without disabilities are more likely to obtain a higher level of education than people with disabilities. For example, only 12.5% of working-age people with disabilities have a bachelor's degree or higher level of education. Almost one third (30.3%) of working-age people without disabilities have at least a bachelor's degree. Getting a college degree is highly valued in our society and is one important step to achieving the "American dream." For many people with disabilities, the "American dream" is left beyond their reach. Figure 4.3 indicates

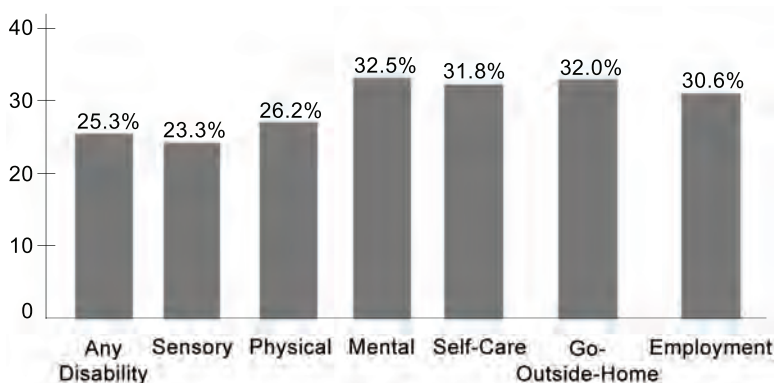


Figure 4.2. The poverty rate of noninstitutionalized working-age people (ages 21–64) with a disability by disability category in the United States in 2006. (From Rehabilitation Research and Training Center on Disability Demographics and Statistics [StatsRRTC]. [2007]. *2006 disability status report* [pp. 32–33]. Ithaca, NY: Cornell University. Adapted with permission.)

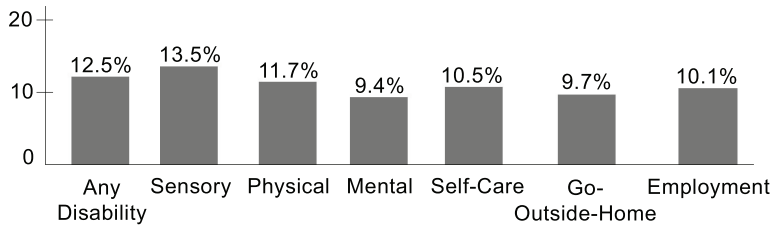


Figure 4.3. The percentage of noninstitutionalized working-age people with a bachelor's degree or more by disability category in the United States in 2006. (From Rehabilitation Research and Training Center on Disability Demographics and Statistics [StatsRRTC]. [2007]. *2006 disability status report* [pp. 40–41]. Ithaca, NY: Cornell University. Adapted with permission.)

the prevalence of a bachelor's degree for working-age people with disabilities by type of disability.

Economic Barriers and Abuse

Unemployment, low wages, and poverty compound the problem of violence and abuse for all people, including people with disabilities. Lack of financial resources limits the options to get out of abusive or potentially abusive relationships and situations. People with disabilities may have no realistic option other than to continue to employ an abusive care provider, stay with an abusive partner, or live with an abusive family member.

COMMUNICATION BARRIERS

Let's look at another newspaper story about women with disabilities accessing domestic violence services.

**Group aims to assist deaf victims of abuse:
Specially trained counselors could help bridge speech barrier**

*written by Suzanne Wilder,
The Columbus Dispatch, Columbus, Ohio, June 16, 2005, p. 01C*

A young woman endured three years of abuse by her high school boyfriend. The abuse ended when her parents learned of the physical and psychological violence and moved her to another school. Sadly, because she was unable to find counseling services that could accommodate her disability—deafness—she had to deal with the aftereffects of the violence and abuse by herself. According to the Director of Communication Services for the nonprofit group Deaf of Ohio, “many deaf women are uncomfortable going to women's shelters because of the communication barriers they face” (p. 01C). As a result, “a lot of times they'll just resort to living with the violence” (p. 01C).

In another newspaper story a woman who is Deaf talked about the communication barriers she encountered at two domestic violence shelters (Daniels, 2004). During her second use of shelter service, interpreter services were provided for meetings with her case manager and group meetings, however she was without a means to communicate with others during nonformal programming times,

resulting in feelings of isolation and distance from the other women receiving services. Communication barriers at domestic violence shelters deny people who are deaf the opportunity to receive informal support and encouragement from other victims of domestic violence living through similar experiences.

Communication barriers are inaccessible public and private sector services caused by the lack of readily available ways to engage in effective communication. Like physical barriers, communication barriers stop people with disabilities from participating fully in their communities. The ADA (1990; PL 101-336) includes requirements about communication to make sure that people with disabilities can access public and private goods and services (U.S. Department of Justice, 2005). The ADA authorized nationwide **telecommunications relay services** to make sure that people with and without hearing or speech impairments can communicate with one another (see Table 4.2). The ADA also requires that reasonable accommodations in the form of **auxiliary communication aids** and services be provided by public and private businesses and organizations to make sure people with disabilities can access goods and services.

Communication barriers that limit access to victim assistance services and the criminal justice system include

- Lack of written materials in alternative formats
- Lack of qualified sign language interpreters
- Lack of knowledge on how to use a text telephone (TTY) or telecommunication device for the deaf (TTD)
- Lack of knowledge about the telephone relay service
- Lack of staff that know how to interact with people who have cognitive limitations or communication disorders (Baladerian, 1997; Carlson, 1997; Cramer et al., 2003; Gilson et al., 2001a; Merkin & Smith, 1995; Nosek et al., 1997)

A recent status report from the U.S. Department of Justice (2007) on enforcing the ADA reported on two criminal justice-related cases involving the failure to provide sign language interpreters. In one of the cases a New Mexico attorney failed to provide a qualified sign language interpreter in order to communicate with his client and withdrew from the case. The New Mexico attorney relied on written notes, e-mail, and the sign language interpretation of his client's 9-year-old son. Under the settlement agreement, the attorney agreed to adopt and enforce a policy of effective communication that included "providing qualified interpreters and other appropriate auxiliary aids free of charge" (p. 5). It is difficult to know

Table 4.2. Accessing telecommunication relay services (TRS)

Title IV of the ADA (1990) requires states to provide telephone relay services that are regulated by the Federal Communication Commission (FCC). The TRS is a telephone service that allows people with hearing or speech disabilities to place and receive telephone calls. TRS is available in all 50 states, the District of Columbia, Puerto Rico, and the U.S. territories for local and/or long distance calls. There is no cost to use the service. All conversations are confidential.

TRS provides a communication assistant (CA) who uses a standard telephone and a TTY/TDD to type voice communication to the TTY/TDD user. The CA reads the TTY/TDD user's typed communication to the voice user. Users can dial 711 from anywhere in the U.S. to access the services.

Source: U.S. Federal Communications Commission (2008).

how widespread communication barriers are in the criminal justice system. It is likely that just a fraction of violations actually get reported and investigated.

For people who are deaf, communication barriers go beyond a lack of readily available ways to communicate. A lack of understanding about people who are deaf and the Deaf community create barriers (Edwards, Vaughn, & Rotabi, 2005). There is widespread misunderstanding about sign language versus the English language and about lipreading. The most common form of sign language used in the United States is **American Sign Language** (ASL). For people who communicate using ASL, ASL is their first language and English, both the written and spoken forms, is most likely their second language. ASL is a complex language that uses “signs made with the hands and other movements, including facial expression and postures of the body” (National Institute on Deafness and Other Communication Disorders [NIDCD], 2000, para. 1). In spoken English, language sounds created by words and tone of voice are used to communicate meaning. ASL also “has its own rules for grammar, punctuation, and sentence order” (NIDCD, 2000, para. 5). Lipreading (or speechreading) is also a less reliable form of communication for people whose first language is ASL or another form of sign language. Only 30% of the English language is visible on the lips (Edwards et al., 2005). There is a lot of room for miscommunication when relying on lipreading. Communicating with a person who is deaf using spoken or written English language is a less reliable form of communication than ASL.

Lack of information about the Deaf community and Deaf culture also creates barriers. For example, Deaf culture does not view deafness as a disability (Edwards et al., 2005). The Deaf community is able to meet most of the needs of its members within the community. Therefore, from the perspective of people who are deaf, problems only occur when they must go outside of their community.

Communication Barriers and Violence and Abuse

It is pretty clear that communication barriers prevent people with disabilities who have already been abused from accessing the services that exist to serve and protect victims. In addition, communication barriers make it more likely that a person will be abused. People who have difficulty communicating are seen as “highly desirable victims” (Ramsey-Klawnsnik & Klawnsnik, 2004, p. 49). Communication barriers make it more difficult to report the violence and abuse and reduce the perceived credibility of victims. Abusers count on communication barriers in order to avoid facing the consequences of their abusive actions.

SERVICE SYSTEM BARRIERS

Virginia rarely prosecutes cases of neglect, abuse;
Lack of expertise, victims' disabilities hamper investigators

*written by David S. Fallis,
The Washington Post, Washington, D.C., May 26, 2004, p. A13*

In this newspaper story, it was reported that in the state of Virginia between 1994 and 2002 there were 4,400 incidents of abuse of vulnerable adults at assisted living

faculties; only 43 cases of abuse and neglect were actually prosecuted. Joseph Soos, a former Alexandria police detective, reported that “law enforcement officials are often reluctant because they lack the expertise and determination to investigate and prosecute this type of case” (p. A13). Also noted was the failure of social workers to report abuse to the police because they are not properly trained or qualified to determine “what constitutes a crime” (p. A13).

The service system barriers in this newspaper story involve several systems: disability services, adult protection services (APS), the police and other parts of the criminal justice system.



Ask Yourself...

Does my community have some of the same service system problems that have been reported in the state of Virginia?

What service system barriers have I encountered?

What service system barriers have the people with disabilities whom I know encountered?

Service system barriers are limitations in the service delivery system that prevent people with disabilities from obtaining the protection, services, and supports they need to prevent abuse. The ADA (1990; PL 101-336) was created to get rid of barriers to accessing public and private services; however, many barriers to equal access still remain. Let’s examine some of the problems with domestic and sexual violence services, disability services, the criminal justice system, and APS.

Domestic Violence/Sexual Violence Services

Domestic violence shelters are very important to people experiencing abuse at home. Shelters are often unable to provide disability-appropriate interventions and meet the personal care needs of women with disabilities (Cramer et al., 2003; Hassouneh-Phillips, 2005; Milberger et al., 2003; Nosek et al., 1997); accommodate women who have children with disabilities (Nosek et al., 1997; Saxton et al., 2001); and they often poorly serve people who are lesbian, gay, bisexual and transgender (Cook-Daniels, 2007b; DeMonnin & Fun, 2005). One woman with a physical disability described her experience:

I tried to get into a shelter, and I couldn’t take a (nonabusive male) care provider with me. Um, I had to be out of there by 8 o’clock in the morning, and it’s wintertime, you know. Um, and also taking my equipment with me and find a place that was accessible. They didn’t have accessible places. (Hassouneh-Phillips, 2005, p. 75)

Domestic violence and sexual assault services are not prepared to meet the needs of men with disabilities (Cook-Daniels, 2007a; Saxton et al., 2006), including men who are gay or transgender (Cook-Daniels, 2007b). Cook-Daniels reported that while nearly all programs serve male victims, the men who use these services report experiencing many problems accessing and using the services. One of the reasons is that men are more likely to be viewed as the abuser rather than the victim. This belief can result in agencies sending a subtle or not-so-subtle message that “men are not welcome here” (Cook-Daniels, 2007a, p. 67).

Domestic violence and sexual violence services are not prepared to address violence and abuse of people with intellectual disabilities (Carlson, 1997, Hook, 2001a). According to Hook (2001a), “domestic violence and rape crisis centers turn away people with intellectual disabilities or provide substandard services” (p. 91).

The ability of domestic violence programs to serve people who are deaf and deaf-blind is another area of concern (Merkin & Smith, 1995). Problems for people who are deaf or deaf-blind include

- Having to teach service providers about communication and Deaf culture
- Decreased privacy and confidentiality because of the need to use a third person for communication
- Use of the children of victims as interpreters, which may undermine the role and authority of their parents

In addition, most shelters are designed for group activities. Without adequate supports for inclusion, an emphasis on group activities can result in communication isolation and increase the likelihood that people who are deaf will return home to their abusers.

Disability Services

Reports of the problems with the disability service system include

- Overprotection
- Failure to recognize abusive situations
- Disbelief of the victim and nonabusing care providers when reports are made
- Attributing claim of abuse to the disability

You may know of other barriers that you or someone you know with a disability has encountered. Let’s look at a few of the problems with the disability service system that contribute to abuse of people with disabilities.

Overprotection Overprotection, particularly for women with disabilities and people with intellectual disabilities, is a serious and widespread problem (Baladerian, 1997; Carlson, 1997; Chenowith, 1997; Collins & Valentine, 2003; Cramer et al., 2003; Powers et al., 2002; Saxton et al., 2001). A care provider of women with mild intellectual disabilities shared her view of the problem of overprotection:

The women in the group are extremely vulnerable to sexual assault because they have been so protected all their lives—like they have been “contained” as children. They have never talked to boys, never been allowed to go out, and so when they do they are open slather [part of a “free-for-all”]. They haven’t had all the building blocks of growing up—like...how to get rid of someone who is annoying you or how you don’t give your address to a complete stranger. (Chenowith, 1997, p. 34)

In general, people with disabilities are not provided with the knowledge, skills, and resources needed to protect themselves from abusive relationships and harmful situations. Information is needed about sexuality and healthy, mutually respectful intimate relationships; recognizing abuse; assertiveness; choice making; and personal rights. Protection for people with disabilities is designed to come

from the people who work within or regulate the systems. Overprotection is often justified as being in the person's best interest. The end result is disempowerment of people with disabilities and increased vulnerability to violence and abuse.

Failure to Recognize Abusive Situations Let's revisit June Doe's story (see Chapter 3). You already know that the sexual assault of June went on for 13 years. Read more about how the administrators of the facility responded to the reports of abuse.

More About June Doe's Story

When June's parents confronted officials at the home, they [...] were told not to listen to their daughter and were admonished for hurting the employee's reputation and name and told that they would have to live with the guilt for their accusations. The parents were told to pray to God for June's comments to end. June's descriptions of the sexual assault did not end, but rather the accusations continued to be consistent and became more graphic. The officials at the institution speculated that June was fantasizing, had dreams of men, had seen her parents in sexual positions or had seen the sexual positions on a television show. Moreover, the officials stated that the accusation was absurd, that it was a shame to accuse the institution of such a thing, and that there had never been such complaints. The officials also discredited, belittled, and demeaned June, asking the parents why the employee would have picked June as she was a blabbermouth and not pretty (Burgess, 2005, pp. 913 & 914).

Lack of staff training in recognizing abuse and silence when abuse is recognized perpetuate the problem (Cramer et al., 2003; Galpin & Parker, 2007; Nosek et al., 1997). Some disability scholars go so far as to say that violence and abuse is designed into the service delivery system for people with intellectual disabilities. The system is characterized by lack of reporting, lack of staff training in recognizing abuse, a failure to keep records of allegations of abuse, lack of staff supervision, barriers to disclosure, and isolation (Cambridge, 1999; McCarthy & Thompson, 1996). June's story certainly supports this belief. During the initial sexual assault it was possible that the people who worked with June did not recognize the signs that she was being abused. However, once reports were made to the administration, other problems with the system clearly came into play.

Disbelief When Reports Are Made Another problem with the system for people with disabilities is that when reports of abuse are made victims are not believed (Andrews & Veronen, 1993; Baladerian, 1997; Baladerian, 2005; Calderbank, 2000; Cramer et al., 2003; Nosek et al., 1997; Saxton et al., 2006). Once again, think about June Doe's story. June's story is a horrifying example of not being believed when abuse is reported. In June's case, her reports of abuse were repeatedly disregarded by the institution. Administrators of the institution even convinced June's parents that she was not to be believed. June became increasingly upset and "would cry, scream, and hyperventilate, while insisting that [the abuse] was true" (Burgess, 2005, p. 914). As was true in June's case, sexual assault is met

with disbelief because of the negative attitudes and false beliefs about people with disabilities, like being viewed as sexually unattractive. Such myths will be discussed later in the chapter.

One man with a disability described his view of the problem for men with disabilities: “We [disabled men] are easily discredited...and for that reason you [care providers] get away with things” (Saxton et al., 2006, p. 7). Not only are people with disabilities not believed, but nonabusing care providers may be discredited and experience retaliation when they report abuse perpetrated by other care providers (Calcraft, 2007; Cambridge, 1999). When care providers report the abusive actions of co-workers it is referred to as **whistle blowing**. Whistle blowing can have serious consequences for care providers who report abuse, such as

- Counterallegations made against the person who reported the abuse
- Questioning of the credibility of the reporter
- Intimidation by the alleged offender and other co-workers (Calcraft, 2007).

One bad experience with whistle blowing can greatly diminish the likelihood that a care provider will report the abusive actions of others again. One personal assistant who reported the abuse of a co-worker described the experience:

I’d never whistle blow again or raise concerns because it really it was completely, I don’t know, I don’t like the way it was all handled, it was handled really wrongly. I was made to feel like I was the one in the wrong. (Calcraft, 2007, p. 20)

People with mental illness also experience disbelief when reports are made (Galpin & Parker, 2007). Just having the medical label of mental illness can raise questions of credibility by mental health practitioners and others. People with severe mental health conditions are often seen as engaging in violent and unpredictable behavior. They are more likely to be seen as the abuser rather than the victim. Systems focus on protecting society from people with mental health conditions, rather than seeing “people with mental illness as vulnerable to abuse and in need of protection” (Galpin & Parker, 2007, p. 10).

The barriers to reporting violence and abuse are quite real and very powerful for both people with disabilities and care providers alike. Threats and intimidation are never an excuse for not reporting abuse. However, it is important to understand the harmful and disempowering environments where some people live and work in order to develop strategies to ensure that reports are made and that people who report are protected.

Attributing the Claim of Abuse to the Disability One specific way of disbelieving reports of abuse is to attribute the abuse to the disability. Once again, think about June Doe’s story. It seems pretty clear that the administrators at the faculty were trying to explain June’s accusations as fantasy or confusion on June’s part because of her intellectual disability. You can imagine that people with intellectual disabilities and severe mental health conditions can be easily discredited, especially by people who would rather not believe allegations of abuse. For example, “a woman with a mental health disability told of providers attributing, without investigation, her report of abuse to the informant’s own hallucinations” (Cramer et al., 2003, p. 194).

The failures of the disability service system have serious consequences for people with disabilities. As was the case in June Doe's story, victims are subjected to repeated and prolonged abuse. Offenders are not held accountable for their criminal actions. People with disabilities are not referred for victim services and are denied the supports they need to heal from the abuse.

Criminal Justice System

The criminal justice system often poorly serves people with disabilities who have been crime victims. Let's examine what is known about the experiences of people with disabilities within different parts of the criminal justice system. Read Nikki's story.

Nikki's Story

Nikki, a 27-year-old woman with Down syndrome, told her mother that the reason that she no longer rode her bike was because "she had been bothered." Fifteen months later her mother overheard Nikki tell a family friend that she was "afraid of the boy who took her into the bushes and hurt her." Upon further questioning it was discovered that a neighborhood boy raped her in the woods behind Nikki's house. The police had no experience interviewing a person with an intellectual disability. They quickly concluded that Nikki was unable to identify the offender and they wanted to give up. However "when allowed to tell her story in her own way, Nikki was able to name her abuser and point out the house where he lived" (Hook, 2001a, p. 90).

Nikki's experience with the police is not uncommon. In fact, there is every reason to believe that police officers have limited knowledge about people with disabilities and their lives (Baladerian, 1997; Guidry Tyiska, 1998; Keilty & Connelly, 2001; Milberger et al., 2003; Nosek et al., 1997; Sobsey, 1994; Powers et al., 2002; Saxton et al., 2001). Calling the police can be of little value in dealing with abusive relationships and situations. One woman with a disability reported:

Sometimes abuse from a provider can be violent. The police may not be familiar with this relationship. They're familiar with spousal abuse, abuse by children of elderly parents. But they don't know about [personal assistant] providers being in a close intimate relationship. (Saxton et al., 2001, p. 409)

Another person with a disability said, "The cops don't understand....it's treated as though it's a social worker problem. That it's not a crime? It devalues disabled people because it's seen as a medical model problem" (Saxton et al., 2001, p. 409). In a study of women with disabilities, the women reported that calling the police was "one of the least helpful strategies" for dealing with domestic violence (Powers et al., 2002, p. 12).

As Nikki's story shows, police officers are often unprepared to respond to violence toward and abuse of people with intellectual disabilities (Baladerian, 1997; Davies, Mansell, Northway, & Jenkins, 2006; Hook, 2001b; Keilty & Connelly, 2001; Modell & Mak, 2008). Areas of concern include not recognizing when someone

has an intellectual disability, responding to people based on stereotypes, and not knowing how to modify interview techniques to obtain a victim statement. Credibility of the victim is often called into question. A sexual assault worker reported, “The first thing the police asked me was ‘Do you believe her’? The impression was that she was making it up to get attention” (Keilty & Connelly, 2001, p. 285).

People who train police officers about violence and abuse of people with disabilities, including the author of this book, know that the problem goes deeper than the lack of training or attitudes of individual police officers (see Table 4.3). “Poor response protocols, lack of motivation to investigate, and systemic resistance to pursuing cases” (Hook, 2001a, p. 90) are the outcomes of a system-wide problem within individual police departments and the larger criminal justice system.

Lawyers, or attorneys, play an important role in helping victims obtain equal protection under the law. Although not a concern only for people with disabilities, the lack of affordable legal services is particularly problematic for people with disabilities because of their overall lower socioeconomic status (Nosek et al., 1997). Unwillingness or disinterest by prosecuting attorneys to prosecute cases involving abuse of people with disabilities is also a problem (Davies et al., 2006; Hook, 2001b; Sobsey, 1994). The newspaper story discussed earlier in this chapter highlighted the problem in one community. Over an 8-year period of time, only 43 out of 4,400 reported cases of abuse, neglect, or exploitation of people with disabilities in Virginia were prosecuted. Another example was the sexual assault of five women with intellectual disabilities. When one woman reported the assault, the District Attorney refused to prosecute on the grounds that the woman “would have zero credibility in court” (Hook, 2001b, p. 3).

Another systemic barrier in the criminal justice system is the inconsistent and narrow definitions of abuse (Cramer et al., 2003; Davies et al., 2006; Sobsey, 1994; Saxton et al., 2006). State laws or statutes determine definitions of *physical assault*, *sexual assault*, *neglect*, and *financial exploitation*. These laws vary from state to state. Therefore, behavior that is considered a crime in one state may not be considered a crime in another state. Very narrow definitions leave out types of abuse that are unique to or particularly harmful to people with disabilities. For example, abuse by control and restraint, such as threatening to or taking away assistive devices, is quite harmful to people with disabilities. On the other hand, very broad definitions of abuse can be a problem because the laws are difficult to enforce. Think about the subtle abuse and gray areas that were discussed in Chapter 3.

Judges also play an important role in making sure victims receive equal protection under the law. The role of judges is to make sure that the rules and

Table 4.3. Examples of law enforcement barriers

Lack of knowledge about people with disabilities
Response to people with disabilities based on negative attitudes, myths, and stereotypes
Lack of knowledge on how to modify interview questions and protocols
Questioning of the credibility of abuse victims based on their disability
Lack of motivation to investigate violence and abuse
Systemwide resistance to pursuing crimes committed against people with disabilities

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Table 4.4. Examples of criminal justice system barriers

Lack of affordable legal services
Lack of knowledge about people with disabilities
Prosecutors and judges responding to people with disabilities based on negative attitudes, myths, and stereotypes
Unwillingness or lack of interest in prosecuting abuse of people with disabilities
Inconsistent and narrow definitions of abuse

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procedures of the court are followed. Judges make decisions about who is competent to give testimony in court. The issue of competency is most often raised with people who have intellectual disabilities and severe mental health conditions. Judges also have “final decision-making authority for imposing sentences in most criminal cases and in civil cases” (Minnesota Judicial Center [MJC], n.d., p. 8). In addition, if there is no jury, judges decide “what are the relevant facts in the case and what laws should be applied to the facts” (MJC, n.d., p. 8). In cases of domestic violence, victims with disabilities rely on judges to grant Orders for Protection (OFP) and to make just decisions in custody disputes involving children. When judges lack adequate knowledge about people with disabilities, it is difficult for people with disabilities to receive equal protection under the law. For example, one woman with a physical disability was found by a judge to be incompetent to serve as a mother based on the fact that she had a disability (Nosek et al., 1997).

The failures of the criminal justice system deprive people of their rights and contribute to perpetuating the abuse of people with disabilities (see Table 4.4). The information in Chapter 6, Understanding the System, will help you and the people you support assert your rights within the criminal justice system.

Adult Protection Services

The role of **Adult Protection Services (APS)** is protecting vulnerable adults and providing services to ensure and maintain their safety. The role of the police is investigating crimes and arresting alleged offenders. APS professionals typically work closely with local police. You will learn more about APS in Chapter 6. There are limitations in the ability of APS to protect and serve vulnerable people with disabilities (Baladerian, 1997; Nosek et al., 1997) (see Table 4.5). One problem is that laws vary from state to state regarding who is protected and in the legal definitions of the various forms of abuse. Another concern is limited funding and large caseloads leading to APS professionals who are overworked. The focus of APS on the elderly, with less emphasis on people with disabilities who are under age 65, is also a concern.

Table 4.5. Examples of Adult Protection Services (APS) barriers

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Variation in legal definitions of <i>vulnerable adult</i>
Variation in legal definitions of <i>abuse of vulnerable adults</i>
Lack of adequate funding for services
Large caseloads
Poor coordination of APS, disability, and other services
Disempowering practices of APS workers and the APS system

People with disabilities have raised concerns about APS professionals taking over and not listening to the preferences and fears of people with disabilities. For example, in one study fear of being institutionalized greatly decreased the likelihood people would report abuse (Saxton et al., 2006). The men in the study reported

[T]here is a real danger when you go to those people [APS]....they think that their answer to protect the disabled person is to take them out of their home and the next thing they find themselves in a nursing home....they look at it as poor victims who need to be protected....they take your independent life....and put you in a disabled person's prison.... (p. 13)

Poor coordination between agencies providing APS and those providing disability services is another limitation of the system. Despite these limitations, APS play an important role in protecting and providing services to adults with disabilities who are victims of abuse.

It is important to be aware of the role and the limitations of APS. APS focuses mainly on the safety and service needs of victims. APS will work with family members and others in the home (or other environment) when it is believed that services will help to improve a situation. APS can help the police in their investigation of the abuse—hopefully leading to the arrest of offenders. However, APS is not part of the criminal justice system. Without the involvement of the police, APS can do very little to prevent offenders from continuing their abuse. APS cannot hold offenders criminally accountable for their illegal actions. The police are the gateway into the criminal justice system. If the police do not become involved, vulnerable adults will not have a shot at getting their day in court. APS should not be used as a substitute for the criminal justice system for vulnerable adults with disabilities. People with disabilities have the right to receive the protections and services of both the APS and the criminal justice system.

Final Thoughts About Service System Barriers

The consequences of a poorly coordinated, unprepared, and unresponsive service delivery system can be quite serious for people with disabilities who are victims of abuse. Victims may feel more alone and become more hopeless. They may believe that there is no help available, that there is no point in reporting further abuse, and that the violence and abuse must be tolerated.

ATTITUDINAL BARRIERS

Instead of beginning this section with a headline or story, think about your own experiences with and understanding of attitudinal barriers. As a person with a disability, you have your own stories about attitudinal barriers. As a family member, friend, or professional you have witnessed how negative attitudes and stereotypes have caused pain to the people with disabilities whom you know.

Attitudinal barriers are the myths, negative views, and stereotypes about people with disabilities that result in the denial of equal opportunity, equal protection under the law, and equal participation in community life. They are connected to and reinforce all other kinds of barriers. As the Social Model of Disability explains, societal attitudes are perhaps the greatest barrier people with disabilities encounter.

Table 4.6. Myths about people with disabilities

Dehumanization myth
Myth of insensitivity to pain
Lesser quality of life myth
Helpless myth
Asexual myth
Sexually unattractive myth
Sexually promiscuous myth
Lack of credibility myth

Negative attitudes about people with disabilities stem from myths or false beliefs. The myths discussed in this chapter create some of the greatest barriers to preventing abuse (see Table 4.6). You likely have many additional myths to add to the list.

Dehumanization Myth

In the late 1980s I was a social worker for 60 adults with intellectual disabilities who resided in a large, private residential facility. There were three men with very severe physical and intellectual disabilities who lived in one of the units. They were totally dependent on others for their care. Early in my employment, I overheard the staff that provided direct care saying that they were working with the “non-mobs” (referring to the individuals’ lack of mobility). I am embarrassed to admit that at first the use of the term “non-mobs” did not prompt me to take any action. Eventually, and I cannot recall the length of time that passed, I began confronting staff when they referred to the people that they were caring for as “non-mobs.” Sadly, whenever the term “non-mobs” was used everyone at the facility knew who was being talked about. In part because of my advocacy the practice of calling the men “non-mobs” was ended. People First language and the recognition that all people had the right to be called by their name became the policy at the facility. Before discussing how this story relates to the dehumanization myth,



Ask Yourself...

What is my reaction to the term “non-mob”?

How is the use of the term “non-mob” dehumanizing?

Dehumanization refers to “the actions, attitudes and beliefs associated with treating a person or a group of people as less than human” (Sobsey, 1994, p. 310). The **dehumanization myth** is the belief that people with disabilities are less than full members of society (Sobsey, 1994; Sobsey & Mansell, 1990). The men were not recognized as people. They were identified solely by their physical and intellectual limitations. When people are not called by their own names, they are stripped of their humanity as if they are less than complete human beings. The dehumanization of people with disabilities can be used by offenders as an excuse for abusive treatment. In the mind of offenders, if people with disabilities are not complete

human beings, then they do not have to be treated with respect and dignity. The principle “do unto others as you would like done unto you” does not apply if you believe that the others are not really like you.

Myth of Insensitivity to Pain

While working at a residential facility for adults with intellectual disabilities, I worked for an administrator who believed in the myth of insensitivity to pain—at least insensitivity to emotional pain. In my role as a social worker, I was responsible for making sure that people received all of the services that they needed to be in good health. From my perspective, this also included good mental health. I knew that people with intellectual disabilities could experience mental health conditions. I knew that some of the adults I supported were experiencing psychological or emotional pain and that they required appropriate mental health services. Sadly, the administrator did not believe that people with intellectual disabilities experienced mental health conditions. From his point of view, people with intellectual disabilities were unable to feel emotional pain.

Perhaps you can relate to this story. Perhaps you or someone you know with a disability was not given appropriate medical or mental health care because of a false belief that they did not experience pain like other people. The **myth of insensitivity to pain** is closely related to the dehumanization myth (Sobsey & Mansell, 1990; Sobsey, 1994). The belief that people with disabilities do not have feelings or feel pain in the same way as people without disabilities is often applied to people with intellectual disabilities. For example

A psychiatrist testified that a woman with autism who was sexually assaulted at the institution of which he was the director could not have been injured by the assault because people with autism do not have feelings. Unfortunately the case was decided on his testimony. (Baladerian, 1997, p. 4)

Another example of the myth of insensitivity to pain is the idea that people with intellectual disabilities who are victims of sexual assault suffer less harm than other people because they do not fully understand what happened to them (McCarthy & Thompson, 1996; Sobsey & Mansell, 1990). This belief has absolutely no basis in reality. Think about June Doe’s story. June experienced **posttraumatic stress disorder** (PTSD) as a result of repeated and prolonged sexual assault. The belief in the myth of insensitivity to pain helps offenders excuse their actions and justify continuing abuse of their victims. Victims are denied treatment for PTSD and other mental health conditions that occur as a result of the abuse. In addition, when this myth is believed by the larger community it can provide the rationale for not providing and funding appropriate supports and services and not seeking justice within the criminal justice system.

Lesser Quality of Life Myth

Latimer parole fair, rights group says

*written by Doug Ward, The Vancouver Sun,
Vancouver, B.C., Canada, February 28, 2008, p. A4*

On October 19, 1993, Tracy Latimer's father took his daughter's life and claimed it was a "mercy killing." Mr. Latimer placed Tracy in his truck, attached one end of a hose to the exhaust pipe and the other end inside the car and used the exhaust fumes to kill her. Tracy Latimer was a 12-year-old girl who had severe cerebral palsy. According to Hughes and Abramson (2000) Tracy could not walk, talk, or feed herself. In November of 1994 Mr. Latimer was convicted of second-degree murder and sentenced to 25 years to life in prison. There was considerable support from the public and media on Mr. Latimer's behalf. A social work professor at the University of B.C. stated "the public response has been that either Mr. Latimer should never have been charged or that he should have been let off more lightly" (Ward, 2008, p. A4). The case was appealed all the way up to the Canadian Supreme Court. The Supreme Court upheld Mr. Latimer's life sentence, with no chance for parole for 10 years. In the end, Mr. Latimer served 7 years in prison. Mr. Latimer was paroled on February 27, 2008. The Executive Director of the British Columbia Civil Liberties Association (BCCLA), upon hearing that parole was granted, said his reaction was "joy that the rule of law was upheld and that the Latimer family finally got a break" (Ward, 2008, p. A4). The Association for Community Living expressed concern saying, "we continue to be concerned that Mr. Latimer has shown no remorse" (Ward, 2008, p. A4). A spokesperson for the Catholic Archdiocese of Vancouver said, "holding Mr. Latimer to the original sentence would have done a better job of sending the message that all Canadians' lives are worth protecting, including those of the disabled" (Ward, 2008, p. A4).

Before discussing Tracy's story,



Ask Yourself...

Do I believe that Mr. Latimer acted out of love and compassion when he killed his daughter?

Would I look at Tracy's story any differently if she did not have a severe physical and intellectual disability?

The story of Tracy Latimer has been making headlines since 1993. The Council of Canadians with Disabilities, among other groups and news organizations, has web sites devoted to tracking the 15-year history of this case. Tracy's story is perhaps one of the most extreme examples of the belief that people with disabilities are "damaged goods." The **lesser quality of life myth** is based on the idea that, because they are "damaged," they have a lesser quality of life, are lesser human beings, and in some cases are "better off dead" (Campbell, 2002; Sobsey & Mansell, 1990; Sobsey, 1994).

Quality of life is very personal. What you think is a good quality of life may be different from what another person thinks is a good quality of life. Although some people without disabilities may think that the lives of people with disabilities are not worth living, this belief does not reflect the reality of the vast majority of people with disabilities (Campbell, 2002). There is no reason to believe that people who have disabilities enjoy their lives less than people without disabilities, with the exception that "the quality of their lives may be damaged" by others (Sobsey, 1994,

p. 316). In fact, Gill (2006) found that people with disabilities “report as much satisfaction with life as anyone else” (p.188).

Belief in the lesser quality of life myth poses significant dangers for people with disabilities, including so-called “**mercy killing**,” abortion of fetuses with disabilities, sterilization (without knowledge or consent), and **passive euthanasia** (failure to provide life-saving medical treatment) in the health care system.

Helpless Myth

Treating people with disabilities as helpless victims “only encourages aggressors to take advantage of them without fear of consequence” (Barile, 2002, p. 3). People with disabilities are often portrayed as weak and treated as helpless. The **helpless myth** implies that helplessness is an automatic outcome of disability (Calderbank, 2000; Sobsey & Mansell, 1990). The belief that all people with disabilities are helpless is dangerous because it suggests that people who have disabilities are completely vulnerable, unable to assert their rights, and incapable of self-advocacy. It is true that people who have more severe disabilities rely to a greater degree on others for care and support. However this is not the case with the majority of people with disabilities. The dangerous outcome of belief in the helpless myth is that we have largely created and maintained a disability service system that is overprotective and disempowering. One important exception is Centers for Independent Living, whose mission is empowerment of people with disabilities.

The helpless myth can also affect how people with disabilities, especially people with intellectual disabilities, are treated in the criminal justice system. Family members, disability service providers, and criminal justice professionals may advocate against prosecuting crimes out of a desire to protect people with disabilities from further trauma (Keilty & Connelly, 2001). Overprotection is based on the helpless myth and promotes disempowerment of people with disabilities.

Asexual, Sexually Unattractive, and Sexually Promiscuous Myths

Before discussing the myths related to sexuality and people with disabilities,



Ask Yourself...

How do you think myths about the sexuality of people with disabilities could contribute to their being sexual assaulted?

When it comes to issues of sexuality, people with disabilities are subject to many different and opposing myths. The **asexual myth** refers to the belief that people with disabilities are not sexual beings. Some people believe that people with disabilities are not capable of having sex, do not desire sex, or should not want to engage in sexual activity (Anderson & Kitchin, 2000). This myth is particularly problematic for women with disabilities because “once a woman’s identity is constructed as asexual, the license to commit many abuses usually follows” (Chenoweth, 1997, p. 36). People with intellectual disabilities are also often thought of as being asexual. An advocate for people with intellectual disabilities described the problem as follows:

Some providers assume that people they serve are not sexual beings: “they’re just not interested in sex; it’s not an issue for them.” Having made this assumption, they proceed blithely to ignore any responsibility they have to be vigilant about possible sexual exploitation of the person with the [intellectual disability], or the responsibility they have to teach about appropriate sexual functioning. (Sundram, 2005b, p. 98)

Belief in the asexual myth provides one reason for not providing sex education. It also provides an excuse for not supporting people with disabilities in having healthy, age-appropriate sexual relationships. As a result, people with disabilities are less likely to recognize, understand, and resist sexual assault.

Equally harmful is the **sexually unattractive myth**. People who buy into this myth believe that people with disabilities are sexually unattractive and therefore are immune from sexual assault. Think back to June Doe’s story. One of the reasons June’s reports of sexual assault by a care provider were discounted by administrators was because June “was a blabbermouth and not pretty” (Burgess, 2005, p. 911). Attractiveness has nothing to do with sexual assault. Sexual assault is about power and control, not about sexual attraction. It is not about physical beauty (however that is defined). The failure to recognize the true causes of sexual assault leaves many people with disabilities, particularly women, vulnerable to sexual predators. A belief in the sexually unattractive myth can result in people with disabilities not being provided with the tools they need to avoid potentially dangerous situations, resist pressure or bullying, and protect themselves. Another danger of this myth is when women with disabilities buy into the belief that they are not attractive. This increases the likelihood that they will put up with abusive partners because they believe no one else will be attracted to them (Nosek et al., 1997).

People with disabilities are also sometimes believed to be **sexually promiscuous** or have an overactive sex drive (Anderson & Kitchin, 2000; Chenowith, 1997; Furey, 1994; Keilty & Connelly, 2001). At this point you may be thinking to yourself: Which is true, people with disabilities are not interested in sex or are overly interested in sex? In one study of women with intellectual disabilities, police officers were quoted as saying, “Just like rabbits. They seem to have a higher sex drive than other people. They seem to get sexual very young, and have a high sex drive. Maybe they have something to prove” (Keilty & Connelly, 2001, p. 280).

The rationale for institutionalization, segregation, and sterilization is based in part on the belief that both men and women with disabilities are sexual menaces (a danger to society) that must be controlled.

Lack of Credibility Myth

You already learned about the problem of disbelief when reports of abuse are made by people with disabilities. The disbelief comes, in part, from believing that when people with disabilities report abuse they are not telling the truth or are exaggerating. The **lack of credibility myth** is perhaps the most damaging belief about people with disabilities, especially within the criminal justice system. Think back to the story about the state of Virginia and the failure to prosecute cases of abuse. Although it is not known for sure, given the problems with the criminal justice system for people with disabilities, it is likely that the issue of credibility had some-

thing do with the low prosecution rate. Think back to the story of June Doe. Her credibility was questioned by the administrators at the facility. Think about your own experiences.



Ask Yourself...

Has my credibility ever been questioned because I have a disability?

Have I questioned the credibility of people with disabilities whom I support?

Have I ever been accused of making up a story to get attention? Have I ever accused a person with disabilities of making up a story to get attention?

Time and again it has been documented that when women with disabilities report violence and abuse they are not viewed as credible (Collins & Valentine, 2003; Cramer et al., 2003; Gilson et al., 2001a; Nosek et al., 1997, 2001). The questioning of credibility is also problematic for people with intellectual disabilities (Baladerian, 1997; Baladerian, 2005; Davies et al., 2006; Keilty & Connelly, 2001; Sobsey, 1994) and people with mental health conditions (Andrews & Veronen, 1993; Cramer et al., 2003; Galpin & Parker, 2007; Jennings, 1999). Whether or not a person is viewed as credible determines how reports of abuse will be handled by care providers in the disability service, vulnerable adult advocacy and protection, and criminal justice systems.

Final Thoughts About Attitudinal Barriers

The following quote from a woman with a physical disability sums up the problem with attitudinal barriers best:

I would say to agencies, I realize I have a disability and that my disability is not so much what is supposedly wrong with me but I find my disability is more your attitude about what is wrong with me....if you would just put your attitude aside and help me, I'd appreciate that greatly. (Cramer et al., 2003, p. 194)

LEARNING ACTIVITY



Identifying Systemic Barriers

Read Joyce's story. Refer to Figure 4.4 for a checklist of systemic barriers that were covered in this chapter. Think about the possible systemic barriers that might affect Joyce's ability to end the abusive relationship with her husband.

Joyce is a woman with multiple sclerosis who met her husband while they were in college. The domestic violence began after they were married. "He seemed to care so much about me. He got a little jealous. Well, that was supposed to happen, right, after all he was in love with me. It started out with the controlling aspect. In other words, he wanted to know who I was with—where I was all the time. Constant jealousy..." Verbal abuse escalated into physical and psychological abuse. "Every

- ☐ Physical barriers
- ☐ Economic barriers
- ☐ Communication barriers
- ☐ Domestic violence/sexual violence service barriers
- ☐ Overprotection
- ☐ Failure to recognize abusive situations (disability services barrier)
- ☐ Disbelief when reports are made (disability services barrier)
- ☐ Attributing the claim of abuse to the disability (disability services barrier)
- ☐ Criminal justice system barriers
- ☐ Adult protection services barriers
- ☐ Attitudinal barriers
- ☐ Dehumanization myth
- ☐ Myth of insensitivity to pain
- ☐ Lesser quality of life myth
- ☐ Helpless myth
- ☐ Asexual, sexually unattractive, or sexually promiscuous myths
- ☐ Lack of credibility myth

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Figure 4.4. Checklist of systemic barriers to preventing violence to and abuse of people with disabilities.

house we ever lived in had either a hole in a wall or a hole in the door. He would always say, 'If you hadn't made me so mad I wouldn't have done it.' And he said, 'You know I'll get the kids....cause all I have to do is go and prove that you're disabled and I'll get the children.' Toward the end he had pushed me down, and of course he said, "You know with your MS you're so damn clumsy you just fell down. In time I began to pull back, thinking, 'I have got to get myself and my daughters out of this.' And when it got right down to it, it was a very scary time. I knew at that point that leaving is usually the most dangerous, and I knew he was getting more and more violent toward me and threatening more violence" (Fitzsimons, 2005, p. 25).

Now that you have read Joyce's story, review the systemic barriers in Figure 4.4. Place an X next to all of the systemic barriers that you think apply to Joyce's situation.

Thoughts About Joyce's Story

The purpose of this learning activity is to help you think more deeply about systemic barriers and to give you a chance to apply what you have learned. You most likely checked several of the systemic barriers. Joyce encountered physical barriers, economic barriers, communication barriers, service system barriers, and many of the attitudinal barriers. Refer to the answer sheet on pages 183 and 184 for Joyce's thoughts about how the systemic barriers affected her.

FINAL THOUGHTS

If you are a person with a disability, you have likely experienced many barriers—some that were discussed in this chapter. If you are a person without a disability,

you may now have a much better appreciation for the barriers that people with disabilities encounter on a daily basis. You should have a good understanding of the systemic barriers that make it harder to prevent violence and abuse. Perhaps you feel a bit overwhelmed by the sheer number of barriers. That's okay; the systemic barriers are a bit overwhelming. It is important to remember that the barriers are obstacles that can be overcome through individual and collective advocacy and self-advocacy. You're getting closer to reading about what you can do as an advocate or self-advocate to overcome barriers. However, first you need to learn about the personal barriers to action to help you get a complete picture of the barriers.

RESOURCES

Web Sites

ADA Enforcement, U. S. Department of Justice, <http://www.ada.gov/enforce.htm>
 Disability Statistic: Online Resource for Disability Statistics, Cornell University, <http://www.ilr.cornell.edu/edi/disabilitystatistics/>
 National Center on Domestic and Sexual Violence (refer to Resources section of web site), <http://www.ncdsv.org>

Curriculum/DVD

Advocating Change Together. (2000). *Changing attitudes: Recognize and challenge everyday misconceptions about disability!* [Curriculum and DVD]. Syracuse, NY: Program Development Associates, <http://www.disabilitytraining.com>

Suggested Readings

Dubin, M. (2005, September). *Domestic violence shelters and the ADA*. Retrieved August 13, 2008, from <http://www.ncdsv.org/images/DVSheltersADA.pdf>
 Rehabilitation and Research Training Center on Disability Demographics and Statistics. (2006). *2006 disability status report United States*. Retrieved August 18, 2008, from <http://www.ilr.cornell.edu/edi/disabilitystatistics/>
 U.S. Department of Justice. (n.d.). *ADA status reports*. Retrieved August 13, 2008, from <http://www.ada.gov/enforce.htm>
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 U.S. Department of Justice. (2006, January). *Communicating with people who are deaf: An ADA guide for law enforcement officers*. Retrieved August 13, 2008, from <http://www.ada.gov/lawenfcomm.pdf>
 U.S. Department of Justice. (2006, April 4). *Commonly asked questions about the ADA and law enforcement*. U.S. Department of Justice, http://www.ada.gov/q%26a_law.pdf
 Washington State Coalition Against Domestic Violence. (2004). *Increasing agency accessibility for people with disabilities: Domestic violence agency self-assessment guide*. Retrieved August 13, 2008, from <http://www.wscadv.org/resourcesAlpha.cfm?aId=59543DD0-C298-58F6-0638C1A7DCD01A9B>

5

Personal Barriers to Preventing Violence and Abuse

Women talk about domestic violence

*written by Jason Bergreen,
The Salt Lake Tribune, Salt Lake City, Utah, October 17, 2005, p. B1*

In this newspaper story two women who are deaf share their experiences of domestic violence by their partners. Susanna put up with 8 years of frequent beatings and rape by her boyfriend. She finally fled to a domestic violence shelter that specialized in helping people who are deaf and hard of hearing after her boyfriend threw their infant daughter against the wall of her apartment. Teri endured 10 years of emotional abuse by her husband. She moved into a safe house with her two children (ages 4 and 8) after learning that there was help available.

It is often difficult for people who have never been abused to understand how people stay with their abusers. Perhaps you have thought or have heard someone say something like “I know I’d never put up with being abused. One hit and he (or she) would be out.” Susanna stayed with her abusive boyfriend for 8 years. Teri stayed with her abusive husband for 10 years. I hope you know that part of the answer to the question “Why did they stay for so long?” is because of systemic barriers. Another reason is because of the personal barriers. **Personal barriers** are the lack of knowledge and skills and the negative thoughts, feelings, beliefs, and fears within a person that result in disempowerment.

Before you learn more about personal barriers,



Ask Yourself...

What kinds of thoughts, feelings, beliefs, or fears do I think Susanna and Teri might have had that kept them from leaving their abusers?

OVERVIEW OF THE ISSUE

You learned about systemic barriers before personal barriers for two reasons. The first reason is personal barriers are often created by and reinforced by systemic barriers. The impact of systemic barriers on personal barriers will become quite clear as you learn more about the specific types. The second reason is that people who want to help victims of violence and abuse tend to focus on dealing with the personal barriers. Why? Because it is easier to “fix” the person being abused than it is to “fix” organizational and societal barriers. However, if we only focus on fixing the person, we will never truly solve the problem.

In the United States in the late 1970s and early 1980s, as a society we began to recognize the problem of domestic violence toward women. The view of domestic violence slowly started to shift away from one of a personal, private family issue to a public problem. **Battered woman syndrome** (BWS), based on the theories of the cycle of violence and learned helplessness, was proposed as an explanation for why some women stayed in abusive relationships (Walker, 2000). Learned helplessness will be explained later in the chapter. Let’s look at the cycle of violence.

The Walker Cycle Theory of Violence (discussed earlier in Chapter 2) explains that each abuse episode has three distinct phases: 1) tension building, 2) the abusive episode, and 3) honeymoon or loving-contrition (the abuser may apologize, show kindness, and act remorseful) (Walker, 2000, pp. 126–127). The third phase provides the positive reinforcement that keeps many women from leaving their abusers. The symptoms of BWS include “low self-esteem, self-blame, anxiety, depression, fear, suspiciousness, and loss of belief in possible change” (Tang, 2003, p. 619). The symptoms of BWS are personal barriers that are created by and reinforced by the abuser and other systemic barriers.

The people that we interact with and the environments where we live, learn, work, and play influence how we feel about ourselves. For example, the messages that you hear from the people in your life shape how you think about yourself as a person. The messages can be empowering or disempowering. People who hear disempowering messages on a regular basis, such as “you can’t,” “you’ll never learn,” “you’re no good,” or “no one else will ever love you,” may internalize these messages and begin to actually believe them. The experience of being beaten down by negative messages and experiences does not only affect people with disabilities.

Let’s look at several personal barriers that are particularly harmful to people with disabilities:

- Learned helplessness
- Low self-esteem
- Self-blame
- Denial
- Sense of responsibility to others
- Fear of retaliation
- Fear of the unknown

- Fear of losing custody of children
- Lack of knowledge and skills
- Poverty

As you read about the personal barriers you may identify a personal barrier that you or someone with a disability you support has experienced that is not mentioned. Not every possible personal barrier is being discussed. What is most important is that you become more aware of how personal barriers overwhelm, discourage, and immobilize victims. Just like systemic barriers, personal barriers increase vulnerability to violence toward and abuse of people with disabilities. Personal barriers also make it more difficult to end abusive relationships and get out of abusive situations. It is also important to be familiar with personal barriers in order to avoid blaming victims who stay in abusive situations. An understanding of the personal barriers helps professionals, family members, and others avoid suggesting easy solutions that do not reflect how dangerous it is to report and leave or get rid of abusers.

Since you are already familiar with the systemic barriers affecting Joyce, the Learning Activity at the end of the chapter will ask you to think about how each personal barrier might apply to Joyce's story. Let's start with learned helplessness.

LEARNED HELPLESSNESS



Ask Yourself...

Have I ever experienced learned helplessness?

Do I know someone who fits my definition of learned helplessness?

How do people learn to be helpless?

Learned helplessness is “the belief that one's actions have no influence on future outcomes” (Sobsey, 1994, p. 164). Learned helplessness is one of the theories used to explain why women in particular stay in abusive relationships. Women who experience abuse over a long period of time lose the ability to predict how others (the abuser) will respond to what they do (Walker, 2000). Let's look at an example of how learned helplessness can happen.

Example of Learned Helplessness

If you cooked your partner's favorite dinner, what reaction do you think that you would get from him or her? Perhaps you might get a hug or be shown some other type of affection. Perhaps you would be praised or thanked for cooking a favorite meal. So, let's say that your partner's reaction was to give you a great big hug and tell you that the meal was delicious. Now two weeks go by and you decide to once again cook your partner's favorite dinner. This time the reaction that you get is totally different. Your partner tells you that you are a horrible cook and dumps the food down the garbage disposal. This is not the reaction that you expected to receive. The person's reaction to your kindness does not make any sense. You try to assert yourself by talking with your partner about how you feel about his or her

treatment of you. You try to find out what might have provoked his or her behavior. Maybe in response to your communication, your partner apologizes and tells you it will never happen again. Now imagine that your partner's pattern of unpredictable behavior occurred all the time and in many different situations. Sometimes your partner is nice and loving in response to your kindness. Other times you are subjected to threats, name calling, destruction of property, or physical assault. Over time, despite all of your efforts to work on your relationship with your partner and after living in constant fear of the next abusive episode, you might come to believe that there is absolutely nothing you can do to change your life. You now fit the description of someone who has learned helplessness.

Learned helplessness is not the same as being helpless. Rather, learned helplessness happens when people learn that their efforts to assert themselves fail over and over again and when people lose a sense of control over what happens to them (at least in relationship to their partner). As a result, they give up and let others have power and control over their lives.

Learned helplessness is particularly problematic for women with disabilities and people with intellectual disabilities. In U.S. society, women more often than men are taught to be compliant and are discouraged from being assertive (Carlson; 1998; Chenowith, 1997; Milberger et al., 2003; Nosek et al., 1997; Saxton et al., 2001). As a result, women with disabilities are more likely to remain in abusive relationships. Services for people with intellectual disabilities emphasize compliance, giving people very little decision-making power and control (Baladerian, 1997; Carlson, 1997; Chenowith, 1997; Furey, 1994; McCarthy & Thompson, 1996; Sobsey, 1994). Compliance is often highly valued and rewarded by parents and professionals alike. Learned helplessness, reinforced by compliance training, leads to **learned compliance**. What do you think happens when people reinforced for complying with the instructions of parents, teachers, bus drivers, and other care providers—really anyone in a position of authority—encounter someone who wants to abuse them? What are the chances that they will resist the abuse?

One care provider who worked with women with intellectual disabilities explained the problem:

We teach women to do everything we say—"sit and have your dinner," "go to the toilet," "put that cup down," etc. So, when a new person says, "take your dress off," of course the woman will comply because that is what we have taught her to do. So many people with disabilities cannot distinguish between when it is OK and when is it not OK to do that. (Chenowith, 1997, p. 35)

Many people with disabilities, particularly people with intellectual disabilities, have learned to comply with the directions of people they believe are in positions of authority—which can be just about anyone. As a result they are less likely to resist and report abuse.

LOW SELF-ESTEEM

Self-esteem refers to a person's own sense of worth. People who have **low self-esteem** have a poor self-concept: they don't feel good about themselves and have negative feelings about their own worth and abilities.



Ask Yourself...

Do I know anyone who I think has low self-esteem? How can I tell that they have a poor self-concept?

How does being abused affect how people feel about themselves?

How does low self-esteem prevent people from getting out of abusive relationships or abusive situations?

One factor contributing to low self-esteem of people with disabilities is their lack of independence and self-sufficiency. In the United States independence and self-reliance are highly valued. Because many people with disabilities require some assistance, they are often viewed as inadequate, never achieving the independence so highly valued in our society (Collins & Valentine, 2003). The truth is no individual, with or without disabilities, is completely independent or self-sufficient. Yet, for people with disabilities the failure to live up to the mythical standard of independence may have a negative impact on their sense of self-worth.

Low self-esteem for both men and women with disabilities also comes from being undervalued in our society (Antle, 2004; Calderbank, 2000; Guidry Tyiska, 1998; Nosek et al., 1997). In our society difference is often viewed negatively and people who are different are often viewed as second-class citizens. Women with disabilities are particularly vulnerable to low self-esteem because they tend to be valued even less in our society than men with disabilities (Carlson, 1998; Chenowith, 1997; Hassouneh-Phillips, 2005; Hassouneh-Phillips & McNeff, 2005; Nosek et al., 2001). People with disabilities, particularly women who do not fit the standard of beauty in our society, often have poor body image. Poor body image can result in self-hate and a willingness to accept abusive treatment. Low self-esteem and the belief that no one else would be attracted to them is one reason that some women with disabilities stay in abusive relationships. One woman with a physical disability acquired later in her life talked about her own sense of self-worth:

I've had relationships with people that I really wasn't all that attracted to and probably wouldn't have before my accident....setting my standards lower thinking that as a woman with a disability, I would not be a partner or seen as a woman who is worthy. (Hassouneh-Phillips & McNeff, 2005, pp. 236-237)

Some women may decide that bad feelings are better than no feelings. Some women may decide that an abusive relationship with a partner is better than no relationship.

Low self-esteem can result from or contribute to emotional or psychological abuse. Abusers emotionally beat up their victims by repeatedly telling them that they are worthless, ugly, stupid, and other harmful messages. One woman with a physical disability explained: "[The abuse was] not so much physical as mental. He was very good at the mental game. And I was very fortunate that he married me..." (Hassouneh-Phillips, 2005, p. 77). The interviewer then asked, "That's what he kept telling you?" The woman responded, "Oh yeah and that nobody would ever want me...and my self-esteem level...was nothing" (Hassouneh-Phillips, 2005, p. 77).

When victims of violence and abuse are also socially isolated they have little opportunity to hear positive messages to make up for the negative messages. Low self-esteem is a personal barrier that is directly caused by and reinforced by other people and the broader society.

SELF-BLAME



Ask Yourself...

Have I ever blamed myself for something that I knew was not my fault?

Why would someone who is being abused blame him- or herself for causing the abuse?

Why would someone with a disability who is being abused blame him- or herself for causing the abuse?

Self-blame refers to blaming one's self for being abused. Self-blame is not unique to people with disabilities. You already know that self-blame is one of the symptoms of Battered Woman Syndrome (BWS). Women in U.S. society are traditionally viewed as responsible for the family, home, and relationships. One of the problems with self-blame is that women who blame themselves for the abuse are more likely to deal with the problem on their own and believe that they can fix the problem (Liang, Goodman, Tummala-Narra & Weintraub, 2005). Assuming responsibility for the abuse may be linked to the role of women as nurturers and fixers of relationships. People who blame themselves keep abusers from taking responsibility for their abusive behavior and prolong the abuse.

For people with disabilities, self-blame is also related to their disability. You are already familiar with many of the negative attitudes about people with disabilities. Self-blame is directly linked to the belief that people with disabilities are a burden on society. This view of one's self as a burden is particularly harmful when people with disabilities must rely on care providers for support (Saxton et al., 2001). When people with disabilities come to believe that they are a burden, they are more likely to blame themselves for the abuse. Some people may minimize their needs, fearing that they are a burden. Some people may feel too embarrassed to keep asking for assistance. Some people may even believe that they deserve to be abused. One man with a disability talked about feeling like a burden because he had to depend upon his daughter for care:

My daughter resented having to do my care....but I—we're stuck. What do we do?... I feel mortified that I have to do this [rely on her]. But I've got to get on with things. How do you carry that [burden], deal with it? It's tricky. (Saxton et al., 2006, p. 8)

As you are already aware, there is very limited information about the experiences of men with disabilities who are abused. However, we do know that self-blame is common among men (without disabilities) who have been sexually abused. Men tend to blame themselves for "instigating the abuse," "for failing to protect themselves," and "for not telling anyone about the abuse" (Romano & De Luca, 2006, p. 76). One man with a physical disability talked about how the way that men are viewed in our society contributes to staying silent and may contribute to self-blame:

Society has always imposed on men that we are supposed to be able to defend ourselves and handle ourselves, and if physically come at, we are supposed to be able to punch them out. I can't punch them out. It's very emasculating...to tell somebody, "I was abused by this person. "... [Disabled] men have a tendency to just swallow it and stay silent." (Saxton et al., 2006, p. 9)

Self-blame is a personal barrier that is created by and reinforced by other people and the broader society. Societal expectations for men and women seem to contribute to the reasons that both men and women with disabilities who are victims of violence and abuse blame themselves.

DENIAL

Denial is the refusal to face the reality of a painful event or life situation.



Ask Yourself...

Have I ever been in denial about some situation in my life? What did I say to myself or others to minimize the situation?

Have I ever known someone who was in denial about some situation in their life? What have I heard other people say to minimize the situation?

Why would someone who is being abused be in denial about the abuse or the severity of the abuse?

Until a person is ready to get help to stop the abuse, fully acknowledging the reality of the situation can be too much for some people to handle. Short-term denial can help victims live through the abuse—in this sense it is a helpful coping strategy. However, using denial over a long period of time is a problem (Liang et al., 2005; Womendez & Schneiderman, 1991).

Some women who are in denial about domestic violence may downplay the abuse by describing it as an unusual event. They may also deny the severity of the abuse by comparing their abuse with the abuse experienced by other people that they know (Liang et al., 2005). Victims of violence and abuse might make minimizing statements, such as these:

- It wasn't really that bad.
- I shouldn't have made him so mad (also a self-blame statement).
- She didn't mean to hurt me. She was just upset.
- He only gets this way when he drinks.
- If I wasn't such a burden, he wouldn't have hit me (also a self-blame statement).

People who are in denial are less likely to seek help; therefore, they put up with abuse for long periods of time, causing more harm to themselves.

The Walker Cycle Theory of Violence talks about the honeymoon or loving-contrition phase of the domestic violence cycle. You will recall that during this phase, abusers will try to make up with their victims by apologizing, buying gifts, making promises, and treating the person with kindness and affection. The periods of niceness reinforce the denial because victims think that the abusers have the

ability to change. As a result, plans to get out of abusive situations get delayed over and over again. This pattern of abuse, warmth, and delaying taking action is particularly dangerous. In most cases the abuse increases in severity and duration and victims' feelings of positive self-worth decrease, making it more difficult to get out of the situation. You will also recall from Chapter 2 that there is some research that shows that the honeymoon phase of domestic violence may not apply to women with disabilities who are in abusive relationships (Copel, 2006). This means that without the period of niceness to reinforce the belief that the abuser can change, denial may affect women with disabilities who are in abusive relationships differently than it affects women without disabilities. Research is needed to learn more about how the cycle of violence and denial applies to women and men with disabilities.

SENSE OF RESPONSIBILITY TO OTHERS



Ask Yourself...

Have I ever done something that I did not think was good for me out of a sense of responsibility to other people?

Do I know anyone who put up with abuse out of a sense of responsibility to other people?

A **sense of responsibility to others** refers to putting up with violence and abuse, willingly or through intimidation (threats, bullying), for the greater good of family or others. This issue may affect women more than men in our society. In many cultures, including the mainstream U.S. culture, women are expected to take care of the family. This is especially true in cultures that value collectivism, meaning individual needs are outweighed by the needs of the entire family (Liang et al., 2005, p. 76). In cases of domestic violence, women with and without disabilities may put up with the abuse for the sake of the children and to keep the family together. For some women the stigma of divorce is so great that it is better to stay in a bad marriage than to be seen as responsible for the breakup of the family or to be labeled as a bad person. Leaving the abuser may mean having to raise the children alone. Leaving an abusive partner may also result in homelessness, financial insecurity, and poverty for female victims and their children (Liang et al., 2005).

A sense of responsibility to others also applies to other types of family relationships. Some people with disabilities may be reluctant to report an abusive family member out of concern for the financial well-being of the family. For example, some families need the cash benefits of adult or minor-age children with disabilities to help support the family. People with disabilities may be unwilling to report an abusive family member out of fear that they will be removed from the home, which could have negative financial consequences for the rest of the family. If the abuser is the primary money earner, the victim or other family members may not report the abuse in order to keep the family from becoming poorer.

FEAR

We have all experienced fear in our lives. Fear is an unpleasant feeling of worry or uneasiness caused by actual danger or the possibility of danger. Fear is a very powerful personal barrier. Fear can be very immobilizing—a person feels stuck, unable to make a decision, unable to take control of his or her life.



Ask Yourself...

What is the most frightening experience that I have ever had in my life?

How did I respond to the fear?

Why would someone who is being abused be afraid to report the abuse? What are the reasons or causes of the fear?

Fear keeps people who are in abusive situations from getting help to stop the violence and abuse. Fear is another one of the personal barriers that is directly caused by other people or systems. We each are affected differently by fear. Some people are more negatively affected by frightening people and situations. There are many reasons or causes of the fear that people who are abused experience. Let's look at three specific causes of fear and how they affect people with disabilities: fear of retaliation, fear of the unknown, and fear of losing custody of children.

Fear of Retaliation

Retaliation means purposely harming someone in order to get even or get back at the person for something that they have done to you. **Fear of retaliation** is being afraid that the abuser or someone trying to protect the abuser will hurt you in order to get back at you for reporting the abuse. In Chapter 4 you learned about the retaliation some care providers experienced when they reported the abusive actions of co-workers. One personal assistant described being intimidated into keeping quiet: "I was told to say nothing. If I reported anything then it was made clear to me that I would have to take the consequences" (Cambridge, 1999, p. 295).

People with and without disabilities may not get help because of fear of retaliation by the abuser and by other people who do not want the abuse disclosed (Andrews & Veronen, 1993; Carlson, 1997; Carlson, 1998; Liang et al., 2005; Powers et al., 2002). Abuse victims fear for their physical safety. When abuse victims have children, they also fear for the physical safety of their children. Fear of retaliation is a very real concern. The fear lives within the mind of the victim, but it is caused by the abuser. The time immediately after leaving an abuser and after getting an Order for Protection (OFP) is a particularly dangerous time for victims of domestic violence (Campbell et al., 2003; National Coalition Against Domestic Violence [NCDV], 2007). Unless victims can be certain that they will be protected from further violence and abuse, some may choose to remain silent.

Fear of the Unknown

In the words of a person with a disability who was abused by a care provider: “The devil you know is better than the devil you don’t know” (Saxton et al., 2001, p. 408). **Fear of the unknown** usually involves feeling uncertain about your future. Fear of the unknown lives within the mind of the person, which is why it is a personal barrier. But it is created by other people and systems. In the case of abuse victims, fear of the unknown is the fear of what will happen to them if they report the abuse. For example, people with disabilities who use personal assistants (PA) must weigh the pros and cons of getting rid of an abusive PA. It is possible that the next PA might be worse (Saxton et al., 2001, p. 408). People with disabilities may be reluctant to report because they do not know how adult protection services (APS) and the criminal justice system will respond and what the outcome will be for them. People with disabilities often fear being removed from their home and institutionalized against their will.

Fear of Losing Custody of Children

We know that fear of losing custody of children is a very powerful motivator for women to stay in abusive relationships. How this fear affects men has not been adequately researched. Women with disabilities are often not viewed favorably in the court system in child custody cases (Guidry Tyiska, 1998; Nosek et al., 1997). Women with disabilities may lack money to hire lawyers who will strongly represent them in a custody battle. Abusers may claim women with disabilities are unfit to be mothers because of their disabilities. Some courts have awarded custody to abusers based on the belief that children are better off with a father without a disability than with a mother with a disability (Guidry Tyiska, 1998, p. 7). Women with disabilities, fearing that the court will award custody to their abusers, may choose to stay in abusive relationships in order to protect their children. It is only when the children become the targets of the abuse that some women contact the police and leave with their children.

LACK OF KNOWLEDGE AND SKILLS

Lack of knowledge and skills refers to not having the information and skills needed to prevent violence and abuse. Based upon what you have learned so far,



Ask Yourself...

What kind of information would be helpful to you in order to prevent an abusive situation?

What are the reasons some people with disabilities lack knowledge and skills to prevent abuse?

In order to answer the second question, think about the issue of power and control. People with disabilities may not get the knowledge and skills they need

because other people in positions of power control their lives. Think about the systemic barriers—organizational and societal—that you learned about in Chapter 4. Systemic barriers limit opportunities and access to information.

Now let's think about the first question. Read what one woman with a disability said about how lack of knowledge influenced her life:

I wasn't able to say, "knock it off" to my family who was doing my personal care. I thought it was normal to be tossed around in my chair. To have a comb dragged through my hair so it comes out. To be left on a toilet for an hour. It took me about five years of hiring people, when I realized that I didn't have to accept those things." (Saxton et al., 2001, p. 403)

The most basic information people need is to be able to recognize that how they are being treated is abusive. People also need to know that they do not have to put up with abuse.

Throughout this book you are learning about the knowledge and skills that you need to prevent violence and abuse. Because of systemic barriers many people with disabilities do not get the information and experiences in life that they need to protect themselves. Areas that people with disabilities lack knowledge and skills in include

- Where to go to get help
- How to make healthy decisions about sexual activities and intimate relationships
- Personal safety skills and ways to decrease their risk for abuse
- Assertiveness skills
- Effective communication skills
- Problem-solving skills

Lack of knowledge and skills is another personal barrier that is directly caused by other people and the broader society.

POVERTY

You already know that people with disabilities are more likely to be less educated, underemployed, unemployed, and poorer than people without disabilities. Refer back to the information about economic barriers presented in Chapter 4. The causes of poverty are complex. The people who study poverty do not all agree on the causes. Some people believe that people are poor because of personal failure that includes characteristics such as laziness and lack of marketable work skills. Some people believe that people are poor because of societal problems such as discrimination and policies that maintain the status quo (the rich stay rich, the poor stay poor). The reasons that a particular person with a disability is poor may be a combination of personal and societal causes. One of the reasons that the Americans with Disabilities Act (PL 100-336) was passed was to eliminate discrimination in the workplace, to help people with disabilities avoid poverty.

You should already know the connection between poverty and abuse.



Ask Yourself...

How does poverty make an abusive situation worse?

Do I know anyone who stayed in an abusive relationship or situation because they were poor, or because they were afraid of becoming poor?

People who obtain greater financial independence and security are able to have more control over their lives. Financial independence gives you greater freedom in choosing where you live, whom you live with, and how you live your life. Poverty limits the options to get out of abusive or potentially abusive relationships and situations. As with all of the other personal barriers, poverty is a personal barrier that is caused by and made worse by systemic barriers.

Final Thoughts About Personal Barriers

Personal barriers are very powerful obstacles to ending violence and abuse. The personal barriers are interconnected with one another, meaning they influence and reinforce one another. In most cases, several kinds of personal barriers are working against a person who is being abused. The longer people remain in abusive situations, the more ingrained the personal barriers become and the more difficult it is to end the abuse. Let's apply what you have learned to Joyce's Story.

LEARNING ACTIVITY

Identifying Personal Barriers

Reread Joyce's story. Refer to Figure 5.1 for a checklist of personal barriers that were covered in this chapter. Think about the personal barriers that might have affected Joyce's ability to end the abusive relationship with her husband.

Joyce's Story

Joyce is a woman with multiple sclerosis who met her husband while they were in college. The domestic violence began after they were married. "He seemed to care so much about me. He got a little jealous. Well, that was supposed to happen, right, after all he was in love with me. It started out with the controlling aspect. In other words, he wanted to know who I was with—where I was all the time. Constant jealousy..." Verbal abuse escalated into physical and psychological abuse. "Every house we ever lived in had either a hole in a wall or a hole in the door. He would always say, 'If you hadn't made me so mad I wouldn't have done it.' And he said, 'You know I'll get the kids....cause all I have to do is go and prove that you're disabled and I'll get the children.' Toward the end he had pushed me down, and of course he said, 'You know with your MS you're so damn clumsy you just fell down. In time I began to pull back, thinking, 'I have got to get myself and my

daughters out of this.’ And when it got right down to it, it was a very scary time. I knew at that point that leaving is usually the most dangerous, and I knew he was getting more and more violent toward me and threatening more violence” (Fitzsimons, 2005, p. 25).

Place an “X” next to all of the personal barriers that you think might have affected Joyce (see Figure 5.1). Write down or ask someone to write down for you your ideas about how each personal barrier you selected affected her.

Thoughts About Joyce’s Story

The purpose of this learning activity is to help you think more deeply about personal barriers and to give you a chance to apply what you have learned. Refer to the answer sheet on pages 184 and 185 for the author’s thoughts about how the

☐ Learned helplessness	
☐ Low self-esteem	
☐ Self-blame	
☐ Denial	
☐ Sense of responsibility to others	
☐ Fear of retaliation	
☐ Fear of the unknown	
☐ Fear of losing custody of children	
☐ Lack of knowledge and skills	
☐ Poverty	

Combating Violence and Abuse of People with Disabilities: A Call to Action by Nancy M. Fitzsimons. Copyright © 2009 Paul H. Brookes Publishing Co., Inc. All rights reserved.

Figure 5.1. Checklist of personal barriers to preventing violence to and abuse of people with disabilities.

personal barriers apply to Joyce. Most of the personal barriers affected Joyce to some degree. It is very likely that low-self esteem, self-blame, fear of retaliation, and fear of losing custody of her children were particularly strong personal barriers for Joyce.

WEB OF POWER AND CONTROL

As a group, personal barriers and systemic barriers are very powerful obstacles to ending violence and abuse. Think about the systemic barriers that you thought applied to Joyce. Imagine how powerless and overwhelmed Joyce must have felt. Imagine how difficult it must have been for Joyce to break free from her husband's web of power and control.



Ask Yourself...

What does the phrase web of power and control mean to me?

What image comes to my mind when I think of a web of power and control?

The idea of a **web of power and control** comes from the *Taking Charge: Responding to Abuse, Neglect, and Financial Exploitation* curriculum (Fitzsimons-Cova et al., 2000). The web of power and control provides a way for people to visually understand how the power and control of an abuser along with systemic and personal barriers make it difficult for victims to break free from abuse. A modified version of the web of power and control is used in this book.

Take a look at the web of power and control depicted in Figure 5.2. A person who is a victim of violence and abuse may feel like an insect trapped in a spider's web. Let's look at each part of the web.

- The spider represents the abuser. The spider weaves its web in order to capture an insect, which represents the victim.
- The strands of the web represent the systemic barriers. The larger the web is, the greater the number of systemic barriers that exist. The larger the web becomes the more difficult it is for the insect to break free.
- The insect is caught in the web of systemic barriers, but also each time the insect tries to break free and fails it becomes more entangled in the web. This self-entanglement represents personal barriers.

Now let's think about how the web of power and control applies to people with disabilities.

- Abusers use their power to control their victims.
- Systemic barriers make it difficult for victims to stop the abuse.
- Each time the system fails to protect and serve victims, they become more hopeless.
- Abusers rely on systemic barriers to maintain their power and control. Abusers become more empowered and continue to abuse their victims.

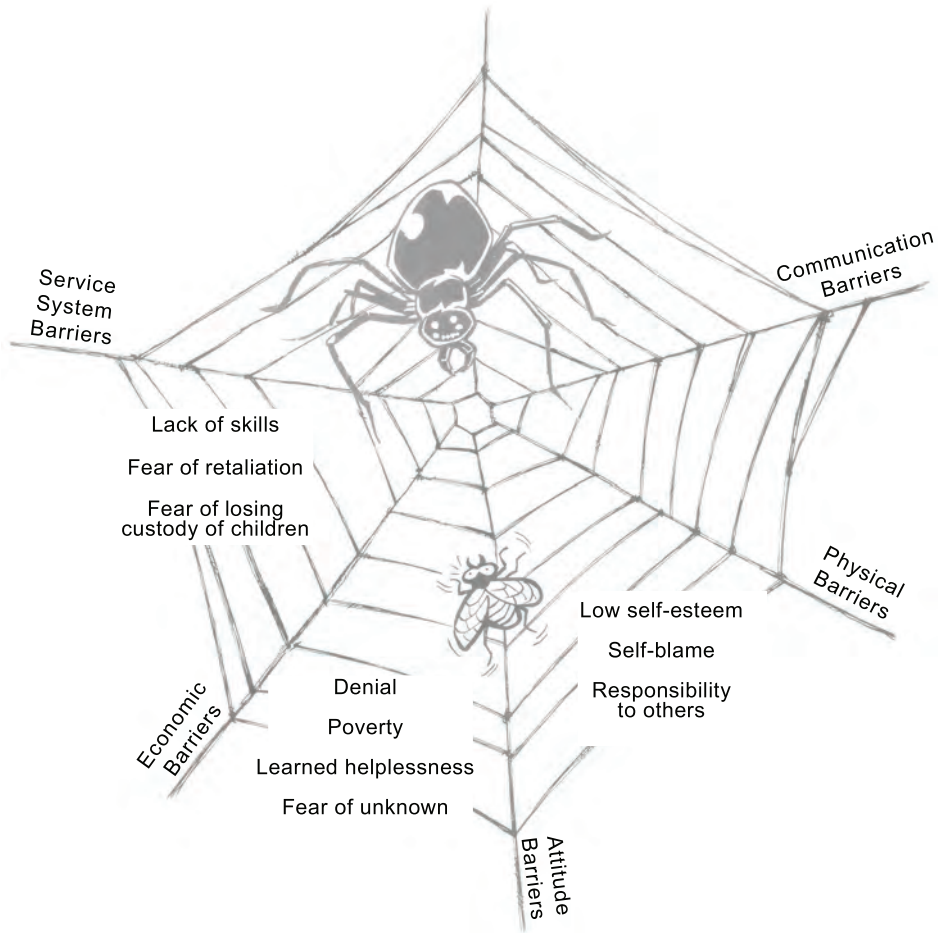


Figure 5.2. This “web” of power and control illustrates how the power and control of an abuser, along with the systemic and personal barriers, make it difficult for a victim to break free from abuse. (From Fitzsimons-Cova, N., Drum, C., Keys, C., Wonderlich, M., & Horner-Johnson, W. [2000]. *Taking charge: Responding to abuse, neglect, and financial exploitation*. Chicago: Institute on Disability and Human Development, Department of Disability and Human Development, University of Illinois at Chicago. Adapted by permission.)

- Chronic abuse further demoralizes victims. Personal barriers become even more ingrained and harmful to victims.
- Over time the victim becomes more and more entangled in the abuser’s web of power and control.

Here is the good news. People with disabilities are not insects forever trapped under the control of a spider. With knowledge, skills, and supports, people with disabilities can break free from their abuser’s web of power and control (Fitzsimons-Cova et al., 2000, p. 51).

FINAL THOUGHTS

Let’s revisit the definition of personal barriers used in this book. Personal barriers are the lack of knowledge and skills and the negative thoughts, feelings, beliefs,

and fears within a person that result in disempowerment. Personal barriers are very powerful obstacles to ending violence and abuse. While personal barriers exist within the person, they are created by and reinforced by other people and systems.

Think back to the three major needs of victims discussed in Chapter 3: to feel safe, to express their emotions, and to know what comes next. Use your understanding of personal barriers to help you support the needs of people with disabilities you know who are being abused or are in a potentially abusive relationship or situation. Listen to and validate people's fears. Help people think through their options. Support people in making decisions that are best for them at that point in their lives. Forcing or bullying people into reporting or leaving abusers may feel no different than how they are treated by their abusers. People who are considered vulnerable adults under the law have less control over their lives when abuse is discovered. If you are a mandated reporter you should inform people with disabilities about your responsibility to report abuse. However, you should also try to empower people considered vulnerable adults as much as possible as their cases work their way through the adult protection and/or criminal justice systems.

If you are a person with a disability who is being or has been abused, you know that your experience is not unique. You probably have a much better appreciation for why people with disabilities remain silent and stay in abusive relationships or situations. Individual and collective advocacy and self-advocacy break down barriers and change systems. Let's move on to examining the systems most directly involved in protecting and serving victims and in promoting equal justice under the law.

RESOURCES

Web Sites

The Minnesota Center Against Violence and Abuse (MINCAVA) is an electronic clearinghouse of publications pertaining to violence and abuse. Go to <http://www.mincava.umn.edu/>. Under *Domestic Violence* and *Sexual Violence* are disability links to obtain publications pertaining to people with disabilities.

The National Center on Domestic and Sexual Violence has many useful publications. Go to <http://www.ncdsv.org>. Under *Resources* click on *Publications*. Click on *People with Disabilities* to obtain publications specifically about domestic and sexual violence of people with disabilities.

The Wisconsin Coalition Against Domestic Violence (WCADV) has many useful publications. Go to <http://www.wcadv.org/>. Under *Publications* click on *Aging and Disabilities* to obtain publications specifically about domestic and sexual violence of people with disabilities.

SafePlace has an array of resources dealing with domestic and sexual violence, including a Deaf Services program and a Disability Services program that specialize in counseling victims of violence and abuse. Go to <http://www.safeplace.org/>

Suggested Readings

Deaton, W.S., & Hertica, M. (2001). *A therapist's guide to growing free: A manual for survivors of domestic violence*. New York: Haworth Press.

Mansell, S., & Sobsey, D. (2001). *Counseling people with developmental disabilities who have been sexually abused*. Kingston, NY: NADD Press.

6 ➡➡➡

Understanding the System

Advocates: Key is to spot signs of assault; Police are investigating the apparent rape of a severely disabled woman

written by Barry Adams and Brenda Ingersoll,

Wisconsin State Journal, Madison, Wisconsin, August 7, 2003, p. B1

In this newspaper story it was reported that a woman with a severe disability who resides in a state facility with 52 other people was taken to the hospital because of medical problems. Doctors discovered that she was 6 weeks pregnant. The woman does not have the mental capacity to consent to sexual relations. In 1997 a Vulnerable Adult Legal Intervention Project was started in Dane County. The program “assigns someone who acts as an advocate, liaison, and interpreter between the victim and the criminal justice system”(p. B1). According to Jennifer Ondrejka, Executive Director of the Wisconsin Council on Developmental Disabilities, one of the things that advocates do is “help the professional ask the questions in better ways so the person is able to successfully respond and explain” (p. B1).

Understanding the system refers to knowing the laws, rights, agencies, programs, and services that protect and support victims and promote justice. Think about the woman in the newspaper story and



Ask Yourself...

What systems do I think will be involved in helping the woman in the story?

What systems in my community would I be working with if I were sexually assaulted?

The victim in the story will (or at least should) be involved with several systems responsible for protecting, supporting, and seeking justice for crime victims with disabilities. The creation of a program specifically designed to support and advocate for vulnerable adults who are crime victims is a good indication of how complex the system can be.

OVERVIEW OF THE ISSUE

The system can be very confusing and overwhelming to anyone, but especially to victims who are also dealing with the consequences of violence and abuse. You will learn about four parts of the system: **victim services, vulnerable adult advocacy**

and protection system, the criminal justice system, and the civil justice system. Remember, the word *victim* refers to a person who has been abused or who has been a crime victim. The word victim does not mean that people with disabilities are victims. People with disabilities are disempowered when they are not provided with the information they need to protect themselves and to promote their own best interests. Sir Francis Bacon, 16th century philosopher and statesman, said “knowledge is power.” Understanding the system will help you advocate on your own behalf and support the self-advocacy of people with disabilities that you know.

VICTIM SERVICES

Before you read about victim services,



Ask Yourself...

What are the rights of crime victims in my state?

Can I be compensated for crime-related expenses?

How do I get a victim advocate to help me as my case works its way through the criminal justice system?

What is an order for protection and how would I get one?

By the end of this chapter, you will know the answers to these questions and so much more about victim services.

Victim services are the array of federal, state, and local services available to help victims obtain justice and to heal from their victimization. These programs are located within state, county, or other government agencies and private nonprofit organizations. In the United States the Victims of Crime Act (VOCA) of 1984 (PL 98-473) authorizes funding for a broad array of services and resources to help victims and to ensure that their rights are not violated (U.S. Office for Victims of Crime [U.S. OVC], 2004). The VOCA fund is administered by the Office for Victims of Crime. Money comes from criminal fines, forfeited bonds, special assessments, and penalties collected by the U.S. Attorney’s Office, U.S. Federal Courts, and the Federal Bureau of Prisons (U.S. OVC, 2002). You should be familiar with the rights of crime victims and the two general types of services: assistance and compensation.

Victims’ Rights

Every state has a **victim’s bill of rights** that specifies the legal rights of crime victims. The specific rights vary depending upon the state. Refer to Table 6.1 for a basic list of victims’ rights. Contact the Attorney General’s Office or the victim assistance agency in your state to learn about the specific rights of victims in your area.

The U.S. Constitution states the constitutional rights of offenders. There are no specific constitutional protections for victims. The National Victims’ Constitutional Amendment Passage (NVCAP) and other victim advocates are working to amend the U.S. Constitution to create universal rights and protections for victims of violent crime. In addition, many states have amended or are attempting to make changes to state constitutions to provide better rights for victims of crime. Victims’ rights

Table 6.1. Victim's rights

In general, victims have the right to

- Be notified of proceedings and the status of the defendant
  - Be present at certain criminal justice proceedings
  - Make a statement at sentencing or other times
  - Receive restitution (compensation for loss or injury) from a convicted offender
  - Be consulted before a case is dismissed or a plea agreement entered
  - Have a speedy trial
  - Keep their contact information confidential
-

Source: NCVC (1999b).

groups want crime victim rights 1) to be protected in the same way that defendants' rights are protected, 2) to be a permanent part of the criminal justice system, and 3) to make sure that the courts have the power to enforce crime victims' rights if they are violated (National Center for Victims of Crime [NCVC], 1999a). Thirty-three states have changed their state's constitution to provide for the rights of victims (NVCAP, n.d.).

Victim Assistance Programs

There are two main types of victim assistance programs: system-based victim assistance programs and community-based victim assistance programs (National Organization for Victim Assistance [NOVA], 2005). Victim assistance includes the following services: crisis intervention, emergency shelter, emergency transportation, counseling, and criminal justice advocacy (U.S. OVC, 2002, 2005). Each state has a victim assistance agency that provides oversight of the statewide victim assistance services system and provides information and referral to victims. In addition, there are many national organizations that provide information on victims' rights, services, and criminal justice resources (refer to the resource list at the end of the chapter). Several of the organizations have 24-hour toll-free hotlines in order to immediately address the needs of victims.

System-Based Victim Assistance Programs System-based victim assistance programs provide criminal justice advocacy services (see Table 6.2). These programs run out of local police or local prosecutor's offices. A victim advocate is assigned to help the victim understand the procedures and practices of the criminal justice system and to support the victim as the case is prosecuted. Victims may not automatically be given a victim advocate. Victims may need to ask that an advocate be assigned to their case.

Table 6.2. System-based victim assistance services

-
- Assistance in filing for state crime victim compensation funds
  - Notification of hearings, plea negotiations, and court dates
  - Someone to accompany victims to court proceedings
  - Explanations of the legal process
  - Interaction on the victim's behalf with attorneys, court personnel, employers, and schools
-

Source: NCVC (2008b).

Table 6.3. Community-based victim assistance services

Crisis intervention
Emergency shelter
Emergency transportation
Obtaining a protective order (e.g., order for protection, harassment)
Counseling
Criminal justice advocacy

Community-Based Victim Assistance Programs Community-based victim assistance programs provide many types of services (see Table 6.3). At first, advocates deal with the emotional support needs of victims, make sure that appropriate referrals for services are made, and ensure that the victim's legal rights are upheld (NOVA, 2005). Advocates also help with the long-term needs of victims. Domestic violence programs and sexual assault programs are the two most common community-based victim assistance programs.

Domestic violence programs are located in communities throughout the United States and provide many services, including "counseling and support groups; information about legal options, the criminal justice system, and social services; shelter; attorney referral; vocational counseling; safety planning; and case advocacy" (NCVC, 2008a, p. 3). Services are provided at no cost to victims. Domestic violence programs primarily serve female victims and their children. You will need to ask if services are available to men who are victims of domestic violence. Victims are assisted regardless of their decision to stay in or leave the relationship (NCVC, 2008a).

Sexual assault programs provide support and services to victims of sexual assault regardless of whether or not the victim chooses to report the assault to the police (NCVC, 2008b). Many communities have written protocols on how to respond to sexual assault victims. **Sexual Assault Response Team (SART)** programs have been created in many communities to respond at crime scenes, hospitals, and police stations to serve the immediate needs of victims. A typical SART team consists of a police officer, an advocate, and a **Sexual Assault Nurse Examiner (SANE)** or doctor. The purpose of the SART program is to reduce the negative effects and trauma associated with sexual assault. This is done by reducing the number of interviews and by giving the victim immediate access to resources (NCVC, 2008b).

Victims of sexual assault are encouraged to undergo the collection of forensic (crime-solving) evidence through the administration of a **rape kit** in order to help in the successful prosecution of their case (Rape, Abuse, and Incest National Network [RAINN], 2008). Typically the rape kit exam is administered by a SANE or a **Sexual Assault Forensic Examiner (SAFE)**. Victims who are unsure if they want to report the sexual assault should still have forensic (crime-solving) evidence collected in case they change their minds later. Advocates explain the importance of and actual procedures used in the rape kit exam. In addition, advocates are present, when requested by the victim, to provide emotional support to victims during

the rape kit exam. A urine sample should be collected from victims who suspect that they may have been drugged (RAINN, 2008).

A rape kit is a standard kit with little boxes, microscope slides, and plastic bags for collecting and storing evidence. This process preserves evidence so that it may later be processed and used in court. The process involves collecting evidence left on [the victim's] body and clothing, including hair and fibers. (RAINN, 2006, p. 1)

Order for Protection Domestic violence, sexual assault, and other victim assistance programs can help victims in getting an Order for Protection (OFP), also known as a *restraining order*. An OFP is a “court-issued order that directs individuals to refrain from specified conduct” (NCVC, 2005, p. 1). OFP are usually related to domestic violence. However, in many states an OFP can also be obtained to protect vulnerable individuals (people who are elderly and people with disabilities), stalking victims, crime victims, and witnesses from harassment by offenders (NCVC, 2005). An OFP is typically issued against someone who is in a domestic relationship or related to the victim, such as a spouse, partner, boyfriend/girlfriend, parent of the victim's child, or blood relative. Specific examples of the protection offered by an OFP are listed in Table 6.4. A **harassment restraining order**, another type of protective order, may be granted by the court for nondomestic relationships. Many forms of aid or assistance are available under an OFP and harassment restraining order. In addition to those listed in Table 6.4, the court may provide other relief determined to be appropriate under the circumstances. The cost of petitioning and serving a protective order varies depending on the type of order, reason for petitioning, and jurisdiction. Many states and communities have funds available to help victims pay for protective orders. In addition, courts may require offenders to pay the cost for getting protective orders.

The process of obtaining an OFP is pretty much the same in each state (see Figure 6.1). A victim advocate can assist you in this process. The first step is for a victim to petition the court for an OFP against a specific individual. A temporary order can be granted by the judge based solely on the evidence presented in the petition. The offender is notified by the police and a hearing is scheduled within a few days or weeks to hear evidence from the victim and the offender. If the judge sides with the victim, a permanent OFP is granted stating the conditions of the OFP, including the length of time of the protective order. An OFP is typically in place for 1–3 years. The conditions of the order can be changed or the length of time can be extended by the court. If the offender violates any of the provisions of the OFP, the police should be immediately notified and the offender should be arrested.

Table 6.4. Types of relief available under an Order for Protection (OFP)

Restricting contact
Prohibiting abuse, intimidation, or harassment
Determining child custody and visitation
Mandating offender counseling
Prohibiting firearm possession

Source: NCVC (2005, p. 1).

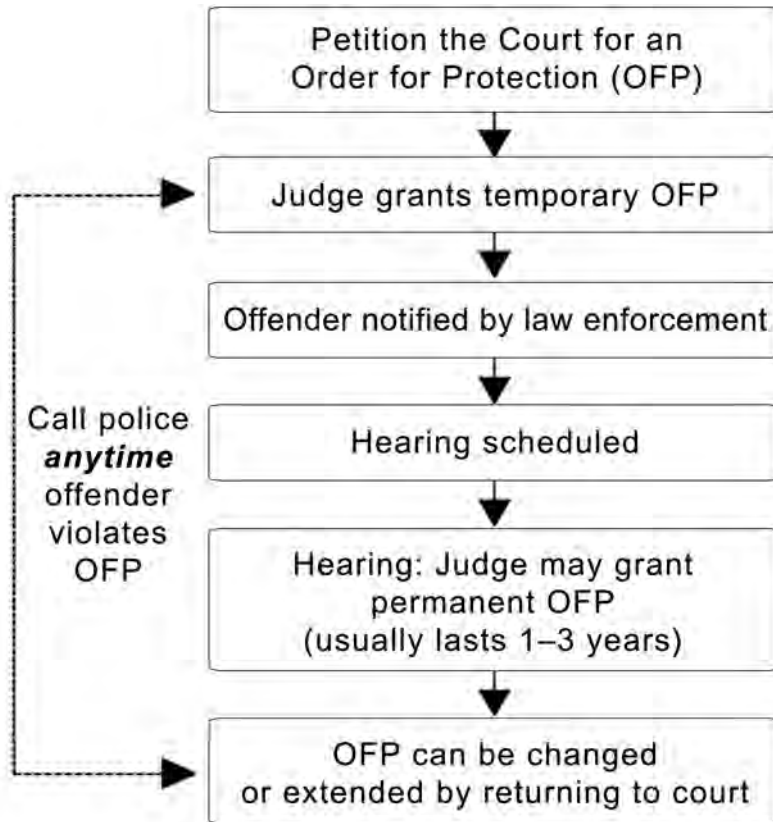


Figure 6.1. The general process for obtaining an Order for Protection (OFP). (Source: National Center for Victims of Crime. [2005]. *Orders of Protection*. Retrieved April 20, 2008, from <http://www.ncvc.org/ncvc/main.aspx?dbName=DocumentViewer&DocumentID=39538>)

A protective order is only effective if everyone does their part in enforcing the order. According to the National Center for Victims of Crime (NCVC, 2005), “the effectiveness of a protective order increases when the victim reports every violation—no matter how minor—to law enforcement” (p. 2). Research shows that a protective order that is not enforced may actually increase a victim’s risk for violence and additional abuse (NCVC, 2005).

Crime Victim Compensation Programs

State-sponsored **crime victim compensation** programs provide direct payment to or on behalf of victims of criminal offenses occurring in the state (including victims of federal crimes) for crime-related expenses (U.S. OVC, 2002; U.S. OVC, 2005). Violent crimes such as “homicide, rape, drunk-driving, domestic violence, and child sexual abuse and neglect” are covered (U.S. OVC, 2002, p. 1). Victims may be compensated for many types of crime-related expenses (see Table 6.5). However, property damage, theft and loss are usually not covered expenses “unless damage is to eyeglasses, hearing aids, or other medically necessary devices” under victim compensation programs (National Association of Crime Victim Compensation Boards [NACVCB], n.d., para. 4). When asked about covering the cost of replacing

Table 6.5. Compensated crime-related expenses

Medical costs and hospital care
Funeral and burial costs
Mental health counseling
Lost wages due to crime-related injury
Loss of support for dependents of a deceased victim
Replacement or repair of eyeglasses
Dental services and devices to repair injury to teeth
Prosthetic devices
Crime scene clean-up

Source: NACVCB, n.d.; U.S. OVC (2005).

a wheelchair, TTY, or other assistive device that was damaged or stolen as a result of a violent crime, the Executive Director of NACVCB responded

Crime victim compensation programs will cover the cost to purchase wheelchairs or other assistance devices if the victim is in need of those devices due to the injury from the crime. For example, if a victim was injured in a drunk driving crash and is now requiring the use of a wheelchair, the victim compensation program will cover that cost. However, if a wheelchair is stolen during a robbery/theft, victim compensation programs generally will not pay the replacement cost because the programs do not cover property crimes. However, some states have indicated that if the wheelchair was damaged or destroyed, absent an attack on the person, they would consider a wheelchair essentially as a part of the person, so it could be covered. If a wheelchair is damaged during an attack on the victim, most compensation programs would cover damage or replacement of the wheelchair, or other prosthetic device. It's always best to check with the compensation program in the state where the crime occurred. (Dan Eddy, personnel communication, October 1, 2008)

You should contact the agency in your state that provides victim compensation to find out the specific crime-related expenses covered. You can access compensation by contacting the victim compensation program in your state. Most compensation programs require victims to report crimes to the police within 3 days of the offense and to file a claim within a defined period of time, typically 2 years (U.S. OVC, 2005). In most states these time limits can be extended if good reason can be given. If victims have collateral sources ("other private or public programs, agencies, companies or other sources that will cover the same costs"), these sources must be used first before state programs compensate for the remainder of the loss (NACVCB, n.d., para. 7).

Final Thoughts About Victim Services

This chapter has covered a lot of information about victim services. Let's review a few key points.

- If you are a victim of a crime you have a right to an advocate. Ask for one.
- Every state has a victim's bill of rights and a crime victim compensation program.
- Every community has services for victims of sexual assault and domestic violence. Find out the availability of service for people with disabilities.

You should take some time to learn about the victim services in your area before you or someone you support needs them. Refer to the Resources at the end of the chapter to learn more.

VULNERABLE ADULT ADVOCACY AND PROTECTION SYSTEM

You have already read a little about adult protection services (APS) in earlier chapters. You may be less familiar with the other systems that deal with protecting vulnerable adults. Before you learn about the three main systems,



Ask Yourself...

What agency is responsible for responding to reports of abuse of vulnerable adults who live in private homes in my area?

What agency is responsible for responding to reports of abuse of vulnerable adults who live in long-term care facilities in my area?

Who would I call if I was concerned about the quality of care that I or someone with a disability was receiving?

Although the systems for protecting vulnerable adults vary from state to state, in general there are three types of vulnerable adult protection and advocacy services: 1) **adult protection services** (APS), 2) **long-term care ombudsman program** (LTCOP), and 3) **protection and advocacy** for individuals with disabilities. There may be other types of advocacy and protection services available in your area. The three types discussed in this chapter are available in every state.

Adult Protection Services

All 50 states have passed laws creating APS to serve victims of elder abuse, with most states also defining adults with disabilities as vulnerable adults under these laws (American Bar Association Commission on Law and Aging [ABA], 2005). The purpose of APS is to “insure the safety and well-being of elders and adults with disabilities who are in danger of being mistreated or neglected, are unable to take care of themselves or protect themselves from harm, and have no one to assist them” (National Center on Elder Abuse [NCEA], 2005, para. 1). State laws vary widely in the

- Age or circumstances that a victim is eligible to receive protective services
- Definitions and types of abuse covered
- Classification of abuse as criminal or civil
- Reporting requirements
- Investigation responsibility and procedures
- Remedies for abuse (ABA, 2005)

APS workers partner with local police in cases involving violation of criminal laws. APS provides an array of services beginning with receiving reports of abuse to monitoring the services received by vulnerable adults (see Table 6.6).

Table 6.6. Common services provided by adult protection services

---

Receive reports of vulnerable adult abuse
Investigate reports
Assess victim's risk
Assess victim's capacity to understand his or her risk and to give informed consent
Develop service plans
Arrange for emergency shelter, medical care, legal assistance, and supportive services
Monitor services

Source: NCEA (2005).

In some states, APS laws only pertain to domestic abuse (abuse in a private home) or to individuals who reside in the community. Some states have separate laws and systems for protecting vulnerable adults who live in long-term care facilities from **institutional abuse**. Other states include protection of adults in institutional settings under APS laws and services. To make this even more complicated, there are some states that have no separate institutional abuse law and cover protection of institutionalized vulnerable adults under the APS law. However, they have a separate state agency responsible for receiving reports and investigating reports of institutional abuse (ABA, 2005). You should contact the Attorney General's office in your state to learn about the laws and systems for protecting vulnerable adults in your area.

The **burden of proof** required to substantiate (prove) an allegation (claim or report) of abuse is far less than in the criminal justice system (see Figure 6.2). The standard used varies depending upon the state and investigating agency. APS may use the **preponderance of evidence** standard, which means that it is more likely than not that the abuse or neglect occurred. Offenders are not determined to be guilty or not guilty. Rather, after an assessment or investigation the outcome is classified using such terms as substantiated, unsubstantiated, founded, unfounded, or undetermined. The classification systems vary under state laws.

Long Term Care Ombudsman Program

LTCOP was created under the Comprehensive Older Americans Act Amendments of 1978 (PL 95-478). Every state has laws creating the LTCOP as a requirement for receiving federal money under the current Older Americans Act Amendments of 2006 (PL 109-365). An **ombudsman** is an advocate (National Long Term Care Ombudsman Resource Center [NLTCORC], 2001). The purpose of the LTCOP is to advocate on behalf of residents of long-term care facilities—such as nursing homes, board and care homes, and assisted living facilities—who experience abuse, violation of their rights, or other problems. The LTCOP also works on improving the overall quality of care provided in long-term care settings. When abuse is discovered the ombudsman reports the abuse to the appropriate authorities in the state, such as APS, the police, or the agency responsible for licensing and certifying long-term care facilities. In some states, the LTCOP also performs the APS role and has the legal authority to investigate and respond to institutional abuse (ABA, 2005).

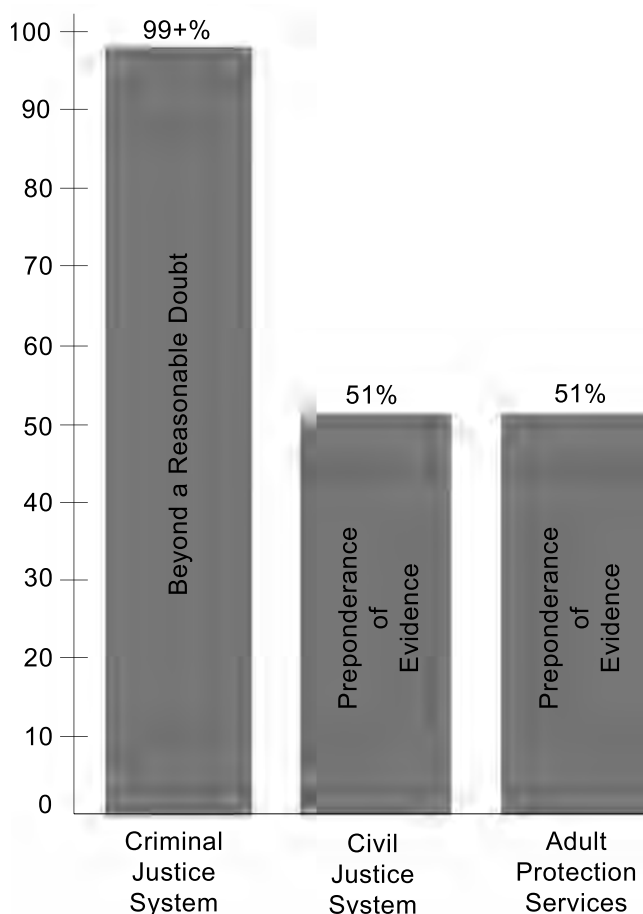


Figure 6.2. The burdens of proof in the criminal justice, civil justice, and adult protection systems.

Protection and Advocacy for Individuals with Disabilities

A **protection and advocacy (P & A)** agency is located in every state “to provide legal representation and other advocacy services, under all federal and state laws, to all people with disabilities” (National Disability Rights Network [NDRN], 2006, para. 1). The system of protection and advocacy is a national network of 57 disability rights agencies mandated under various federal laws. P & A agencies monitor, investigate, and attempt to get fixed poor conditions in facilities that care for people with disabilities. In addition, these agencies advocate for inclusive education, financial benefits for people with disabilities, affordable and accessible healthcare, accessible housing, and equal employment opportunities (NDRN, 2006). A closely related program is the **Client Assistance Program (CAP)**. CAP provides information and assistance to people seeking or receiving vocational rehabilitation services under the federal Rehabilitation Act (NDRN, 2006, para. 1). Many CAP agencies are located within P & A offices.

Final Thoughts About the Vulnerable Adult Advocacy and Protection System

You have just read a very basic overview of the protection and advocacy services that may be available to help you or the people with disabilities you know. Each state has a system for protecting vulnerable adults who live in private homes (domestic settings) or who live in some type of long-term care setting (e.g., group homes or nursing homes). You should take some time to learn about the systems in your area. Refer to the Resources at the end of the chapter to learn more.

CRIMINAL JUSTICE SYSTEM

The criminal justice system consists of four parts: law enforcement (commonly referred to as the police), prosecution, judiciary (the courts), and corrections. For many people, knowledge of how the criminal justice system works is based on what they see on television. And as you know, what is shown on television does not always reflect reality. In this section, you will learn the process that a criminal case goes through from reporting the crime to the police to sentencing an offender (see Figure 6.3). You will learn the definition of many legal terms that it will be

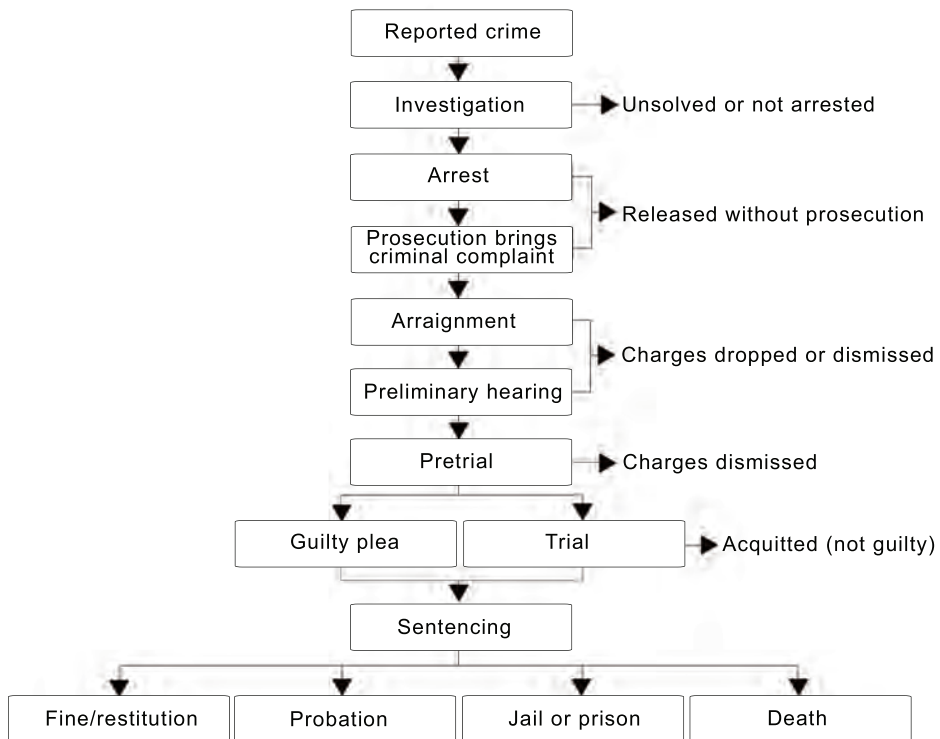


Figure 6.3. The general process through which a criminal case moves in the criminal justice system. (Source: Bureau of Justice Statistics. [2004, January 14]. *The justice system: What is the sequence of events in the criminal justice system*. Washington, DC: Bureau of Statistics, Office of Justice Programs, U.S. Department of Justice. Retrieved July 10, 2008, from <http://ojp.usdoj.gov/bjs/justsys.htm>)

helpful for you to know. As you read the chapter, remember that when the word **defendant** is used, it refers to the offender—the person who allegedly committed the crime. With the information provided you will be better able to advocate for yourself and others involved with the criminal justice system.

The criminal justice process begins after a crime is committed and is reported to the police (National Crime Victim Bar Association [NCVBA], 2007). **Crime** is defined as “a type of behavior that society has declared illegal and has decided to punish” (Hames & Ekern, 2006, p. 121). Some are crimes against property and some are crimes against people. Some behavior may be a crime (as in child sexual abuse) and some may not be a crime (such as verbal abuse) (NOVA, 2005). You should consult with police in your area to determine what is and is not considered criminal behavior in your state. Criminal offenses are considered crimes or offenses against the state (Hames & Ekern, 2006). The plaintiff in criminal cases is always some governmental representative. For example, the plaintiff would be “The People of the State of Minnesota” rather than the victim. The victim’s role is mainly as a witness for the state. The prosecutor makes decisions based upon what is in the best interest of the state, not the victim.

An investigation begins as soon as the police are aware that a possible crime has been committed. The police make an arrest once “enough evidence has been collected to establish probable cause” (Hames & Ekern, 2006, p. 409). **Probable cause** means “an officer has a reasonable basis for the belief that a person should be searched or arrested” (Hames & Ekern, 2006, p. 394). After an arrest is made the prosecuting attorney decides if and what charges will be filed against the defendant—the offender. The first document filed with the court is the **criminal complaint**, “a written statement explaining the significant facts of the case” (Hames & Ekern, 2006, p. 410). Usually within 24 hours of filing the criminal complaint, the defendant will have his or her initial appearance in court before a judge. At this initial appearance the defendant will be informed of the charges filed against him or her and notified of rights. The judge will decide if the defendant is eligible for release, and bail will be set if it is granted. Finally, a date will be set for the preliminary hearing.

At the **preliminary hearing**, usually held within 10 days from the initial appearance, the judge hears evidence to determine whether probable cause exists. In some jurisdictions, a grand jury indictment is required to determine whether or not probable cause exists. A **grand jury** is “a jury that is called upon to receive and review accusations and complaints in criminal matters” (Hames & Ekern, 2006, p. 621). If probable cause is not established, the defendant goes free. If probable cause is established, formal charges are filed either in the form of an **information**, defined as “an accusation made by a prosecutor,” or an **indictment**, defined as “a written accusation given by a grand jury” (Hames & Ekern, 2006, p. 418).

The next court appearance for the defendant is the **arraignment**. “At the arraignment, the charge is read and the defendant enters a plea” (Hames & Ekern, 2006, p. 418). A **plea** is the defendant’s “response to the charges” (Hames & Ekern, 2006, p. 407). Criminal defendants have three plea options: 1) not guilty, 2) guilty, or 3) nolo contendere. If a defendant pleads guilty, the prosecutor and the defendant’s attorney will discuss a **plea bargain**. Most criminal cases result in plea agreements.

If a defendant pleads not guilty, the case will proceed to trial. A **nolo contendere plea** means that the defendant neither admits guilt nor denies the charges (Hames & Ekern, 2006, p. 420). The court will treat this as a guilty plea. The advantage of a nolo contendere plea is that in most states the plea cannot be used against the defendant in a civil lawsuit, whereas a guilty plea can be used against the defendant.

The next steps in the process include formal **discovery** of the evidence, **pretrial motions** (e.g., motion to dismiss, motion for change of venue [location for the trial], motion to suppress evidence), and finally the actual trial (Hames & Ekern, 2006). In order to prove that the defendant is guilty of the charges, evidence is presented by the prosecuting attorney. The defendant's attorney will also present evidence to support the claim that his or her client is not guilty. Each state has an evidence code that spells out the rules of evidence.

There are several different types of **evidence**: testimony, actual, documentary, and demonstrative. Table 6.7 explains each of the four types. As a victim of a crime, you would be a lay witness who gives testimony about the crime. A lay witness is someone "who gives testimony about a subject of which [she or he] has personal knowledge" (Hames & Ekern, 2006, p. 427). In addition, evidence can be direct or circumstantial. Direct evidence is evidence that "actually proves a point" (Hames & Ekern, 2006, p. 432). The testimony of an eyewitness and a confession by a defendant are examples of direct evidence. Circumstantial evidence refers to "indirect evidence that provides the jury with information from which inferences may be drawn" (Hames & Ekern, 2006, p. 432). An inference "is a logical conclusion of a fact that is not supported by direct evidence" (Hames & Ekern, 2006, p. 432). Circumstantial evidence is more common than direct evidence.

The burden of proof in a criminal case is much higher than in a civil case or in a case investigated by APS (see Figure 6.2). You will learn about civil cases later in this chapter. In a criminal trial, the prosecutor will have to present enough evidence for the jury, or the judge in some cases, to find the defendant guilty **beyond a reasonable doubt** (Hames & Ekern, 2006). The **verdict** in a criminal case can either be guilty or not guilty (a not guilty verdict is sometimes referred to as an acquittal). If the jurors cannot all agree on a verdict, which is called a **hung jury**, then the judge declares a mistrial and the case can be retried in front of a new jury. The decision to retry or not is made by the prosecuting attorney's office. As a victim, you have very little say in the decision to retry. The defendant may appeal a guilty verdict. The case is closed if the jury gives a not guilty verdict.

Table 6.7. Types of evidence

Type	Explanation
Testimony	Evidence that is delivered under oath, either orally or by affidavit [sworn statement], by a competent witness.
Actual	Tangible [real, touchable] items that could be admitted into evidence, such as a weapon used in a crime.
Documentary	Writings such as reports, business records, and correspondence.
Demonstrative	A type of actual evidence or exhibits created for use in court, [including] diagrams, charts, and photographs.

Source: Hames and Ekern (2006, pp. 427, 429).

When a defendant is found guilty, the court will give some sort of punishment, such as a monetary fine, imprisonment, and/or **probation** (release to the community with conditions) (Hames & Ekern, 2006). The money collected from fines goes to the state, not to victims. In some cases the criminal court may order the offender to pay restitution to the victim. **Restitution** is the “reimbursement of certain expenses incurred by a victim, or persons who have become responsible for the maintenance and support of a victim as a result of a crime” (NCVBA, 2007, p. 2). According to the NCVBA, even when the court orders restitution, lack of enforcement in collecting the money and limitations on the type of damages that can be awarded result in restitution not meeting the needs of victims.

Final Thoughts About the Criminal Justice System

You have just read a pretty straightforward description of the process from reporting a crime to sentencing an offender. Hopefully you have enough information to feel knowledgeable about the system without being confused or feeling overwhelmed. Knowing this information should help you to feel empowered to advocate for yourself or for someone you support who has been a victim of a crime. Let’s review a few key points that you should remember:

- First and foremost, ask for a victim advocate to help you (or the person you know) understand the process and provide support as the case works its way through the criminal justice system. Keep in contact with your advocate throughout the process.
- Decisions are made by the prosecutor’s office based on what is in the best interest of the state, not necessarily in the best interest of the victim.
- Be aware that the process can take a very long time.
- Ask to see your victim or **witness statement** before giving testimony evidence to help you recall the details of the crime.

You are aware of some of the barriers for people with disabilities in the criminal justice system. Advocacy and self-advocacy will be needed to ensure that people with disabilities receive equal justice under the law. Let’s move on to looking at the last system—the Civil Justice System.

CIVIL JUSTICE SYSTEM

Crime victims have the right to file a **civil lawsuit** seeking financial compensation (payment) from the offender or from a third party whose conduct created conditions that allowed a crime to occur (NCVBA, 2007). Before you read more about the civil justice system,



Ask Yourself...

Do I know anyone who has filed a civil lawsuit to receive financial compensation for a crime committed against them? If so, what was the outcome?

Do I know that in some cases people with disabilities who have been abused have the right to file civil lawsuits?

The Civil Justice System, through the filing of a civil lawsuit, provides the opportunity for victims of certain offenses to sue offenders and those third parties who are indirectly responsible for the crime for financial compensation (payment). An example of a third-party defendant is a disability service provider that did not properly check the backgrounds of employees or transferred employees to other locations following allegations of abuse that were not reported and investigated. A **tort** is the term used in civil cases to refer to the “wrongful act” (NCVBA, 2007, p. 9). The situations in which a civil lawsuit may be filed include: assault, battery, wrongful death, false imprisonment, intentional or reckless infliction of emotional distress, fraud, or negligence (NCVBA, 2007).

It is important to understand that differences exist between the civil and criminal justice systems. According to the NCVBA (2007),

The civil justice system does not attempt to determine the innocence or guilt of an offender. Offenders are not put in prison. Rather, civil courts attempt to determine whether an offender or a third party is liable for the injuries sustained as a result of the crime. A civil court’s finding of liability usually means the defendant must pay the victim, or the victim’s family, monetary damages. (p. 4)

One of the other important differences is the burden of proof—*preponderance of evidence*—is far less than in the criminal justice system (see Figure 6.2). In addition, civil cases do not require a unanimous verdict by the jury (Hames & Ekern, 2006). The required number of jurors needed to obtain a liable verdict varies under states’ laws. Because the burden of proof is far less in a civil case, it is possible for an offender to be found not guilty in the criminal justice system, but **liable** in a civil case (NCVBA, 2007). There are also time frames or *statutes of limitations* in which a civil lawsuit can be filed. The time frames vary depending upon the state and the particular case.

The civil process begins by getting an attorney to represent the victim (see Figure 6.4 for a flow chart of the civil lawsuit process). You can contact the National Crime Victim Bar Association for a referral to an attorney in your area. The attorney will ask detailed questions about the crime, offender, and damages sustained by the victim (NCVBA, 2007). Usually attorneys represent victims on a **contingency fee basis**, meaning the attorney is only paid if the victim is awarded a monetary settlement (NCVBA, 2007). Victims may be responsible for paying court costs such as filing fees and deposition fees. Some attorneys require the victim to pay a **retainer fee**, money kept in a special account to cover costs related to the case (NCVBA, 2007). Unused money is returned to the victim at the conclusion of the civil suit.

The victim’s attorney begins the civil case by filing a **complaint**, or a document with the court, on behalf of the **plaintiff**, or victim, which “sets out the facts of the case and the legal claims being made” (NCVBA, 2007, p. 11). If needed to protect the victim, the privacy of victims can be protected by filing suits under pseudonyms (false names), obtaining confidentiality agreements with the defendant, filing cases under seal or closed to the public, and recording videos of depositions (NCVBA, 2007).

The defendant’s attorney then issues their response, called the **answer**. The legal process of **discovery** involves the plaintiff and the defendant’s attorneys investigating the facts of the case, interviewing witnesses, obtaining significant

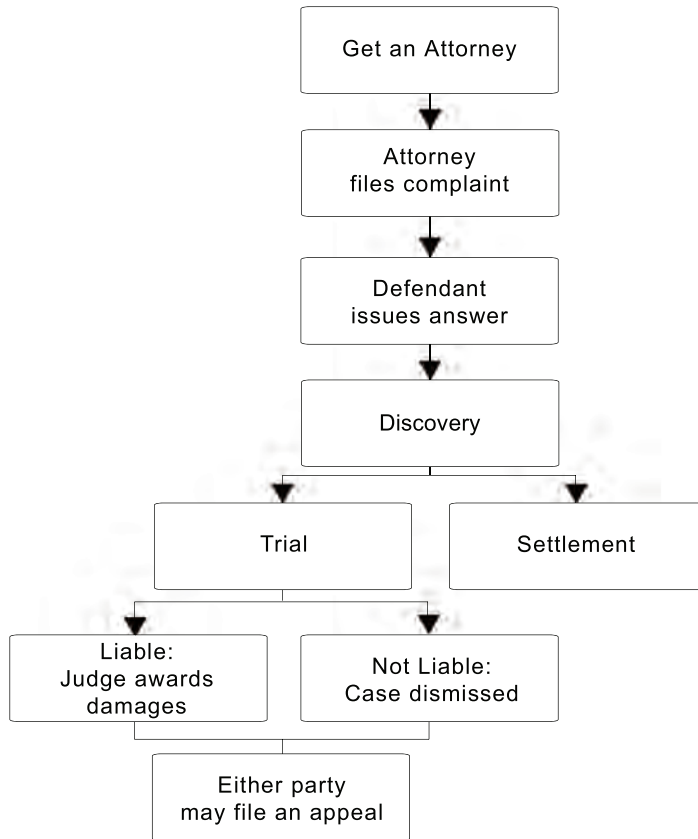


Figure 6.4. The general process through which a civil lawsuit moves in the civil justice system. (Source: National Crime Victim Bar Association. [2007]. *Civil justice for victims of crime*. Washington, DC: Author. Retrieved April 20, 2008, from <http://www.victimbar.org/vb/AGP.Net/Components/documentViewer/Download.aspx?DocumentID=43749>)

documents, and obtaining depositions under oath from victims, witnesses, and defendants (NCVBA, 2007). A **deposition** is “the testimony of a witness, given under oath, outside the courtroom and taken before a court reporter” (Hames & Ekern, 2006, p. 620). If a settlement cannot be agreed to by both parties the case will proceed to a judge or jury trial.

At trial the plaintiff must prove his or her case by a *preponderance of the evidence*, meaning that it is more likely than not that the wrongdoing occurred. If the plaintiff wins, the judge or jury will award damages. There are two types of damages that can be awarded by judges or juries, compensatory and punitive:

- **Compensatory damages** “pay for the losses suffered by the injured party”
- **Punitive damages** “punish and deter criminals or third parties” (NCVBA, 2007, p. 13)

If the defendant is found not liable, the case is dismissed. Either party may file an appeal. Occasionally offenders may also sue or countersue victims for defamation or slander (saying something that is not true that damages a person’s reputation) (NCVBA, 2007).

Final Thoughts About the Civil Justice System

Filing and winning a civil lawsuit can be a very empowering experience for people with disabilities who have been abused. Victims get to tell their story in a public forum. A *liable* verdict means that the offender is held responsible for causing pain and suffering and is made to pay for his or her actions. One of the limitations of the civil justice system is actually getting the money awarded by the court from the offender. It is easier to collect from third-party defendants such as long-term care facilities than it is to collect from individual offenders. Despite this limitation, the civil justice system is an important system for people with disabilities who are abused to obtain justice under the law.

Before you complete the next Learning Activity, take a look at the overview of the system in Table 6.8. Make sure that you are clear about when to use each

Table 6.8. Overview of the system

System	Use when
Victim services system	You need to know your rights as a crime victim. <i>Call your state's Attorney General's office.</i> You need someone to help you as your case gets prosecuted in the criminal justice system. <i>Get a victim advocate through your local police or prosecutor's office.</i> You need help dealing with domestic violence. <i>Call your local domestic violence shelter.</i> You need help getting an order for protection (OFP). <i>Call your local domestic violence shelter, sexual assault services provider, or legal aid office.</i> You need help dealing with a sexual assault. <i>Call your local sexual assault services provider.</i> You need to be compensated for crime-related expenses. <i>Call your state's crime victims compensation program.</i>
Vulnerable adult advocacy and protection services system	You are a vulnerable adult who is being abused and need protection and services. <i>Call your local adult protection services (APS).</i> You live in a long-term care facility and are being abused or having your rights violated. <i>Call your state's long-term care ombudsman.</i> You live in a long-term care facility that is providing poor services. <i>Call your state's protection & advocacy (P & A) agency.</i> You are being denied your rights in education, financial benefits, healthcare, housing, or employment. <i>Call your state's P & A agency.</i>
Criminal justice system	You believe you have been a victim of domestic violence, sexual assault, financial exploitation, or other crime. <i>Call the police.</i> You want a judge to grant you an OFP. <i>Work with your local domestic violence shelter, sexual assault services provider, or legal aid to get your petition before the court.</i> You need to report a violation of an OFP. <i>Call the police.</i> You want an offender criminally prosecuted for the abuse or other crimes perpetrated against you. <i>The prosecuting attorney decides if criminal charges are going to be filed and if the case is going to be prosecuted.</i>
Civil justice system	You want to sue an offender for financial compensation for the abuse or other crime. <i>Call an attorney in your area who handles civil lawsuits.</i> You want to sue a third party (e.g., a long-term care facility or disability service provider) that you believe is indirectly responsible for the abuse or other crime being perpetrated against you for financial compensation. <i>Call an attorney in your area who handles civil lawsuits.</i>

system and whom you should contact. Let's apply what you have learned about all of the systems to Joyce, Henry, and June's stories.

LEARNING ACTIVITY

➡➡➡ **Using The Systems**

➡➡➡ **Joyce's Story**

Once again review Joyce's Story (refer to 85 for more details). Think about the systems that could help Joyce.

Joyce is a woman with multiple sclerosis who met her husband while they were in college. The domestic violence began after they were married. The verbal abuse escalated into physical assault and psychological abuse. He threatened to get sole custody of their children if she tried to leave him or report the abuse.

Review the checklist of systems in Figure 6.5. Place an X next to all of the systems that you think Joyce could use to get out of the abusive relationship and to protect herself and her children. Think about which system Joyce should call first for help. After reading Henry's and June's stories, revisit the checklist. After reading Henry's and June's Stories, revisit the checklist.

Thoughts About Joyce's Story

Remember the personal barriers that you thought applied to Joyce's story? You know that fear of retaliation and fear of losing custody of her children, along with some of the other personal and systemic barriers, might make it less likely that Joyce would call the police for help. You also know that not all domestic violence shelters readily accommodate the needs of women with disabilities. However,

	Joyce	Henry	June
Crime victim advocate	—	—	—
Domestic violence shelter	—	—	—
Sexual assault service provider	—	—	—
Crime victim's reparation agency	—	—	—
Adult protection services	—	—	—
Long-term care ombudsman	—	—	—
Protection and advocacy agency	—	—	—
Criminal justice system	—	—	—
Civil justice system	—	—	—

Combating Violence and Abuse of People with Disabilities: A Call to Action by Nancy M. Fitzsimons. Copyright © 2009 Paul H. Brookes Publishing Co., Inc. All rights reserved.

Figure 6.5. Checklist for choices of systems.

despite this possible barrier, Joyce would benefit from contacting her local domestic violence shelter. Joyce and her children could receive shelter. She would get support in reporting the abuse to the police. She would also get help in getting an OFP. The shelter could help Joyce deal with her immediate need to be safe, provide counseling to help her deal with the trauma of being abused, and help her plan for her short-term and long-term future. Refer to the answer sheet on pages 185 and 186 for more thoughts about the systems that could help Joyce.

Henry's Story

Read Henry's Story. You first read about Henry's story in Chapter 3. Think about the systems that could help Henry.

Henry is a 52-year-old man who is legally blind. He lives in his own home. Henry recently had hip replacement surgery. He has a home care provider named Cheryl who visits him four times a week to assist with personal care and house-keeping tasks. One day when Cheryl was emptying the kitchen wastebasket she found an empty liquor bottle, beer cans, and cigar butts. Later, when Cheryl was helping Henry with his bath she noticed bruises on his upper arms. When Cheryl asked Henry about the bruises, he made up an excuse about bruising easy. Cheryl also discovered that there was little food in the house. She learned that Henry was short of money because he had given money to his son who recently lost his job. When Henry's son arrived at the home he got angry that Cheryl was there. He called Henry a "blind idiot" and yelled at his father for letting strangers in the house. Henry appeared frightened and told Cheryl that she could leave early. Henry's son stormed downstairs, stating he was going to get a beer and watch television. Henry assured Cheryl that he was fine and that his son was just under a lot of stress.

Refer to the checklist of systems in Figure 6.5. Place an "X" next to all of the systems that you think Henry could use to protect himself from his abusive son. If you were Cheryl, which system would you call to report possible abuse?

Final Thoughts About Henry's Story

You've already read about how in U.S. society men are expected to be able to defend themselves. Men who do not live up to society's expectations may feel ashamed or blame themselves for the abuse. Henry was clearly afraid of his son, but he was not willing to tell his care provider what was really going on. He may have been embarrassed or he possibly felt some responsibility for his son. Cheryl has every reason to suspect that Henry is being abused by his son. Henry is probably considered a vulnerable adult under state law. As a mandated reporter Cheryl is required to report her suspicion to APS. APS is responsible for ensuring Henry's safety and providing services. The police are responsible for investigating to determine whether a crime has been committed and whether there is probable cause to arrest Henry's son. Refer to the answer sheet on page 186 for more thoughts about the system that could help Henry.

June's Story

You are now quite familiar with June's story. Review a few details of June's story. Think about the systems that could help June and the other people who live at the residential facility.

June is a 37-year-old woman who has a moderate intellectual disability. She was repeatedly sexually assaulted while living in an institution for people with intellectual disabilities. June's sister and parents reported their suspicion that she was being sexually assaulted to the administrators at the institution. The first and all additional reports of sexual assault made to administrators at the institution were ignored. Thirteen years after the first report, officials from the institution finally acknowledged that June had been sexually assaulted by the suspected staff member. The offender confessed to sexually assaulting June and 15 other female residents at the institution.

Refer to the checklist of systems in Figure 6.5. Place an X next to all of the systems that you think should be involved to help June and to protect the other residents of the institution from violence and abuse.

Thoughts About June's Story

Clearly the system failed June. June needs services to help her deal with and heal from the trauma of being repeatedly sexually assaulted. You know that not all sexual assault service providers and mental health service providers know how to adapt their services to meet the needs of people with intellectual disabilities. However, despite this possible barrier, June needs professional help to heal from the abuse. The police, prosecuting attorney, and judge all play important roles in making sure that the abuser is held criminally responsible for sexually assaulting June and 15 other women at the institution. The vulnerable adult advocacy and protection system needs to get involved to hold the institution responsible for failing to protect June and other residents at the institution and to work to fix the system. June's parents can and should file a civil lawsuit on behalf of their daughter against the institution for repeatedly failing to protect June. Refer to the answer sheet on page 187 for more of the author's thoughts about the systems that could help June.

FINAL THOUGHTS

Not understanding the systems that protect and serve victims of abuse is a major barrier to preventing violence and abuse. You should now have a much better understanding of the systems. Your next step is to learn about the specific laws, rights, agencies, programs, and services in your area. Refer to the Resources listed at the end of this chapter. Take some time to research the systems in your area that you or someone you know with a disability can call to help stop and prevent future abuse. Fill out the *My Safety Network Resources Worksheet* in Appendix A (see pp. 179–181). Make several copies of your *My Safety Network Resources Worksheet*. Put them in places that are safe and easily available for you or someone else to access.

It is time to move on to learning about some specific strategies and skills for preventing violence and abuse. In the next chapter you will learn about ways that you can empower and protect yourself. This information should be shared with people with disabilities you know so that they can be proactive in preventing violence and abuse.

RESOURCES

Suggested Readings

The Office for Victims of Crime (OVC) has many publications and videos dealing with victim issues, including

- *Enforcement of Protective Orders*, September 2006
- *State Crime Victim Compensation and Assistance Grant Programs*, April 2004
- *What You Can Do If You Are a Victim of a Crime*, April 2002

Go to the OVC web site to review these and other publications, <http://www.ojp.usdoj.gov/ovc/publications>

The National Center for Victims of Crime (NCVC) has a *Get Help* series that provides a wide array of information on crime victim issues, including

- *Constitutional Rights for Crime Victims*, 1999
- *Overview of the Criminal Justice System*, 1997
- *Rights of Crime Victims*, 1999

Go to the NCVC web site to download these and other publications, <http://www.ncvc.org>

Additional Resources

Civil Justice for Crime Victims (NCVBA, 2007), http://www.ncvc.org/vb/main.aspx?dbID=DB_VictimsInfo126

How to Get Help After a Victimization (NOVA, 2005), <http://www.trynova.org/victiminfo/victimizationhelp>

The Justice System: What is the sequence of events in the Criminal Justice System (U.S. Bureau of Justice Statistics Office of Justice Programs, [n.d.]), <http://www.ojp.gov/bjs/justsys.htm>
When to Call Your State P & A/CAP (National Disability Rights Network, [n.d.]), <http://www.ndrn.org/aboutus/pwd.htm>

National Victim, Advocacy, and Legal Organizations

Abused Deaf Women's Advocacy Services (ADWAS), 1-206-726-0093 (TTY only*), 1-206-236-3134 (24-hour TTY crisis line), <http://www.adwas.org>

National Adult Protection Services Association, 1-217-523-4431, <http://www.apsnetwork.org>
 (Provides a web link for each state to report abuse.)

National Association of Attorneys General, 1-202-326-6000, <http://www.naag.org>

National Association of Crime Victim Compensation Boards, 1-703-780-3200, <http://www.nacvcb.org>

National Center for Victims of Crime (NCVC), 1-800-FYI-CALL (1-800-394-2255), 1-800-211-7996 (TTY), <http://www.ncvc.org>

National Center on Elder Abuse, 1-302-831-3525, <http://www.ncea.aoa.gov>

National Clearinghouse on Abuse in Later Life, 1-608-255-0539, <http://www.ncall.us>
 National Coalition Against Domestic Violence, 1-303-839-1852, 1-303-839-1681 (TTY), www.ncadv.org
 National Disability Rights Network (Protection and Advocacy for Individuals with Disabilities), 1-202-408-9514, 1-202-408-9521 (TTY), <http://www.ndrn.org> (Provides a web link to contact each state's P&A.)
 National Domestic Violence Hotline, 1-800-851-SAFE (7233), 1-800-787-3224 (TTY)
 National Fraud Information Center, 1-800-876-7060 (Hotline), <http://www.fraud.org>
 National Long Term Care Ombudsman Resource Center, 1-202-332-2275, <http://www.ltcombudsman.org>
 National Organization for Victim Assistance (NOVA), 1-800-TRY-NOVA (1-800-879-6682), 703-535-6682 (general information), <http://www.trynova.org>
 National Resource Center on Domestic Violence, 1-800-537-2238, <http://www.nrcdv.org>
 National Sexual Assault Hotline, 1-800-656-HOPE (4673); online hotline at rainn.org
 National Sexual Violence Resource Center, 1-877-739-3895, 1-717-909-0715 (TTY), <http://www.nsvrc.org>
 National Victims' Constitutional Amendment Passage (NVCAP), 1-800-529-8226, <http://www.nvcap.org>
 Office for Victims of Crime (OVC), 1-800-851-3420, 1-877-712-9279 (TTY), <http://www.ojp.usdoj.gov/ovc> (Provides a web link to contact each state's Victim Assistance and Compensation Programs.)
 Rape, Abuse and Incest National Network (RAINN), 202-544-3064 (general information), <http://www.rainn.org>
 The National Crime Victim Bar Association, 1-800-FYI-CALL (attorney referral), <http://www.ncvc.org>



Empowering People with Disabilities to Prevent Violence and Abuse

with Dorothy Bell Wagner

WSU's Developmental Disabilities Institute
receives grant to fight abuse of women with disabilities

Michigan Chronicle, Detroit, Michigan, February 23–March 1, 2005, p. A3

In this newspaper story it was reported that Wayne State University's Developmental Disabilities Institute was awarded an \$85,000 2-year grant to implement and evaluate a program to prevent abuse of women with disabilities. An earlier grant was received from Blue Cross/Blue Shield of Michigan Foundation to study the problem. According to Sharon Milberger, Associate Director of the Developmental Disabilities Institute, "Now, thanks to the foundation, we are able to build on this base of knowledge and systematically combat this serious problem" (p. A3). The proposed program consisted of conducting training sessions on safety to 150 adolescents and women with physical disabilities throughout 28 counties in lower Michigan.

The project described in the newspaper story demonstrates the importance of moving beyond understanding the problem—to providing people with disabilities with the information and skills they need to prevent violence and abuse. The project is one community's effort to break down the barriers that perpetuate violence toward and abuse of people with disabilities. Recall that **prevention** is used to refer to reducing the risk for violence and abuse. Prevention decreases the likelihood that someone will be abused; however, it does not eliminate the risk. Conducting training sessions on personal safety is one way to help empower people with disabilities to prevent abuse and be in greater control over their lives.



Ask Yourself...

What information and skills do I have to help prevent me from being abused?

What information and skills do I or people with disabilities I know need to learn to prevent abuse?

OVERVIEW OF THE ISSUE

Each of us needs information and skills to keep ourselves safe (or as safe as is possible) and the opportunity to practice and master the skills to the best of our abilities. Education and training, whether provided at home, at school, or by victim, disability, law enforcement, or other service provider organizations, is a key part of abuse prevention. Violence and abuse prevention training areas recommended for people with disabilities include

- Personal safety
- Individual rights
- Assertiveness
- Effective communication
- Social skills
- Sex education
- Interpersonal and intimate relationships
- Hiring and managing care providers

There are training materials available, some specifically created for people with disabilities, to learn about abuse prevention. The specific curriculum and methods of teaching may need to be adapted to meet the learning needs of training participants. The information and skills can be taught one on one, in small groups, or in larger workshops. What is most important is that the delivery method meets your needs or the needs of the people you support.

In this chapter you will learn about four areas of violence and abuse prevention: 1) assertiveness, 2) healthy, mutually respectful interpersonal and intimate relationships, 3) personal safety, and 4) hiring and managing care providers. A person with a disability needs this information to protect him- or herself and prevent abuse. A person without a disability can also use this information to protect him- or herself and prevent abuse and to share with people with disabilities. Think about the ways that this information can be used in individual and collective action to combat violence and abuse in the community. Let's begin with looking at assertive behavior and communication.

ASSERTIVENESS

Assertive behavior is "to act on your own best interest, to stand up for yourself without undue anxiety, to express honest feelings comfortably, to exercise your personal rights without denying the rights of others" (Alberti & Emmons,

2001, p. 6). The ability to be assertive is an essential skill needed to prevent violence and abuse. Think of people you know who appear sure of themselves and assertive.

Ask Yourself...

How do assertive people act or behave?

How do I know that a person is assertive?

Now think about yourself and a time that you were assertive.

Ask Yourself...

How did I act or behave?

How did I feel about myself?

Did I achieve my goal or the outcome that I wanted?

There is one more question to think about before you learn more about assertiveness.

Ask Yourself...

Why is the ability to be assertive an essential skill needed to prevent violence and abuse?

You already know about the connection between power and control and abuse. Care providers may use their power to control people with disabilities. The following quote highlights the importance of assertiveness in preventing abuse: "Assertiveness is a tool for making your relationships more equal" (Alberti & Emmons, 2001, p. 5). Abuse is less likely to occur when relationships are based on mutual respect and equality. *Mutual respect* refers to each person in a relationship being valued and treated with dignity.

There are three basic styles that people use to interact with one another: Assertive, Passive (sometimes called submissive or nonassertive), and Aggressive. Take a look at Table 7.1 to learn about each of the behavioral styles. Now,

Ask Yourself...

Which type of behavioral style best fits me?

Perhaps you are still not quite sure which behavioral style best fits you.

Ask Yourself...

Are there certain people, places, or situations with which I am most comfortable being assertive?

Are there certain people, places, or situations with which I use a passive behavioral style?

Are there certain people, places, or situations with which I use an aggressive behavioral style?

Table 7.1. Assertive, passive, and aggressive behavioral styles for interacting with others

Assertive	Passive	Aggressive
Knows what one wants	Lets others get what they want	Knows what one wants
Uses “I messages” to clearly communicate wants, needs, thoughts, and feelings while respecting others’ wants, needs, thoughts, and feelings	Denies own rights in favor of those of others Avoids or accommodates others to excess	Uses “you messages” to demand, control, manipulate, humiliate, put down, and minimize others’ worth
Stands up for legitimate rights without bullying others or being bullied by others	Lets other make decisions Seldom gets what one wants	Denies rights of others in favor of own rights
Does not demand rights at the expense of others’ rights	Fails to express wants, thoughts, and feelings or does so indirectly	Lacks respect for the wants, needs, thoughts, and feelings of others
Tries to negotiate a win–win situation	Hopes others will be nice Creates a lose–win situation	Creates a win–lose situation Stops at little to get what one wants
May achieve desired goal	Does not achieve desired goal	Achieves desired goal by harming others

Sources: Alberti and Emmons (2001), Chambers Clark (2000), Havelin (2000), Schlebusch (2000), Smith (2002).

The ability to be assertive can depend on the person you are interacting with, the place, or the situation. No one is assertive all the time. Let’s move on to learning about the components of assertiveness.

Components of Assertiveness

The first component of assertiveness is the belief that you have rights and that you have the skills to be assertive. Take a look at the *Bill of Assertive Rights* and read it out loud (see Table 7.2).



Ask Yourself...

- Do I believe in my right to be assertive?*
- Do I believe that the people with disabilities whom I support have the right to be assertive?*

An important part of being assertive is having the right attitude. People who are assertive show their assertiveness to others in verbal and nonverbal ways. Let’s begin with the verbal parts of assertiveness.

Table 7.2. Bill of Assertive Rights

1. I have the right to be treated with dignity and respect.
2. I have the right to not feel guilty for asserting my rights.
3. I have the right to say no.
4. I have the right to express my feelings, even those others might not approve of.
5. I have the right to change my mind.
6. I have the right to ask for help to achieve what I want.

Source: Smith (2002, p. 164).

Verbal Components of Assertiveness The verbal parts of assertiveness are tone of voice, inflection, volume, and fluency (Alberti & Emmons, 2001; Brain Injury Resource Center [BIRC], 1998). Let's look at each verbal part of assertiveness.

- *Tone of voice* refers to the pitch or sound of your voice, such as harsh, soft, angry, or whiny.
- *Inflection* refers to how you emphasize or the way you deliver the words you speak, such as monotone (unchanging tone) or emphasizing certain parts of a word.
- *Volume* refers to the loudness with which you speak.
- *Fluency* refers to the flow and rate (or pace) of your speech.

When you are being assertive, you speak in a conversational way without being intimidating. You want to speak clearly and slowly enough to be understood without long pauses. When you are being assertive, you are aware of and in control of how you are speaking.

Nonverbal Parts of Assertiveness Nonverbal parts of assertiveness are eye contact, body posture, distance/physical contact, gestures, and facial expression (Alberti & Emmons, 2001; BIRC, 1998). As you read about the nonverbal parts of assertiveness, remember that there are cultural differences that influence nonverbal ways of behaving assertively and communicating.

- *Eye contact.* In general you want to look at or toward the other person, without staring, as a way "to show interest and respect for the other person and to improve the directness of your message" (Alberti & Emmons, 2001, p. 56).
- *Body posture.* Stand or sit up straight (if possible) facing toward the other person. Do not sit if the other person is standing. If you are unable to stand, ask the other person to sit to maintain a more equal balance of power. If possible, lean forward slightly to communicate interest. Keep your arms and legs uncrossed to convey a relaxed, open attitude.
- *Distance and physical contact.* Maintain a distance that is comfortable for you and for the other person. You will know if you are getting too close if the other person backs away. Standing or sitting too close may offend the other person, make them uncomfortable, or invite greater intimacy than you want.
- *Gestures.* Gestures (body movements) can help you emphasize the important points of your message. Be careful not to use a gesture that could be perceived as threatening or offensive. For example, raising your arms while making a fist with your hands could intimidate (frighten, scare) others.
- *Facial expression.* Be in control of your facial expression. Try to make your face match your words.

Control over the nonverbal parts of assertiveness takes practice. Later in this chapter you will learn ways to practice verbal and nonverbal assertiveness skills. There are three more parts of assertive behavior that you need to know about: timing, content, and listening (Alberti & Emmons, 2001). Let's start with timing.

Timing *Timing* refers to when you choose to express your feelings and deal with a situation. It is usually best to express yourself in the moment rather than waiting until the situation has passed (Alberti & Emmons, 2001). However, there may be times when you are not prepared to assert yourself in the moment. That is okay. There may be times when it is best to wait to have a discussion. If someone is clearly angry or behaving in a violent, out-of-control, or unpredictable way, it is probably best to wait until a later, safer time to talk. You may also choose to wait until you can find a place and a time to have a conversation in private.

Content *Content* has to do with what you actually say. Try to choose your words carefully. One of the characteristics of assertive behavioral styles for interacting with others is using “I messages” or “I statements” (Hughes & Abramson, 2000). When you use “I statements” you are taking ownership for what you are thinking and feeling. Using “I statements” helps you to avoid putting the other person down and saying hurtful things that you later might regret saying. For example, instead of saying, “Can’t you ever pick me up for work on time? Don’t you ever think of anyone but yourself? You’re the most selfish person I have ever met!” you might use assertive communication, saying something like “I’m feeling really frustrated that you are often late picking me up for work. My job is really important to me. I’d like things to be different in the future. I’m hoping we can figure out how to fix this problem.”

Now imagine the verbal and nonverbal communication that is likely to go along with each of the two statements.



Ask Yourself...

Which statement is more likely to result in a positive outcome to the situation?

The second statement is an example of assertive communication and is more likely to lead to a positive outcome for both people involved.

Active Listening All of the parts of assertive behavior have focused on how you communicate. However, according to leading scholars on assertive behavior, listening may be the most important component of all (Alberti & Emmons, 2001, p. 61). **Active listening**, also referred to as *assertive listening* and *empathic listening*, involves tuning in and focusing all your attention on the other person, paying close attention to the other person’s message, and “actively attempting to understand before responding” (Alberti & Emmons, 2001, p. 62). Let others know you are interested in what they say by giving the person your full attention, leaning forward slightly to create interest, and using words that show your interest (BIRC, 1998) (see Tip Box 7.1). Also check to make sure that you have understood the other person by summarizing what you hear and asking if you are understanding correctly (BIRC, 1998) (see Tip Box 7.2). Active listening is easier said than done. It takes time, practice, and a desire to become a skillful listener.

Learning Assertiveness

You should have a pretty good understanding of the basics of assertive behavior and communication. Hopefully you have begun to assess your own skills and

Tips for communicating your interest in the thoughts and feelings of others

- I'd like to hear your views on...
- Would you tell me more about how you see the situation?
- I'd like to hear your thoughts on...
- Help me understand this from your point of view.

Source: Brain Injury Resource Center (BIRC; 1998, para. 4).

TIP BOX 7.1**Tips for checking for understanding**

- If I understood you correctly...
- Are you telling me that ...?
- I heard you say _____, did I understand you correctly?
- Your view is _____, is that right?

Source: BIRC (1998, para. 6).

TIP BOX 7.2

comfort with being assertive. There are many ways that you can improve your own ability to be assertive or the assertiveness of people with disabilities you support. Consider trying some of the following strategies:

- *Mirror practice.* Practice speaking in front of a mirror. Pay attention to your facial expression, body posture, and the fit between your words and gestures.
- *Audio practice.* Make an audio recording of yourself speaking. Play the recording and pay attention to your verbal communication. Listen for "I statements." Ask someone you trust to listen to the recording and give you feedback.
- *Video practice.* Make a video recording of yourself speaking. Play the video and pay attention to your verbal and nonverbal communication. Listen for "I statements" and watch your gestures. Ask someone you trust to watch the video and give you feedback.
- *Role play with others.* Role play different versions of how a conversation that you want to have with another person might go. Have your role-play partner respond to you in different ways so that you can practice being assertive.
- *Imagine a scene in your mind.* Imagine yourself having the conversation with another person using your best assertiveness skills.

In all of the practice options, you can create a fictional (made up) situation or use a real-life situation to improve your skills or to prepare for an actual conversation.

Assertiveness and Preventing Violence and Abuse

The most effective self-advocates and advocates use assertiveness to achieve their goals. Knowing your rights is not enough. You need to be able to assert yourself in order to make sure that your rights, including your right to live free from violence and abuse, are upheld. Assertiveness may help you or someone with a disability you know to

- Obtain abuse prevention education and training
- Create and maintain nonviolent, mutually respectful relationships with partners, family, friends, professionals, and others
- Identify, correct, and if need be, end harmful relationships with partners, family, friends, and professionals
- Obtain the supports and services needed to live according to your own preferences
- Ensure that your rights and the rights of others are not violated
- Successfully use the system to receive the supports, services, and equal justice entitled to all victims of abuse
- Through individual or collective action change systems to make them more responsive to the needs of people with disabilities

Let's apply what you have learned in a learning activity.

LEARNING ACTIVITY

Recognizing Styles for Interacting with Others

Read the scene involving Christopher and Lisa (personal assistant). Think about Christopher's options for handling the situation. Read each of the three examples of how Christopher could respond to Lisa. Identify the assertive response, the aggressive response, and the passive response. Review Table 7.1 comparing assertive, passive, and aggressive behavioral styles for interacting with others.

Christopher's Dilemma

Christopher is paralyzed on the left side of his body from a stroke. He needs help getting in and out of his wheelchair. One morning his paid care provider Lisa came to work in a bad mood. She told Christopher she wasn't happy about having to come to work an hour early to help him get to an early doctor's appointment. Lisa mumbled under her breath that she didn't understand why Christopher's wife

couldn't help him. When Lisa was helping Christopher get into his wheelchair, she handled him somewhat roughly, jerking him around a bit as she helped position him in the chair.

Identify the assertive, passive, and aggressive response.

Response #1: Behavioral Style: _____

Christopher looks down and thinks about what he should do. While looking at his knees he softly says, "I'm sorry you're having a bad day." Lisa ignores him. Christopher waits a few more seconds and then quietly says, "I don't think I'm sitting quite right. Would you mind helping me reposition a bit?" Lisa looks over at Christopher and rolls her eyes, groans, and says, "Can't you see I'm doing something? Just wait a minute."

Response #2: Behavioral Style: _____

Christopher looks at Lisa and calmly says, "Lisa, please sit down. I would like to talk with you about a concern that I am having about how you are treating me this morning." Lisa looks over at Christopher and rolls her eyes, groans, and says, "Can't you see I'm doing something? Just wait a minute." In a calm but strong tone of voice, Christopher looks directly at Lisa and says, "Lisa, I don't like the way that you are treating me. I would like you to be more careful when you are getting me into my wheelchair. Right now I'm not sitting properly. I need you to help reposition me. Then I think we should sit and talk about what is going on here—I'm not comfortable with how our morning is starting."

Response #3: Behavioral Style: _____

Christopher looks at Lisa with an angry look on his face, with his right hand clenched in a fist and raised in the air, and yells, "What the hell do you think you're doing! Stop being so rough! You almost tore my arm off! You really seem to have an attitude problem today! Stop being so lazy and come over here and help me get in a better position!" Christopher glares at Lisa while waiting for her to respond.

Thoughts About Christopher's Dilemma

The purpose of this activity is to make sure you can identify the three behavioral styles. In the first response Christopher is behaving in a passive behavioral style. He begins by apologizing to Lisa as if he has done something wrong. He is asking for help but in a way that gives Lisa the option to say no. She does mind helping him and tells him he has to wait. In the third response Christopher is behaving in an aggressive behavioral style. He's yelling, demanding, and putting Lisa down. Notice all of the "you statements" and the threatening body language—a raised

fist. In the second response Christopher is using an assertive behavioral style. His communication is calm, clear, and direct. He uses “I statements.” His response is strong, but not overbearing. His nonverbal behavior shows self-confidence.

The assertive response is the best option to handle Christopher’s situation with his PA. However, it is also important to take into consideration the *timing* of your assertive communication. In most cases it is best to express yourself in the moment, rather than wait. However, there may be times when waiting to have a more in-depth discussion is your best option. You may want to think about and plan what you are going to say. You might want to give the other person some time to calm down. Knowing more about Christopher and Lisa’s relationship and typical patterns of interaction would help determine the best way to deal with the situation at the very moment this scene is taking place.

Final Thoughts About Assertiveness

People who are assertive are not automatically protected from violence and abuse. No one lives a risk-free life. However, because assertive people believe in themselves, know that they have rights, are sure of themselves, engage in respectful interaction with other people, and use their assertiveness to take control of their own lives, they are better able to prevent and protect themselves from violence and abuse. When others say, “You can’t,” “You don’t need to know,” or “You won’t understand,” assertiveness will help you to say, “I can,” “I have the right,” “I need to know,” and “I want to try.”

HEALTHY, MUTUALLY RESPECTFUL INTERPERSONAL AND INTIMATE RELATIONSHIPS

Let’s begin with looking at different types of relationships. **Interpersonal** refers to relationships between people. Throughout your lifetime you will have hundreds of interpersonal relationships. One type of interpersonal relationship is an intimate relationship. **Intimate relationships** are relationships between people of a “very personal or private nature” and involve “very close association, contact, or familiarity” (Merriam-Webster Online Dictionary, 2008). People typically have intimate relationships with spouses or partners, family members, and close friends. For many people with disabilities, their network of intimate relationships may also include paid and unpaid care providers. Sexual relationships are the most intimate type of intimate relationship.

Most people learn how to treat others and how they should be treated by others from their families. How we are treated by our parents and siblings affects how we treat others and how we expect to be treated by others. The first intimate relationships that we observe are most likely between our parents or a parent and a partner. Children placed in day care form interpersonal relationships with other adults and children and continue to learn acceptable and unacceptable interpersonal behavior. Our network of adult and peer relationships expands when we begin attending school. Our understanding of how we should be treated and how we treat others continues to grow. We may experience different expectations in the different places where we spend time. We also learn about relationships from the

media—movies, books, television, and magazines (Hughes & Abramson, 2000). As we grow older we are exposed to more places, more people, and more images in the media, resulting in many more interpersonal and intimate relationships. Ideally these relationships, or the majority of them, are positive. However, the ideal may not have been your experience or the experience of people you support.

Learning the Difference Between Abusive and Nonabusive Relationships

One way to prevent abuse is to define, teach, and talk about healthy and unhealthy interaction in relationships—particularly intimate relationships. It is not enough to ask someone, “Have you been abused?” or “Are you being abused?” As you already know, people might not think they were or are being abused. It is important to teach and talk about very specific behaviors or actions that are abusive. However, it is not enough to only talk about ways that people should *not* be treated. We also need to talk about the characteristics of relationships that are based on equality and the behaviors that reflect healthy, mutually respectful interpersonal and intimate relationships.

One way to teach the difference between abusive and nonabusive relationships is to use the Abuse of People with Disabilities Caregiver Power and Control Wheel (Disability Abuse Wheel; see Figure 2.6) (WCADV, n.d.a) and the Non-Violent Caregiver–Care Receiver Equality Wheel (Equality Wheel; see Figure 7.1) (WCADV, n.d.b). You are already familiar with the Disability Abuse Wheel. Relationships with care providers that engage in behaviors identified in the Disability Abuse Wheel are not relationships based on equality.

Before looking at the Equality Wheel (see Figure 7.1),



Ask Yourself...

What words would I use to describe a healthy, mutually respectful relationship?

Write the words or ask someone that you trust to write the words down.

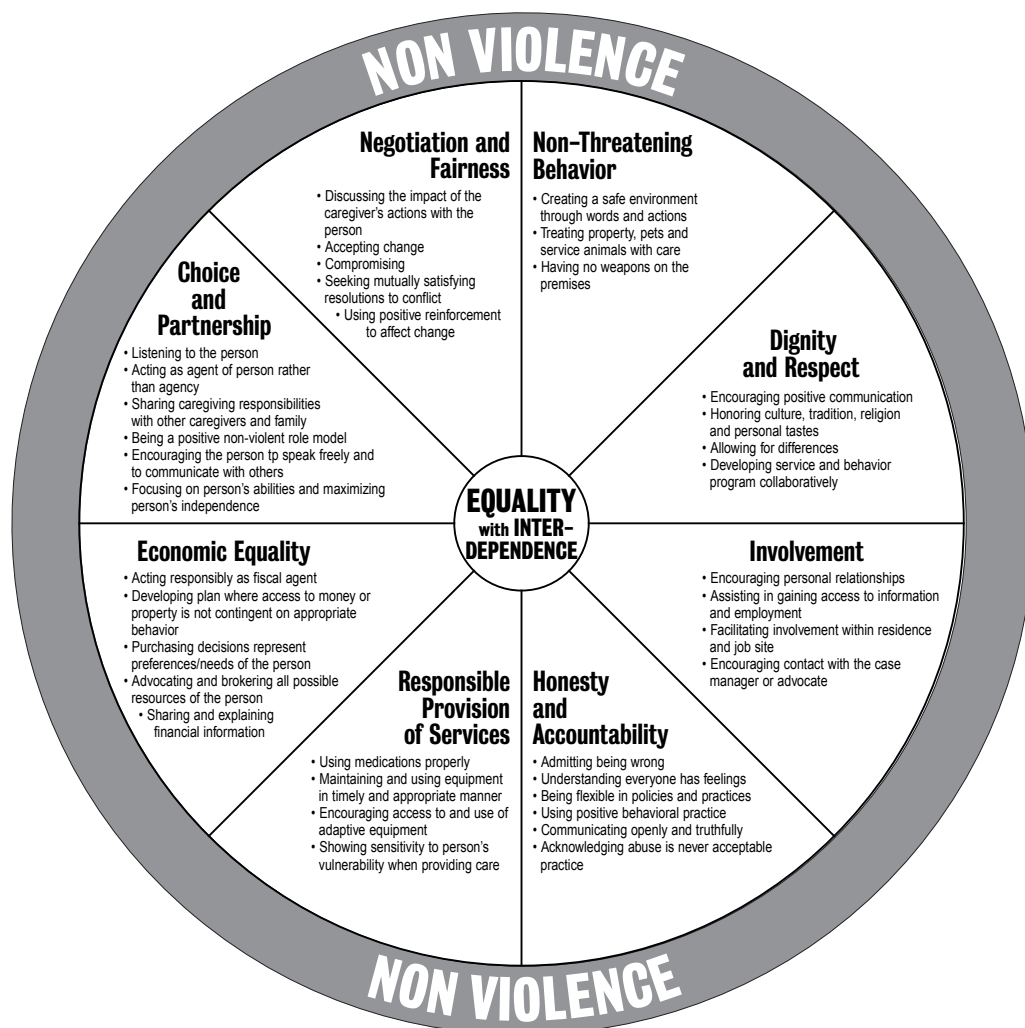
Now take a look at the Equality Wheel (see Figure 7.1). Review the characteristics of nonviolent care provider–care receiver relationships. Add to your list the words that are important to you that describe a healthy, mutually respectful relationship.

LEARNING ACTIVITY

Examining the Words that Describe a Healthy, Mutually Respectful Relationship



Use the worksheet in Figure 7.2 to examine each of the words that you think describe a healthy, mutually respectful relationship. Starting with the one word that is most important to you, write the word in the space provided. Then write or ask someone that you trust to write your answers to each question. You may make photocopies of this page for future use.



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Figure 7.1. The Non-Violent Caregiver-Care Receiver Equality Wheel is based on the Equality Wheel developed by the Domestic Violence Intervention Project, Duluth, Minnesota to describe care provider-care receiver relationships based on equality with interdependence.

Use the Disability Abuse and the Equality Wheels as tools to help you or to help the people with disabilities you support to

- Define the qualities of harmful intimate relationships.
- Define the qualities of healthy, mutually respectful intimate relationships.
- Improve and strengthen generally positive intimate relationships.
- Explain to care providers the way that you or the people you support expect to be treated.

What does _____ mean to me?

_____

_____

How do I know that someone is treating me with _____ in our relationship?

_____

_____

What behaviors or actions show _____?

_____

_____

You may not feel comfortable writing down the names of people for the last two questions. That's okay. What is most important is that you think about and identify for yourself the people in your life.

Who are the people in my life who treat me with _____?

_____

_____

Who are the people in my life who don't treat me with _____?

_____

_____

Combating Violence and Abuse of People with Disabilities: A Call to Action by Nancy M. Fitzsimons. Copyright © 2009 Paul H. Brookes Publishing Co., Inc. All rights reserved.

Figure 7.2. Worksheet to help define a healthy, mutually respectful intimate relationship

- Identify specific areas lacking in a relationship that could be improved. Ask whether the relationship is worth improving.
- Identify intimate relationships that may not be worth maintaining.

Final Thoughts About Healthy Interpersonal and Intimate Relationships

Everyone should have high standards for how they are treated by others. Unfortunately we live in a society that often undervalues people with disabilities, resulting in an acceptance of lower quality and sometimes abusive treatment. Education about healthy and unhealthy interpersonal and intimate relationships empowers people with disabilities to set high standards and to make healthy choices about the people they want to be a part of their lives.

PERSONAL SAFETY SKILLS

There are many things that you can do to lessen your risk for violence and abuse—or for falling victim to any type of crime. Knowing and using personal safety skills will empower you and the people with disabilities you know to take greater control. Let's begin with thinking about the terms **safety** and **safe** and what these words mean to you.



Ask Yourself ...

What does safety mean to me?

How do I recognize when I'm feeling safe? How do I recognize when I'm feeling unsafe?

What are red flags or warning signs for me that a person, place, or situation might not be safe?

What would I do if I was in a relationship that didn't feel safe? Who would I call or tell? Where would I go? Where could I get help?

As you can imagine, personal safety is a very broad topic—so broad that entire books are written about it. In this chapter you will learn some basic information about five areas of personal safety:

- General safety
- Unsafe feelings
- Privacy and the safety of your body
- Safe secrets and unsafe secrets
- Safety planning

Use the resources provided at the end of the chapter to learn more about personal safety and what you can do to reduce your risk for abuse. Let's begin by looking at some general ways that you can keep yourself safe.

General Safety

Offenders look for people they think are easy targets or victims. They also watch for opportunities in which there is little chance that they will get caught. You are less likely to be a victim if you do not look like an easy target (Harteau & Keegel, 1998). Always remember that “the best self-defense is to avoid becoming a victim” (Bozeman, 2004, p. 435).

Your first line of self-defense is to show yourself to others as a person who is self-confident. Remember what you learned about the nonverbal parts of assertiveness. Body posture (the positioning of your body) is very important when offenders are selecting their victims (Bozeman, 2004). To the best of your ability, sit, stand, and walk with your head held up and your shoulders back. You want to show an image of self-confidence.

It is also very important to be aware of your surroundings. It is easy to get lost in your own thoughts. It is also easy to get caught up in a conversation on your cell phone. Lack of awareness of your surroundings can create the perfect opportunity to be victimized by a stranger. Putting into practice some general safety tips when you are out in public will minimize risk (see Tip Box 7.3).

There are specific safety practices that you can use for each place and situation that you encounter.

General safety tips for going out in public

- Sit, stand, and walk with confidence.
- Be aware of the people around you.
- Know where you are going.
- When you meet other people, don't look down or away. Make eye contact (as is culturally appropriate), but don't stare.
- Carry your wallet in a shirt pocket, front pants pocket, or the inside pocket of a jacket.
- Use a belt-style pack instead of a purse. Wear it in the front under your clothes.
- If possible, carry your purse inside your jacket.
- Don't wear headphones when you are out in public by yourself. If you choose to wear headphones, set the volume low enough that you can hear what is going on around you.
- When possible walk in the middle of the sidewalk instead of close to buildings or the street.
- Know where to get help.
- Learn an alternative route of travel in case you come upon an unsafe situation.
- Carry a cell phone. Make sure the battery is charged. Have it readily available to use.
- When in danger, yell "Fire!" instead of "Help!"

Sources: Bozeman (2004), Harteau & Keegel (1998), Harteau & Keegel (1999).

TIP BOX 7.3**Ask Yourself...**

What are the most common public places that I go?

What are the most common situations where I am by myself?

Let's look at two common situations: using cash machines and taking public transportation.

Many people now use a cash machine (automatic teller or ATM) as an easy way to get money. However, they can be dangerous places. Review the safety tips for using cash machines (Tip Box 7.4). Practice the tips at the cash machine you use most often. Help the people with disabilities you support to learn and practice the safety tips when using cash machines.

People with disabilities often rely on public transportation, in particular public buses. Other passengers and the bus driver can pose a potential risk to your

Safety tips for using a cash machine (ATM)

- Avoid using cash machines alone at night.
- Use ATMs in areas with good lighting.
- Have your card ready before you are standing in front of the cash machine. Avoid fumbling to find your ATM card in your wallet, purse, or belt bag.
- If someone is standing too close, politely ask them to step back, or leave and come back when the person is gone.
- If someone is hanging around you or seems suspicious, leave and go to another ATM.

Sources: Harteau & Keegel (1998, 1999).

TIP BOX 7.4

safety. If at all possible, try not to be alone on the bus with only the bus driver or very few other passengers. This is not always possible. One way to help to protect yourself is to use your cell phone to call someone you know while riding the bus. Tell the person on the telephone, in a voice loud enough that others will hear, where you are, when you will arrive at where you are going, that you will call if the bus is running late, and that you will meet them at the agreed-upon location. Even if you're not actually meeting the person, other people don't know this. Review and practice the safety tips for using public transportation (see Tip Box 7.5). Help the

Safety tips for using public transportation

- Sit toward the front.
- Have your money or ticket readily available.
- Don't count your money in front of others.
- Move to another seat if you feel uncomfortable.
- Don't share personal information with strangers, the bus driver, or casual acquaintances (people that you don't know very well).
- If you wear a hearing aid, make sure it is turned on and turned up.
- If someone who looks suspicious is getting off at your stop, wait and get off at the next stop.
- Tell the bus driver if you are concerned about another passenger's behavior on the bus.

Sources: Harteau & Keegel (1998, 1999).

TIP BOX 7.5

people with disabilities whom you support to learn and practice the safety tips when using public transportation.

Final Thoughts on General Safety

You’ve learned about a few areas of general safety. Prevention is your best self-defense. Reduce your risk for being a victim of a crime by

- Knowing your strengths and limitations
- Knowing your surroundings
- Securing your home and your possessions
- Projecting self-confidence
- Thinking and planning ahead

Refer to the Resources at the end of the chapter to learn about general safety, including safety in your home, in your car, in an elevator, and on a date. Let’s move on to learning how to recognize when you are feeling unsafe.

Recognizing Unsafe Feelings

Unsafe feelings may also be called a *sixth sense*, a *gut feeling*, or your *intuition* (Davis, 2000; Harteau & Keegel, 1999).



Ask Yourself...

Have I ever had the feeling that a person, place, or situation was not quite right—that I was not safe?

Another important part of personal safety is to identify what it feels like when you think that you might be in danger (see Table 7.3). Once you know what it feels like—and it may feel different for different people—then trust your gut feeling that you are in an unsafe situation. For example, if someone approaches you on the street asking for directions, sits next to you on the bus, or gets onto the elevator with you, and you get a creepy, uncomfortable feeling, trust your instinct. You do not have to give a person directions; you can say you don’t know and walk away. You do not have to stay seated next to a person; you can move to another seat. You do not have to stay in the elevator; you can get out and take the next available elevator. You do not have to be afraid that you might hurt the other person’s feelings (Harteau & Keegel, 1998). Use assertive thinking, behavior, and communication to take action and deal with the situation right away. Remember, prevention is your best self-defense.

Table 7.3. Examining your sixth sense

Pay attention to

- Change in your heart rate (your heart begins to beat faster)
- Tightness of your muscles
- A sick feeling in your stomach
- Changes in your body temperature, such as sweating or a cold, clammy feeling

Table 7.4. Parts of the Ring of Safety

Sex education
Privacy awareness
The ability to refuse to comply
A trusted friend who is safe to talk to
Understanding of personal rights
Healthy self-concept and self-confidence
Options for healthy sexuality

Sources: Hingsburger (1994, 1995).

Privacy and Safety of Your Body

Let's begin thinking about the safety of your body from sexual assault by reading a quote from a leading scholar on sexuality and people with developmental disabilities. "People with disabilities, maybe more than others, need to become their own first line of defense" against sexual victimization (Hingsburger, 1994, p. 73). According to Hingsburger, people with disabilities need a **Ring of Safety**—"a set of skills that give them the ability to repel (keep away) unwanted advances or to report advances immediately upon occurrence" (Hingsburger, 1994, p. 73) (see Table 7.4). Let's examine one of the most neglected areas of prevention of sexual assault, privacy awareness.

Privacy Awareness



Ask Yourself...

What do the words private and privacy mean to me?

How did I learn about privacy?

When you really think about it, privacy is a fairly complex concept that can be difficult to teach. In order to understand privacy and prevention of sexual assault, you need to understand

- Personal information versus public information
- Private places versus public places
- That the body is private and some parts of the body are particularly private—typically the penis, vagina, buttocks, anus, breasts, mouth, and lips (Hingsburger, 1990; Hingsburger, 1995)

People with disabilities are at a serious disadvantage when it comes to learning about privacy and having their privacy respected. Bathrooms and bedrooms are generally seen as private places. However, this is not necessarily the case for people with disabilities.

Private rooms...like bathrooms and bedrooms are routinely violated by staff [and other care providers] who feel free to walk in on people with disabilities without knocking or permission. [Care providers] may sit and chat to a person with a disability who is sitting naked on the toilet. (Hingsburger, 1994, p. 74)

Sexual behaviors like masturbation are generally seen as private business. Again, this is not necessarily the case for people with disabilities.

How many meetings do you go to wherein people discuss a [person's] entire life, right in front of them? I have been in meetings and watched as a young man with a developmental disability has comfortably listened to a staff discuss the fact that she was aware that he masturbated to ejaculation because of the mess on his sheets. This same man has a problem with discriminating (knowing the difference between) public and private places. SURPRISE!! SURPRISE!! (Hingsburger, 1995, p. 73)

Understanding the concept of privacy is a key part of learning to protect yourself and the people you support from sexual assault. People with disabilities often do not learn about basic privacy because parents and professionals do not teach it. The best way to teach about privacy is by “doing privacy” (Hingsburger, 1995, p. 74). It is also important to “teach accurately about the body,” meaning that your entire body is private, not just certain parts of your body (Hingsburger, 1995, p. 78). You should be in control of when you are touched, where on your body you are touched, and how you are touched (see Tip Box 7.6). “If you don’t understand that your body is yours and no one can touch it without your permission, then you simply accept what happens to it as being part of what it is to be powerless” (Hingsburger, 1995, p. 74).

Safe Secrets versus Unsafe Secrets

A secret is something kept hidden; something kept from the knowledge of others (Merriam-Webster On-Line, 2006–2007).



Ask Yourself...

- *What kinds of secrets are safe to keep secret (not tell someone else)?*
- *What kinds of secrets are unsafe to keep secret (not tell someone else)?*

Tips for creating privacy

- *Require permission.* Ask care providers to request permission to touch you.
- *Change or adapt the environment whenever possible to increase privacy.* For example, lower a shower curtain to provide some privacy but still allow a care provider to see if there are concerns about your physical safety.
- *Keep private subjects private.* Assert your right to have your private business, like personal hygiene, sexuality, and bodily functions kept private (not talked about in public or between care providers without your permission).

Source: Hingsburger (1995).

A **safe secret** is a secret that causes no physical, financial, or psychological harm (or potential for harm) to the person or people asked to keep the secret. You might be asked to keep a surprise birthday party or a friend's real hair color a secret. These kinds of secrets are harmless. An **unsafe secret** is a secret in which the person or people asked to keep the secret are being or are at risk for being physically, sexually, financially, or psychologically harmed.

Abusers use secrets in many different ways to keep their victims from reporting the abuse.

- *The special relationship.* Abusers tell their victims that they have a very special relationship. Victims are manipulated into keeping an unsafe secret. Abusers convince their victims that their relationship is something special for only the two of them to share.
- *Threats of harm to others.* Abusers threaten to harm pets or other people in order to keep their victims from reporting the abuse. People believe that they have no choice but to keep the unsafe secret out of fear for the safety of the people and/or pets that they love.
- *Threat of harm to the abuser.* Abusers also bully victims into keeping unsafe secrets by telling victims that something bad will happen to them (the abusers) if their secret is discovered. If the abuser is a parent or someone that the victim loves, they may feel like they have to keep the secret in order to protect the abuser.

You may recall that one of the parts of the Ring of Safety is a trusted person who listens. Everyone should have someone in their life that can be trusted with his or her most personal thoughts, feelings, and fears. This person is someone that can be turned to for advice about whether or not to keep a secret. Remember what you learned about unsafe feelings. Use your *intuition* to help determine whether a secret is a safe or an unsafe secret. Let's move on to the last area of personal safety covered in this book, safety planning.

Safety Planning

Safety planning refers to having a plan for what action you will take in the event that you feel threatened or are in danger of being abused. This section is only going to focus on safety planning as a form of prevention. Safety planning resources are provided at the end of the chapter for helping people who are already in an abusive situation or relationship.



Ask Yourself...

Who would I call if I felt unsafe in my home?

Where would I go if I felt unsafe at home?

What would I take with me if I quickly needed to leave my home and did not know when I could return?

It is better to have a plan in place that you never need than to be in an abusive (or potentially abusive) situation or relationship without a plan.

One important part of safety planning is knowing the resources available in your community to help you. It is much easier to learn about the resources when you do not actually need them. In Chapter 6, Understanding the System, you learned about the system of services available to help abuse victims. You know that you can call the police at 911. If you support people with intellectual disabilities, you may need to teach the appropriate use of 911 in order to prevent abuse of the emergency system. If you have not already done so, now is the time to identify the resources in your community. If needed, ask for help from someone you trust. Use the My Safety Network Resources Worksheet in Appendix A (see pages 179–181). Another important part of safety training is to identify at least one person you really trust whom you could call when you are feeling unsafe. The person or people you identify are your **personal safety network**. In order to complete this part of safety planning,



Ask Yourself...

What does the word trust mean to me?

How do I know that I can trust someone?

What does it feel like when I feel unsafe?

How will I know when I should call someone I trust?

You may be in a situation where you would be in even greater danger if your abuser knows that you are calling the police. It is a good idea to come up with a **secret word** or **code** that you can use to tell the people in your personal safety network to call the police in case you would have to call while the abuser is present (Hughes & Abramson, 2000).

You never know when your safety will be at risk.



Ask Yourself...

How will I respond?

If able, will I run? Will I scream? Will I fight back?

What escape routes will I use at home? At work?

Again, the time to plan and practice how you will respond is not in the heat of the moment when your safety is at risk—it is better to plan and practice when you are safe. Learn the different ways that you can get out of your home, work, or other places that you spend time in the event that your safety is at risk. Practice using different escape routes. Consider taking a self-defense class. Most people have some ability to defend themselves. Taking a class will help identify your strengths and make the most of your abilities. In order to prevent an attack, make as much noise as possible to attract attention (Bozeman, 2004). Shouting “NO!” in a loud, assertive voice may be enough to prevent abuse (Hughes & Abramson, 2000). Use the tips for stopping an attack if your safety is at immediate risk (see Tip Box 7.7). Your goal is to “inflict the amount of discomfort [pain] needed to be free from the attacker [using whatever means available] and to move as quickly to safety as possible” (Bozeman, 2004, p. 436).

Tips for stopping an attack

- Shout “No!”
- Yell “Fire!” Make as much noise as possible to attract attention.
- Attach a loud horn to your wheelchair or scooter. Use it to attract attention.
- Physically fight back. Hit, bite, pinch, kick in the groin, poke in the eyes.
- Use a purse, backpack, or cane as a weapon to hit your attacker.
- Vomit, gag, defecate, or urinate to try to prevent being sexually assaulted.
- If you use a wheelchair or scooter, use it as a weapon to ram into your attacker and protect yourself.

Sources: Bozeman (2004), Harteau & Keegel (1998, 1999).

TIP BOX 7.7

You also need to plan for what you will need if you must quickly leave your home (see Table 7.5). If you are in a safe living situation, it may be enough to know what kinds of items you would need and where they are located in your home. If you are currently in an abusive relationship or situation, have a bag packed and ready for use at a moment’s notice. The Wisconsin Coalition Against Domestic Violence has developed safety planning tools specifically for people with disabilities. Refer to the Resources at the end of the chapter.

Final Thoughts About Personal Safety

You or the people with disabilities that you know do not have to be easy targets for violence and abuse. Lessen the risk for abuse by learning and practicing the safety skills that will best protect you or the people with disabilities that you support.

Table 7.5. Items to pack for an emergency exit

Money, checks, credit cards
Driver’s license, “green card,” other identification cards
Extra car keys
Prescription drugs
Spare eye glasses or contact lenses
Birth certificates and social security numbers for yourself and children
List of important telephone numbers
Several days’ worth of clothing
Important legal documents (e.g., custody papers, divorce decree)

Sources: Harteau and Keegel (1998), Hughes and Abrahamson (2000), National Clearinghouse on Abuse in Later Life (NCALL) (2000, 2003).

Obtaining the safety information and skills you need may require self-advocacy on your part. You know that the systems for people with disabilities are often set up for others to protect them. Reach out to people who will support you in learning how to prevent violence and abuse. Remember that a CIL is a good place to start to get support for self-advocacy, and a good place to get help with our next topic: hiring and managing care providers.

HIRING AND MANAGING PEOPLE WHO HELP YOU

An important part of violence and abuse prevention is having the right kind of care providers. For decades people with disabilities have advocated for **consumer-directed services** and more public funding for personal assistant services (Benjamin, 2001; Scala & Nerney, 2000). The idea behind consumer-directed services is to empower people with disabilities to make their own decisions about hiring and managing the people who assist them on a day-to-day basis. Hiring and managing care providers (also called personal care assistants [PCAs] or personal assistants [PAs]) is not always easy to do.

Ask Yourself...

If I received funding to hire my own PA, where would I begin? How would I find the right person for the job?

What kinds of qualities and skills in a PA are important to me?

Where would I go to get help hiring and managing a PA?

We are going to focus on the basic information that you need to hire and manage a PA. Refer to the Resources at the end of the chapter to access more information about hiring and managing PAs. Many of the tips will help in your relationships with other care providers, often family members and friends. Let's start with learning about the different options for getting a PA.

Community Resources

Each state has different ways to pay for and provide PAs or PCAs (see Table 7.6). Each state also has different policies and processes for consumer-directed services, including how much control and choice you have in how money is spent (Benjamin, 2001). A state or county human service (also called social service) or other state or

Table 7.6. Funding for personal assistant services

Medicare: Limited, short-term funding
Medicaid: Find out if your state has a Medicaid waiver program that provides personal assistance services
Individual state-funded programs
Private insurance coverage: Check your health insurance policy
Department of Veterans Affairs: Veterans may apply at your local Department of Veterans Affairs Office
Vocational rehabilitation: If you are receiving vocational rehabilitation services
Noncash options: To exchange for services such as offer room and board

Source: Casebolt and Gilson (2000).

county agency (such as public health, disability services, or rehabilitation services) will decide if you are eligible for consumer-directed services. Depending on where you live, you will most likely work with either a state or county service coordinator (also called case manager) or someone at your local CIL to get assistance. There are different models for consumer-directed services, such as:

- A service coordinator who works for the state or county assesses need, determines eligibility for services, and decides the number of personal assistant hours that will be funded by the state. The service coordinator may assist with hiring and monitoring services on an ongoing basis. The service coordinator may act as the **fiscal agent** (pays the PA).
- The state contracts with local CILs to assess need and assist in hiring and training PAs. The CIL may provide a list of potential PAs and help with doing criminal and other **background checks**. The CIL may act as the fiscal agent (paying the PA).

Some states require that you get their approval before hiring a PA. Some states require that you use a fiscal agent. Some states will not allow you to hire a family member. Some states help with doing criminal and other background checks on potential PAs. Depending on where you live, you may get lots of help or very little help hiring and managing PAs. Where you live also determines how much control you have over whom you hire and how you manage your PA (see Table 7.7).

Hiring and managing a PA is a lot like running your own small business. Keep a file on each potential employee and carefully document interviews and conversations that occur as you begin the hiring process. Having files on potential candidates will come in handy the next time you are looking for a personal assistant (Casebolt & Gilson, 2000). It is also recommended that you have a backup PA in place for times when your primary care provider is sick or needs to take days off (Burdshall, n.d.). Be aware that if you decide to be the fiscal agent, you will need to

- Get an employer tax identification number through the U.S. Internal Revenue Service (IRS)
- Contact your state’s Department of Labor or Employment to find out about your state’s tax requirements
- Pay your PA’s wages, including deducting Social Security and Medicare taxes (Casebolt & Gilson, 2000)

Hiring a PA may seem like a hard and perhaps scary task, especially if you are doing it on your own without the help of a fiscal agent, service coordinator, or CIL. One of the best ways to make the process a little less scary is to talk with

Table 7.7. Finding help with hiring a personal assistant

Contact your local

- Center for Independent Living (CIL)
- State or county human services, social services, or disability services agency
- State or county public health office
- Vocational rehabilitation agency

Source: Casebolt and Gilson (2000).

other people with disabilities who have hired their own personal assistants. Talk to as many people as possible so that you can learn from many different people's experiences.

Another option for getting PA services is using an agency; one option is a home health care agency. One of the main benefits of using a home health care agency is that they do most of the work for you, including screening, hiring, and managing the PA (Burdalls, n.d.). In addition, home health care agencies will provide back-up care providers in case your usual PA is absent (Benjamin, 2001). The main drawback of using a home health care agency is the services are not consumer-directed, meaning the agency controls the services you receive, not you (Benjamin, 2001). Scheduling and care decisions may be made based on agency policy, not your preference; for example,

- If you need help getting ready for bed, you may have to go to bed at the time the PA is scheduled by the agency to be at your home, not necessarily when you want to go to bed.
- You may prefer to take your shower in a certain way, but the agency may not permit the PA to follow your preference due to agency policy.

Another drawback to home health care services is it will typically cost you more working through an agency than hiring a PA on your own. On the other hand, hiring and managing a PA on your own is a lot of work. You will need to weigh the pros and cons of home health services and choose the best option (in some cases the best available option) for you.

Identifying the Qualities of Your Personal Assistant

One of the first steps in hiring a PA is to identify the qualities (personal characteristics and skills) you want this person to have. Refer back to the words you listed about healthy, mutually respectful relationships and



Ask Yourself...

What are the qualities in a PA that are important to me?

Think about the kind of personality and any other qualities this person needs to have to be able to fit in your environment (Casebolt & Gilson, 2000). For example, include whether or not the person likes animals or has an allergy to any pets, or whether it's important to you that the person be a nonsmoker. See Table 7.8 for examples of personal assistant qualities.

Figure out your care needs and the skills required to meet your care needs. There are three main types of assistance:

- Assistance with the **activities of daily living** (ADLs), including direct personal care such as bathing, toileting, and dressing
- Assistance with **instrumental activities of daily living**, including indirect support such as help with grocery shopping, cleaning, laundry and driving
- Assistance with medical care such as medication management, colostomy bag, or other care that requires medical training (Casebolt & Gilson, 2000)

Table 7.8.   Examples of personal assistant qualities

Morning person or night person
Always on time
Nonsmoker or nondrinker
Good cook
Has computer skills
Likes animals
Has a good sense of humor
Has a valid driver's license
Drives own car
Is able to lift (determine approximate number of pounds)

Sources: Burdsall (n.d.), Casebolt and Gilson (2000).

Once you know your care needs, figure out if you want a live-in or a live-out PA, part-time or full-time, and the specific days and hours you need your PA to work (Burdsall, n.d.). You may also want to rate your preferred PA qualities. Some qualities may be absolutely essential, some important, and some nice but not necessary (Casebolt & Gilson, 2000, p. 55). After you have figured out your care needs and preferred PA qualities, you are ready to write your job description.

Advertising the Position

Once you have the job description written (see Table 7.9), it should be easy to write the advertisement. In the ad, provide a short description of the job, focusing on the most important tasks for the position. Be aware that you cannot list preferences based on sex, marital status, age, national origin, religion, and race/ethnicity because it is considered discrimination and is against the law (Burdsall, n.d., p. 3). Be sure to include the pay, any benefits, live-in or live-out status, full- or part-time status, days and number of hours per week, and a way for applicants to contact you. Decide what information you want applicants to give you, for example, cover letter, resume, name, and telephone numbers of references (preferably professional references from teachers and former employers). In order to increase your safety, consider using a post office box or a business address for replies rather than giving out your telephone number. Never give your address (Casebolt & Gilson, 2000). See Figure 7.3 for a sample advertisement.

Table 7.9.   Information to include in a job description

List of the job duties
Number of hours per week
Schedule of days and times
Pay (hourly wage)
Benefits (e.g., paid sick days, paid vacation, meals, mileage)
Job qualifications (e.g., CPR certification, ability to lift a certain number of pounds, care providing experience, valid driver's license, computer skills)
Description of specific tasks such as bathing, dressing, transfers, cooking, grocery shopping

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Sources: Burdsall (n.d.), Casebolt and Gilson (2000), Ulicny, Adler, Kennedy, and Jones (2006).

Personal Assistant Needed

Part-time PA needed for female with a disability

M–F 6–8 AM & 6–10 PM

Non-smoker, some lifting required,

must like dogs

\$10/hour

Send letter noting qualifications and
name & telephone numbers of 3 references to:

P.O. Box 111

Anytown, State 55555

Figure 7.3. Example of a newspaper advertisement to hire a personal assistant.

There are many ways that you can look for a PA (see Table 7.10). You’ll need to figure out the best options for you based on your community and resources. We highly recommend working with your local CIL. CILs provide training on how to search for a PA. Some CILs have PA referral services to help you get connected to potential care providers. CILs also provide a great way to connect with other people with disabilities who can offer you ideas and may know of people qualified for your position. You may want to place an ad in your local newspaper. Contact your local paper to find out the cost of posting an advertisement. Colleges and universities are another good source. Many colleges and universities have job banks for their students where you can post the position for free. High turnover is an issue with college students due to summer vacations, internships, graduations, and school transfers (Casebolt & Gilson, 2000). Word of mouth is another good option. Talk to family members, friends, co-workers, neighbors, and other care

Table 7.10. Ways to find a personal assistant

Centers for Independent Living (CIL)
Senior centers, agencies on aging
Your doctor’s office or other health care facility
Colleges or universities, particularly nursing, social work, education programs
A home health agency
An ad placed in your local newspaper
Local employment office
Posting fliers on community bulletin boards
Word of mouth—make contacts through family members, friends, neighbors

Sources: Casebolt and Gilson (2000), Ulicny, Adler, Kennedy, and Jones (2006).

providers to spread the word about the position and to identify people they know who might be a good fit.

Screening, Checking References, and Interviewing

Once you start receiving responses you will want to screen the applicants. Review your personal preferences and needs as well as your job description while reviewing each of the applications to figure out who appears to best fit the job. You might want to have someone you know and trust also screen applicants for a second opinion. Consider starting with a telephone interview. During the telephone interview, find out if applicants are still interested in the position, tell them more about the job, and learn more about the people applying for your position. Prepare a list of questions to ask in advance.

If you asked applicants to send you a list of references, now is a good time to check references for applicants that you would like to interview face to face. During the screening call, tell applicants that you would like to call their references. You can also wait to check references until after the face-to-face interview; the choice is yours. However, always check professional references before hiring anyone. Typically people ask for and check three or four references. Call each of the references. Begin by explaining who you are, why you are calling, and the type of position you are offering (Casebolt & Gilson, 2000). When you question references, ask them specifically about the applicant’s dependability and honesty. Ask how long they have known the applicant and how long they worked with him or her. Find out about the applicant’s strengths and weaknesses. Ask whether or not they think the applicant is a good fit for the job of personal assistant. One of the most important questions you can ask an employer is whether they would hire the person again if given the opportunity (Burdsall, n.d.; Ulicny et al., 2006). Refer to Table 7.11 for ideas about what kind of information you might seek when contacting a reference.

For applicants whose telephone interviews go well and who have good references, schedule face-to-face interviews. You might want to send a job application in the mail and ask applicants to bring the completed form to the interview. Ask applicants to telephone you in advance if they need to cancel the interview. It is best to meet applicants at a neutral, public location—never at your home or theirs (Burdsall, n.d.). You may want to invite someone you know and trust to

Table 7.11. Information to get from a former employer concerning a job candidate

Length of employment
Job duties
Dependability of candidate—showing up to work when scheduled and on time
Response to feedback and supervision
Ability to learn new tasks
Ability to work independently
Quality of relationship with co-workers, supervisors, customers/clients/consumers
Reasons for leaving the job

Sources: Burdsall (n.d.), Ulicny et al. (2006).

Table 7.12. Things to ask in an interview for a personal assistant
Reason applying for the position
Work experience including past work as a personal assistant or related experience and length of employment
Education and any special training
Goals for the future
Type of work enjoyed the most and the least
Experience and comfort around people with disabilities
Applicant's method(s) of handling stress and stressful situations
Experience specifically related to the job tasks
Applicant's driving record

Sources: Burdsall (n.d.), Casebolt and Gilson (2000).

be nearby or to join you for the interview. Prepare the questions you will ask ahead of time (see Table 7.12). The interview is your chance to get to know the applicants; do a lot of listening and let them do a lot of the talking in response to your questions.

During the interview, explain the job, ask questions to determine if the person is qualified and a good fit for you, and answer their questions about the position (Burdsall, n.d.; Casebolt & Gilson, 2000). Give applicants a copy of the job description. Use the job description or an interview checklist that you have prepared in advance to help conduct the interview. Make sure you discuss scheduling needs in detail, both yours and theirs. Also discuss the rate of pay, tax deductions, and benefits. Use the interview to get to know the applicant and find out what you have in common and where you might have differences. Remember, no matter how qualified an individual is or how well his or her abilities match your needs, if for any reason you do not feel comfortable with the person, do not consider hiring him or her (Burdsall, n.d.). Follow your gut instinct.

Criminal and Other Background Checks

It is important to conduct a criminal background check before a PA begins working for you to make sure that they do not have a history of violence, abuse, or other criminal behavior (see Table 7.13). The process and fees for obtaining a criminal background check vary by state (Ulicny et al., 2006). Your local CIL or police department is a good place to go to get information and help with getting a criminal background check. In states that require you to use a fiscal agent or service coordinator (case manager), those professionals will be able to help you get

Table 7.13. Types of background checks
State criminal background
Federal criminal background
State nursing assistant/care provider registry
Sex offender registry
Academic record
Prior employment

a background check completed. Many states provide online sex offender registries. States also maintain registries of nursing assistants and other care providers who have substantiated reports of abuse. You should check these registries as part of your background check process. Be aware that the information you receive from background checks may be incomplete because of limited date ranges or limitations in the records that are maintained. People with criminal records or substantiated abuse in states other than your own will not appear in your state’s background check systems.

Selecting and Hiring Your Personal Assistant

Now it is time to select the PA that you think is the best fit for you. Hopefully you have several qualified applicants to choose from; however, this is not always the case. Whom you hire is a very important decision. Review all of the information you have collected. Get a second opinion from trusted family and friends.



Ask Yourself...

- Did I feel comfortable with this person?*
- Did he or she seem comfortable answering my questions?*
- Did he or she seem comfortable with me?*

Once you have made your decision, contact the person and offer the position. Clarify the hourly wage, benefits, and work days/hours. If the applicant accepts the position, prepare a written employment agreement (job contract; see Table 7.14). Both you and the care provider will sign the written agreement. You should inform any other applicants that the position is filled.

Strategies for Managing Your Care Provider

You want to be in charge of setting the expectations for your care receiver–care provider relationship from the very beginning. Setting and then maintaining boundaries is a very important part of creating your care receiver–care provider relationship.

Table 7.14. Information to include in a written employment agreement

Names of employer and care provider
Wages and benefits (e.g., mileage, meals, vacation, holidays)
Pay schedule
Days and hours of work
Job responsibilities (refer to the job description)
Unacceptable behavior (e.g., smoking, drinking alcohol, swearing)
Termination expectations (e.g., how much notice, reasons for termination without notice)
Date of agreement
Signature of employer and care provider

Sources: Burdsall (n.d.), Family Caregiver Alliance (2001), Ulicny et al. (2006).



Ask Yourself...

What does the term boundaries mean to me?

Why is setting boundaries an important part of abuse prevention?

Let's examine the term *boundaries*. Some boundaries are real things—for example, a fence is a type of physical boundary. A fence keeps wanted things or people in and unwanted things or people out. Personal boundaries are typically invisible, meaning as people we do not have fences that surround us to keep other people away or prevent them from touching us. What we can do to protect ourselves is to set and enforce **personal boundaries** that protect our physical space, our emotional space, our social space, and our personal property. As the care receiver (and sometimes employer) you want to be in control of your care. One way to be in control of your care is to figure out and to explain and enforce your personal boundaries with care providers.

You should give your PA training for the job. During this training, you should begin to establish your rules for how the PA interacts with you and has access to your home and your personal possessions. Maintaining personal boundaries with your PA can be difficult, especially if the PA lives with you, is a close family member or friend, or is someone you have worked with for many years. Nevertheless, it is important that your care provider respects your wishes for your privacy, and your belongings, and how you prefer to be cared for.

It is important that you openly discuss confidentiality (privacy) issues with your PA (see Table 7.15). If you are thinking about using a family member or friend as a care provider, discuss these issues as you plan for your working relationship. Maintaining your personal boundaries and privacy may be more difficult when a spouse/partner or close relative is providing care, which is why it is important that communication on these issues be clear and open (Burdshall, n.d.). If a PA is living with you, it is important that you also respect his or her privacy.

If you have a live-in PA, you will have many additional issues to discuss, including the use of free time, access to space (rooms) in your home, visitors (times,

Table 7.15. Issues to discuss with your care providers

Sharing personal information about you with others: Discuss the information about you that you expect to be kept confidential (e.g., your address, your telephone number, your last name, family information, medical information, financial information).

Use of your personal property: Decide if and what personal property may be used by your care provider. Your care provider should always ask for your permission to use your personal property.

Use of phone for personal calls while working: Discuss the use of your telephone for receiving and making telephone calls.

Policy on smoking: Address whether, where, and when it is acceptable to smoke.

Use of your car: Discuss use of your car for work-related travel. Think about insurance coverage and liability if using your car. You should make sure the person has a good driving record.

Use of your home during work breaks: Discuss where your care provider can take work breaks (e.g., inside and outside of your home, specific rooms in your home, off the premises). Discuss the use of your refrigerator to store food/beverages and the stove/microwave to prepare meals. Discuss the use of your television, radio, computer, or other such devices during work breaks. Discuss the appropriateness of taking a nap.

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how often, overnight guests), and housekeeping expectations. If you need assistance above and beyond the hours or duties you and your PA have agreed on, it is best to discuss this with the PA as soon as possible. Be sure to discuss payment for these additional services and hours as well.

Good communication skills are an important part of creating and maintaining the relationship with your care provider (see Tip Box 7.8). You may find that it is more difficult to assert yourself and clarify your needs when working with a family member or friend who is a care provider for fear of being thought of as too demanding or difficult (Burdsall, n.d.). Nevertheless, it is important that you advocate for yourself, clearly communicating your preferences and needs to your care providers. If you think that a care provider does not understand your expectations or if tasks are not performed correctly, you should discuss the issue as quickly as possible and get it resolved (Burdsall, n.d.). Ask for feedback about how you are explaining things. Perhaps you are not explaining clearly. Use assertive communication to engage in a conversation with your care provider (see Tip Box 7.9). Your goal is to positively resolve the issue rather than having to fire a PA and start the hiring process all over again.

As a good employer, you will want to provide your PA with evaluations of his or her work performance. Periodic evaluation can improve communication between you and your PA, motivate your PA, identify training needs, document unsatisfactory work, and provide you with an opportunity to provide praise and

Tips for managing care provider relationships

- Do not share personal information that is not needed for care providers to perform their job (such as family history; disagreements with partners, family, or friends; finances; health or medical issues).
- If you are able to afford a home monitoring system of some kind, have it installed before hiring a care provider.
- Have caller ID installed on your telephone to track incoming telephone calls.
- Do not allow a care provider to rearrange your home (unless for a good reason and then only with your permission). This can be a sign that the care provider is trying to assume control of the household.
- Always stay in charge; never put one care provider in charge of other care providers.
- Have friends and family make unexpected visits to your home.
- Never give or lend money to a care provider.

Source: McDonald (2007).

Tips for discussing a concern with care providers

- Set aside enough time to fully discuss the issue or concern.
- Give full attention to your care provider.
- Focus on the care provider's actions (behaviors), not the person.
- Define the issue as a mutual problem that you want to solve.
- Talk about the specific problem. Give clear examples. Don't accuse.
- Use "I statements" when describing your feelings and reactions.
- Describe how you might have played a part in the problem.
- Let your care provider explain the problem from his or her perspective.

Source: Minnesota Department of Human Services (2007, p. 31).

TIP BOX 7.9

positive feedback (Casebolt & Gilson, 2000). It is a good idea to discuss performance evaluations and the evaluation criteria sometime during or shortly after the hiring process. Consider conducting the first performance evaluation about 90 days after the PA is hired. Provide written feedback, identifying both strengths and areas for improvement. Set a time to review the evaluation with your PA. Give your PA time to read the evaluation, ask questions, and respond. If there are areas needing improvement, it is a good idea to set up a timeline for the PA to meet your work expectations (Casebolt & Gilson, 2000). Both you and your PA should sign the evaluation after reviewing it. Keep a signed copy for your records. After the initial evaluation, you should conduct performance evaluations once a year (or more often if needed). Don't forget to show your appreciation to your care provider on a regular basis by saying "thank you" for the good work that they do.

Final Thoughts About Hiring and Managing Personal Assistants

Remember that an important part of abuse prevention is having the right care providers. Consumer-directed services will give you the most control over who provides your care but the process requires a lot of work on your part. Agency-based services (like home health care) give you less control over your care providers but provide a lot of support in managing your care. Regardless of which option for care you choose, use the information about assertiveness, creating and maintaining healthy and mutually respectful relationships, safety, and managing care providers to guide your working relationship with the people who support you. Use the Resources at the end of the chapter to learn more about hiring and managing PAs.

FINAL THOUGHTS

As an empowered self-advocate you can decrease your own personal risk of being abused by using the information and skills that you have learned about being assertive, creating healthy and mutually respectful relationships, personal safety, and hiring and managing personal assistants. Help to empower others by sharing this information with people with disabilities whom you know and support. Join together with other self-advocates and advocates to create ways to make sure that all people with disabilities have access to the violence and abuse prevention information that they need. Through your collective action you can begin to break down systemic barriers that make it difficult for people with disabilities to protect themselves and prevent violence and abuse.

RESOURCES

Web Sites

The Center for Opportunity and Outcomes for People with Disabilities, <http://www.tc.columbia.edu/oopd/index.asp?Id=Home&Info=Mission+Statement>
 National Clearinghouse on Abuse in Later Life, <http://www.ncall.us>
 The National Council on Independent Living, <http://www.ncil.org>
 The Research and Training Center on Independent Living, <http://www.rtcil.org/>
 SafePlace, <http://www.safeplace.org>

Curriculum

Hughes, C.M., & Abramson, W.H. (2000). *Stop the violence, break the silence: A training guide*. Austin, TX: SafePlace, 512-385-5181 or 512-482-0691 (TTY), <http://www.austin-safeplace.org>
 Khemka, I., Hickson, L., & Reynolds, G. (2005). *ESCAPE Curriculum*. New York: Center for Opportunity & Outcomes for People with Disabilities, <http://www.tc.columbia.edu/oopd/index.asp?Id=Center+Projects&Info=Abuse+Prevention+and+Escape+Curriculum+Decision+Project+%2D%2D+ESCAPE+DD>, 212-678-0376

Suggested Readings

Alberti, R., & Emmons, M. (2001). *Your perfect right: Assertiveness and equality in your life and relationships*. Atascadero, CA: Impact Publishers, 1-800-246-7228, <http://www.impactpublishers.com>
 Blanchett, W.J., & Wolfe, P.S. (2002). A review of sexuality education curricula: Meeting the sex education needs of individuals with moderate and severe intellectual disabilities. *Research and Practice for Persons with Severe Disabilities*, 27(1), 43–57.
 Blum, G., & Blum, B. (2004). *Feeling good about yourself: A guide for people working with people who have disabilities or low self-esteem*. Decatur, IL: Blue Tower Training, <http://www.bluetowertraining.com>
 Brandl, B. (2003). *Safety planning: How you can help* (safety planning for people with a cognitive disability). National Clearinghouse on Abuse in Later Life, Wisconsin Coalition Against Domestic Violence, 608-255-0539, <http://www.ncall.us>
 Burdsall, D.L. (n.d.). *Hiring and management of personal care assistants for individuals with spinal cord injury*. Santa Clara, CA: Spinal Cord Injury Project at Santa Clara Valley Medical Center, <http://www.tbi-sci.org>
 Casebolt, G., & Gilson, S.F. (2000). *Managing personal assistants: A consumer guide*. Washington, DC: Paralyzed Veterans of America, <http://www.pva.org>

- Hanson, M. (Ed.). (2000). *Safety planning: A guide for individuals with physical disabilities*. National Clearinghouse on Abuse in Later Life, Wisconsin Coalition Against Domestic Violence, 608-255-0539, <http://www.ncall.us>
- Harteau, J., & Keegel, H. (1998). *A woman's guide to personal safety*, Minneapolis, MN: Fairview Press. (No longer in print. May be available at a public library or from used-book vendors.)
- Harteau, J., & Keegel, H. (1999). *A senior's guide to personal safety*, Minneapolis, MN: Fairview Press. (No longer in print. May be available at a public library or from used-book vendors.)
- Hingsburger, D. (1995). *Just say know: Understanding and reducing the risk of sexual victimization of people with developmental disabilities*. Eastman, Quebec, Canada: Diverse City Press.
- Horn Anderson, O. (2000). *Doing what comes naturally: Dispelling myths and fallacies about sexuality and people with developmental disabilities*. Decatur, IL: Blue Tower Training, <http://www.bluetowertraining.com>
- Ulicny, G.R., Adler, A.B., Kennedy, S.E., & Jones, M.L. (2006, March). *A step-by-step guide to training and managing personal assistants: Consumer guide*. Lawrence, KS: Research and Training Center on Independent Living, University of Kansas, <http://www.rtcil.org/> (Includes sample documents that you can use for hiring and managing personal assistants.)
- Vogt, F. (2007). *See Sally kick ass: A woman's guide to personal safety*. Parker, CO: Outskirts Press, <http://www.outskirtspress.com>

8

Putting the Guiding Principles into Action

The Advocacy and Empowerment Project

with Willi Horner-Johnson and Charles E. Drum

Anti-crime workshop works with disabled

*written by David Heinzmann,
Chicago Tribune, Chicago, Illinois, November 10, 1999, p. 4*

This newspaper story is about abuse of people with disabilities and one project developed to address the problem. The story tells about a workshop that was held in Chicago's Beverly neighborhood at CARC, a developmental disability service provider agency. Through discussion, role playing, and video presentations, workshop participants, including people with disabilities, learned ways to identify and prevent abuse. The workshop was one of 20 that organizers from University of Illinois at Chicago (UIC), Institute of Disability and Human Development planned to hold throughout the year. According to Nancy Fitzsimons-Cova, research assistant professor at UIC, "the program is long overdue." Fitzsimons-Cova stated that "the project should reach about 600 people" with the hope that service agencies such as CARC "will incorporate the program into their work" (p. 4).

The newspaper story you just read discussed the Advocacy and Empowerment Project ("the Project" for short). By the end of the Project, 22 workshops were conducted by 28 community trainers throughout Illinois with 465 people participating in the training. When the 41 members of the Regional Workgroups are added in, over 500 people with and without disabilities were directly affected by the Project.

The goal of this chapter is to show how the guiding principles can be used in a collective action to combat violence and abuse of people with disabilities. You now know that many of the barriers to preventing violence and abuse are systemic barriers. The Advocacy and Empowerment Project is an example of one strategy

to promote systems change. In addition to information about the Project, general tips for organizing to promote change are embedded throughout this chapter to increase your understanding of how to promote systems change. It is our hope that learning about the Project will get you thinking about what you can do in your own community to combat violence and abuse. This chapter is about planting a seed from which your ideas for individual and collective action will grow. Let's begin with a brief overview of the Project.

OVERVIEW OF THE ADVOCACY AND EMPOWERMENT PROJECT

The idea for the Project came from the members of the Illinois Coalition on Disability and Abuse (CODA), who felt strongly that training was needed to educate and empower people with disabilities to address the abuse in their own lives. A **coalition** is an organization made up of many organizations (Homan, 2004). See Table 8.1 to learn about the benefits of working in a coalition and Table 8.2 for steps in forming your coalition. Dr. Charles E. Drum, the original Project Director, wrote and was awarded a grant from the U.S. Department of Education, National Institute on Disability and Rehabilitation Research (NIDRR) to fund the Project. The primary goal of the Project was

To provide knowledge, skills, and resources to people with disabilities, family members, and advocates that would empower them to prevent abuse and enforce the rights of adults with disabilities who have been abused. (Fitzsimons-Cova & Horner-Johnson, 2000, p. 1)

This goal was achieved through development of a curriculum called *Taking Charge: Responding to Abuse, Neglect, and Financial Exploitation* (Fitzsimons-Cova et al., 2000) that was used to conduct *Taking Charge* workshops for advocates and self-advocates.

Project Highlights

Let's review some of the major steps taken to achieve the Project's goal.

- *Expanding the Advisory Board.* The CODA Steering Committee (or Advisory Board) was expanded to include people with disabilities, people from minority racial/ethnic groups, and representatives from the criminal justice, adult protection, and victim service systems. The purpose of CODA was to provide guidance and feedback on the Project. See Tip Box 8.1 for tips on how to identify **stakeholders**.

Table 8.1. Benefits of coalitions

Broaden the support for your issue
Provide greater access to resources (e.g., volunteers, money, space, technology, expertise, relationships with people in positions of power)
Can inform and put into action large numbers of people in a short time
Help to gain acceptance from community leaders
Enhance your credibility in the community
Provide greater legitimacy for your issue

Source: Homan (2004, pp. 381–382).

Table 8.2. Steps in forming a coalition

1. Decide whom you want to get involved.
2. Contact people and explain why joining is in their self-interest—how joining will benefit them or their organization.
3. Get a firm commitment from each organization, including the names of the person or people from the organization who will be involved in your coalition.
4. Actively involve representatives from each coalition organization.

Source: Homan (2004, p. 383).

Tips for identifying stakeholders

Begin the process of identifying your stakeholders by asking

- Who is experiencing the problem?
- Who is benefiting from the situation staying as it is?
- Who would benefit from change?
- Who makes decisions about the issue?
- Who needs to behave in a different way to solve the problem?
- Who is likely to oppose a change?
- Who is likely to support a change?

Source: Homan (2004, p. 220).

TIP BOX 8.1

- *Forming Regional Workgroups.* Two Regional Workgroups were formed to collaborate on the creation of the *Taking Charge* curriculum. A total of 41 people served on the workgroups, including one in Northern Illinois and one in South Central Illinois. Each workgroup included people with disabilities and representatives from disability services and the criminal justice, adult protection, and victim service systems. See Tip Box 8.2 for tips on how to get people involved in your collective action.
- *Creating the curriculum.* The first draft of the curriculum was created over the period of about 1 year using the facilitated conversation method, a collaborative process between Project staff and Regional Workgroup members. The **facilitated** (or **focused**) **conversation method** was developed by the Institute on Cultural Affairs USA, and involves a multistep process of planning and discussion. See Table 8.3 to learn about how we used the facilitated conversation method. The method was used by the Project as a way to obtain a high level of involvement, interaction, and input from Regional Workgroup members. Changes were made to the curriculum over the next 2 years of the Project, based on feedback from our collaborators.
- *Recruiting community trainers.* Project staff made presentations to disability advocacy groups and collaborated with CODA and the Regional Workgroups

Tips for getting people involved

- *Contact people.* Start with contacting people you know. Expand to contacting people that others in your effort know. Personally invite people to join your effort in a one-to-one conversation.
- *Give people a reason to join.* People are motivated by their own self-interest. The reasons people join include belief in your issue or project, liking the people involved, and enjoying the activities your group engages in.
- *Ask for participation.* Not everyone will say “yes.” But people often say “yes” when asked directly. Be enthusiastic. Talk about the ways they can contribute and how their contribution will help achieve the group’s goal.
- *Maintain involvement.* Once you get people to say “yes” and show up, you need to keep them involved. Make special efforts to welcome new members and give people something to do right away.

Source: Homan (2004, pp. 247–252).

TIP BOX 8.2

Table 8.3. How we used the facilitated conversation method

During a year-long process, the Regional Workgroups

1. Identified general topic areas to consider for inclusion in the curriculum
2. Selected three major topic areas to include in the curriculum
3. Formed smaller workgroups to focus on each topic area
4. Developed outlines of the specific issues to cover under each topic
5. Discussed the best methods for presenting each issue during the workshop
6. Identified resource materials needed to develop and present the curriculum
7. Mapped out the order and way that information would be presented

to recruit community trainers. A total of 45 people applied, and 40 were accepted as potential trainers.

- *Training community trainers.* Training sessions consisted of a 1-day introduction to the curriculum, a 2-day practice session, and a follow-up meeting to prepare trainers to plan and conduct a workshop in their community. Twenty-eight community trainers completed the training.
- *Pilot workshops.* Project staff and community trainers conducted 8 pilot (trial run or practice) workshops throughout Illinois. A total of 241 people participated in the workshops.
- *Community trainer facilitated workshops.* During the third year of the Project, community trainers collaborated with Project staff to plan and conduct 14 workshops throughout Illinois (see Figure 8.1). A total of 212 people



Figure 8.1. Year 3 *Taking Charge* workshop participants. (From Fitzsimons-Cova, N., & Horner-Johnson, W. [2000]. *Illinois joint training initiative on disability and abuse: Advocacy and empowerment through knowledge dissemination project. Final report*. Chicago: Institute on Disability and Human Development, Department of Disability and Human Development, University of Illinois at Chicago. Reprinted with permission.)

participated in the workshops. Half of the participants were people with disabilities.

- *Evaluating the curriculum.* Three methods were used to get information about whether the Project was making a difference: Workshop Evaluation Form, Before and After Training Assessment, and Follow-up Survey. See Table 8.4 for a summary of feedback obtained from workshop participants. The results of the evaluation are presented in the final Project report (Fitzsimons-Cova & Horner-Johnson, 2000).
- *Dissemination of the curriculum.* A total of 215 free copies of the curriculum were mailed to a variety of organizations, including one for each CIL and P & A agency, and to chapters of the Coalition of Citizens with Disabilities throughout the United States. The curriculum was also available for purchase through the Institute on Disability and Human Development (IDHD) at the University of Illinois at Chicago (UIC).

Table 8.4. Feedback from participants at the Taking Charge workshops

As a result of attending a <i>Taking Charge</i> workshop, participants reported that they
Learned new information about violence and abuse
Were more confident that they had adequate information and skills to prevent violence and abuse
Had more positive attitudes about people with disabilities
Learned new information that actually helped them prevent violence and abuse

Source: Fitzsimons-Cova & Horner-Johnson (2000).

Refer to the Resources section at the end of the chapter to learn how you can get the Advocacy and Empowerment Final Project Report. Let's move on to looking at how each guiding principle was used to achieve the Project's goals.

Collaboration in Practice

One of the major successes of the Project was the collaboration that occurred between people with disabilities, family members, and professionals from the university and from state and community-based organizations. The purpose of expanding CODA, forming Regional Workgroups, and recruiting community trainers was to build collaboration between **stakeholders**—meaning people with disabilities, family members, and professionals involved (or who should be involved) in preventing violence and abuse of people with disabilities. The important new stakeholders that joined the Project were people with disabilities and professionals from the criminal justice, adult protection, and victim service systems. (See Tip Box 8.1 for tips on identifying your stakeholders).



Ask Yourself...

Who are the key stakeholders in my community who should be involved in combating violence and abuse of people with disabilities?

What can I do to build collaboration between these stakeholders?

It is not enough to just bring people together to work on a task force, committee, or workgroup. As you have probably experienced, just because people are sitting in the same room does not mean that they are collaborating with one another. The reason the Project staff used the facilitated conversation method to create the curriculum was to make sure that all Regional Workgroup members were actively involved and had equal input. Using this method is very time consuming. However, the benefits outweigh the drawbacks. One of the most important benefits for the Project was the increased exchange of ideas among all participants. Using this process created a unique and empowering collaboration between people with very different views on how to combat violence and abuse of people with disabilities.

Another way that collaboration was put into practice was through the team approach to conducting the workshops. All of the pilot workshops were conducted by Project staff in partnership with community trainers. All of the year 3 workshops were conducted by teams of community trainers. All of the teams included people with disabilities and professionals, and some of the professionals were also people with disabilities. Usually professionals from different parts of the service system worked together. The collaborative team approach also provided workshop participants with a model for how they could collaborate with people from different walks of life to combat violence and abuse of people with disabilities.

The final year's workshops were planned and conducted in partnership with Project staff, the trainers, and co-sponsors (local disability, advocacy, or victim services organizations). Collaboration was the key principle affecting the decision to conduct the workshops in partnership with community trainers and co-sponsors.

Tips for spreading the word about your collective action

- Word of mouth—you tell one person, they tell another person, and so forth
- Fliers and posters
- Billboards
- Newsletters
- Brochures
- Speaker's bureau—present to local groups in your community
- Newspapers—community announcements, letters to the editor, featured stories
- Radio and television public service announcements (PSAs)
- Internet and online resources (e.g., web site, electronic newsletter, Listserv, discussion group)

TIP BOX 8.3

Co-sponsors provided resources and helped publicize the workshops in their communities. Trainers, with the support of co-sponsors, took the lead in planning, publicizing, and conducting the workshops in their communities. As Project staff, we provided guidance, support, and assistance as needed throughout the planning process. See Tip Box 8.3 for tips on how you can spread the word about your collective action.

Collaboration on the Project did not just magically happen. Making collaboration one of the guiding principles was intentional. Using a collaborative approach was the only way that the Project would achieve its goal (see Tip Box 8.4). Creating true collaboration between all of the Project's stakeholders took work. It certainly meant that the Project staff and other professionals had to put away the idea that they were the experts or that they had all the answers. The Project was a success because of collaboration.

Strengths Perspective in Practice

Everyone connected with the Project was committed to upholding a strengths perspective, meaning maintaining a focus on what people could do and how they could contribute. One way that the Project lived up to this principle was through our collaboration with community trainers. The *Taking Charge* workshops covered a lot of information, but because we used a team approach to conducting the workshops, no one person had to know all of the information. We were able to tap into the strengths of our community trainers. Some trainers were better at presenting information, others were better at facilitating a discussion, and some people were

Tips for making collaboration work

- Provide opportunities for creating a sense of ownership in the group or project.
- Privately and publicly acknowledge the good work that collaborators are doing.
- Act in a trustworthy manner to build trust.
- Maintain clear, open lines of communication. When possible, use personal face-to-face communication.
- Decide on the way that decisions are going to be made. Consensus (agreement upon by all members of the group) decision making is preferred but it can be time consuming to get a consensus. Majority decision making is another option.
- Decide on the leadership of your group, including the roles and authority of the leaders.
- Put decisions made by the group in writing.

Source: Homan (2004, pp. 420–422).

TIP BOX 8.4

good at conducting the group activities. Project staff worked with community trainers to help them identify their strengths as individuals and as teams.

We also created a support trainer role. The idea for the support trainer came from people interested in being involved in the Project, but who did not feel comfortable presenting the information to an audience. It is important to remember that people's level of participation may vary—this is normal for any group or project (see Table 8.5). By creating the support trainer position we were able to keep more people involved (see Table 8.6). We also increased the chances that one day someone who was a support trainer would feel empowered enough to become a presenter of the *Taking Charge* curriculum.

Another way that we used a strengths perspective was in our collaboration with the community trainers who took the lead in planning workshops during the third year of the Project. Each lead trainer was responsible for doing most of the

Table 8.5. Levels of participation

Leadership level: The core group of participants who are actively involved in making decisions, providing direction, and doing the work of the group or project

Worker level: Ongoing active participants who follow the lead of the leadership of the group or project

Assister level: Occasional active participants who periodically lend a hand when asked

One-shot participant level: Do something for the group or project once or for a short period of time and then disappear

Advisor level: Provide expert advice as needed

Inactive general supporter level: Provide public endorsement (support for) the efforts of the group or project

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Source: Homan (2004, pp. 235–238).

Table 8.6. Role of support trainers

Set up before and clean up after the workshop
Register workshop participants
Answer questions and assist participants as needed
Assist trainers with equipment (e.g., TV/VCR/DVD player, projector)
Work with participants in small group activities
Provide emotional support to participants

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planning of a workshop in their community, including finding a co-sponsor. Dr. Willi Horner-Johnson (graduate student on the Project at the time) was the main contact with all of our lead trainers. In some cases, lead trainers needed very little support and guidance from Project staff. In other cases, Project staff were very involved in helping lead trainers put together their workshops. Imagine how rewarding it was for Project staff and lead trainers when a lead trainer was unsure about her or his planning abilities, but succeeded in planning the workshop with less help than he or she anticipated. This is an example of the strengths perspective in action.

Self-Advocacy in Practice

It is no accident that the name of the curriculum and workshop is *Taking Charge*.



Ask Yourself...

What comes to my mind when I think of the words “taking charge”?

You will recall that self-advocacy is the action part of empowerment. The vision for the Project was to provide people with disabilities with the information and skills that they needed to prevent violence and abuse and to enforce their rights. *Taking charge* is about taking action. And taking action is what self-advocates do. Self-advocates speak up for themselves.

While the term *self-advocacy* is not part of the formal goal statement of the Project, promotion of self-advocacy was definitely the intention of everyone involved. People with disabilities were purposely recruited to participate in all aspects of the Project. As members of CODA and/or Regional Workgroups, people with disabilities used self-advocacy to make sure that the curriculum reflected the experiences and needs of people with disabilities. As community trainers, people with disabilities modeled self-advocacy to workshop participants. The contents of the *Taking Charge* curriculum reflected the principle of self-advocacy (see Table 8.7). As workshop participants, people with disabilities learned information and self-advocacy skills to help them take charge by advocating for themselves and others with disabilities.

Self-Determination in Practice

You already know that self-determination is very closely associated with self-advocacy. The primary way that the Project applied the principle of self-

Table 8.7. Overview of the *Taking Charge* curriculum

<i>Module 1—Disability and Maltreatment.</i> Presents different ways to define disability, with an emphasis on the social approach to disability. The social approach is applied to abuse of people with disabilities.
<i>Module 2—Your Safety, Your Rights.</i> A video shows people with disabilities in situations that could lead to abuse. The actors show how to take charge in each situation.
<i>Module 3—Recognizing Abuse, Neglect, and Financial Exploitation.</i> Definitions of different types of abuse, described in terms of a continuum from subtle to obvious.
<i>Module 4—External Barriers to Action.</i> Discussion of myths about people with disabilities and how these myths make it difficult to stop abuse. Physical barriers and the ADA are also briefly mentioned.
<i>Module 5—Internal Barriers to Action.</i> Describes various internal barriers and emphasizes that the longer the abuse continues, the greater the impact on the victim.
<i>Module 6—Taking Charge!</i> Participants learn how to be assertive, to move from being a victim to being a survivor, and put their knowledge into action during a small group activity.
<i>Module 7—Understanding the System.</i> Participants learn about community resources, the administrative (adult protection services) and criminal justice systems.
<i>Module 8—Self-Advocacy and Empowerment: Putting It All Together!</i> Participants engage in role playing to use all the information learned during the day and practice skills for stopping abuse.

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determination is through the information presented at the *Taking Charge* workshops. One of the ways to promote self-determination is through an understanding of systemic and personal barriers. Some of the same kinds of barriers were discussed in the *Taking Charge* workshop as external and internal barriers. In the workshops, participants learned about the obstacles to getting out of abusive relationships and situations. Another way to promote self-determination is by understanding the systems that are supposed to protect and service people with disabilities who have been abused. At each of the workshops, participants were provided with a list of their local resources. Family members and professionals attending the workshops were encouraged to support the self-determination of victims by recognizing the power of the barriers, by clearly explaining available resources and options, and to the greatest degree possible, by supporting the self-determination of people with disabilities who have been abused.

Empowerment in Practice

You know that empowerment is a value that guides how people practice, a process of increasing power, and an outcome. You are now pretty familiar with the Project.



Ask Yourself...

In what ways do I think the Project was guided by the principle of empowerment?

How do I think the Project promoted the empowerment of people with disabilities?

Let's look at a few of the ways that the Project promoted the principle of empowerment. The Project was guided by the value of empowerment. You will recall that an empowerment approach focuses on strengths and works in partnership with people with disabilities (see Tip Box 8.5). The Project focused on strengths and collaborated with people with disabilities.

Through the experience of being a Regional Workgroup member and/or a community trainer, people with disabilities participated in an ongoing collaborative

Tips for empowering others

- *Ask questions of and ask for input from others.* Recognize good ideas. Allow other people to have better ideas than your own.
- *Reroute questions.* Ask others in the group to answer questions. In response to a question that you are asked say something such as, “I’m not sure. Jane, I wonder what you think about...” Be careful about putting people on the spot.
- *Share the decision making.* Make sure that decisions are made by many, not just a few people or the same people all of the time.
- *Recognize the ideas and accomplishments of others.* Give people credit and recognition for their ideas and efforts on a regular basis.
- *Rarely accept statements of “I can’t” or “I don’t know.”* These are statements of inability. Focus on abilities and ask people “What can you do?” or “How can you help?”
- *Share the responsibility and authority.* Spread the tasks around so that everyone is contributing.
- *Promote the acceptance of mistakes and acknowledge your own.* We all make mistakes. A lot of learning comes from the mistakes that are made. Don’t make a big deal about your own and others’ mistakes.
- *Recognize your successes.* “Empowerment occurs through success” (p. 201). Pay attention and celebrate the minor and major successes to keep people engaged, committed, and energized.

Source: Homan (2004, pp. 200–201).

TIP BOX 8.5

process with the goal of increasing personal power. The Project also provided a process for people with disabilities who participated in the workshops to increase their personal power. You will recall that in order for people to have control over their lives, they need

- To be aware of barriers
- Knowledge and skills to make a change in their lives
- Supports and opportunities to practice skills in making change

At the *Taking Charge* workshops participants discussed barriers, were provided knowledge and skills to prevent violence and abuse, and were given the opportunity to practice what they learned. Empowerment as a process was clearly used to guide the Project.

The goal of using an empowerment approach and the empowerment process is helping people to become empowered. Think about all of the ways that the Project worked to uphold the principles of collaboration, strengths, self-advocacy, and self-determination. The same examples demonstrate how the Project achieved its goal of empowering people with disabilities, family members, and advocates to prevent violence and abuse and enforce the rights of people with disabilities. Unfortunately, we never formally asked the Regional Workgroup members or community trainers how participation contributed to their own empowerment. We did get feedback from a small group of workshop participants who told us that the information and skills helped them prevent and stop abuse of people with disabilities (Fitzsimons-Cova & Horner-Johnson, 2000).

Final Thoughts About Guiding Principles

It is important to think about the guiding principles that are important to you up front—at the beginning of any collective action to combat violence and abuse. It will be easier for you to collaborate with others when you share similar values. The guiding principles determine how people interact and treat one another. Practicing the guiding principles can help to minimize conflicts and help to resolve disagreements when they occur. Having shared values can help to bring people to the table, but not necessarily keep people involved. Throughout the Project we learned many valuable lessons on how to maximize the participation of our stakeholders (see Tip Boxes 8.4 and 8.5), particularly people with disabilities. Let's move on to thinking about some of the simple but very important ways that we supported our collaborators.

LESSONS LEARNED FROM THE ADVOCACY AND EMPOWERMENT PROJECT

We used a number of strategies to make it as easy as possible for people with disabilities (and others) to actively participate. Keep these tips in mind as you think about how you might involve people with disabilities and others in collective action to combat violence and abuse in your community.

Location, Location, Location

To allow participation of people with disabilities, finding an accessible meeting location is very important. Unfortunately, when people from the site assure you that the facilities are accessible, you cannot always take their word for it. Whenever possible, check out the space for yourself. When selecting a location, you should also think about the acceptability of the site. Ask yourself if there are any reasons people with disabilities would not want to go to a meeting at the location. Look into effective and reliable ways to have people participate without having to physically come to the meeting location (e.g., audio conference, video conference).

Meeting Times

Think about possible conflicts you may encounter, and try to find a time that works well for the largest number of people possible. People with disabilities may use

paratransit and buses as a means of transportation. It is important to find out when these transit services are available when determining your meeting times.

Reasonable Accommodations

Another key to including people with disabilities is providing reasonable accommodations. For events like meetings and workshops, you may need to provide qualified sign language interpreters for people who are deaf or hard of hearing. If the meeting is long, you will need two interpreters who can trade off. Interpreters often need to be booked well in advance, so be sure to plan ahead. People who are blind or have a visual impairment may need written material in an alternate format. Other types of reasonable accommodations may be needed by your collaborators or participants. Ask everyone in advance what accommodations they need in order to participate fully.

Refreshments

Providing food and beverages is a small way of thanking people who are sharing their time with you. If your meeting or event is during a meal time, and it is financially feasible, providing a full meal will be appreciated. If it is at another time of the day, light refreshments will be enough. Do not forget to accommodate the special dietary needs of participants, such as vegetarians, people with diabetes, and people who eat kosher.

Dealing with the Emotional Well-Being of People

Meetings, events, or projects dealing with violence and abuse require extra attention to the emotional well-being of participants. Discussing violence and abuse can be very painful, particularly when some of the participants may have been abused in the past, may currently be in an abusive situation, or may know someone who has been or is being abused. This applies to people with and without disabilities. Some people may have buried thoughts and feelings from past experiences that are triggered during the discussion. Other people may realize for the very first time that the way they are being treated by family, friends, professionals, or others is wrong—and may in fact be criminal. It is important to pay attention to people's emotions, and be sensitive and respectful if issues arise. It may help to designate a quiet space where people can go to take a break. Some people may prefer to be alone, while others may wish to talk to someone for support and potential referral to local resources. Keep in mind your responsibilities as a mandated reporter if someone who is considered a vulnerable adult in your state discloses abuse. Refer back to Chapter 3 for details on making a report while respecting the rights and self-determination of the person with disabilities who disclosed the abuse to you.

Keeping in Touch

If you are including people in an ongoing project that will involve multiple meetings, stay in touch between meetings. Project staff contacted each Regional Workgroup member at least once between meetings via mail, e-mail, or telephone.

We used these contacts to provide additional information and updates, obtain feedback, and remind people of the next meeting (see Tip Box 8.6). Contact between meetings is an opportunity to check in to make sure you are meeting people's needs and find out how future meetings can be improved.

It has been 8 years since we finished the Project. All of the Project staff have moved on to other universities and opportunities. All of us have been involved in various projects to empower and improve the lives of people with disabilities in our communities. Some of us have continued working on projects to combat violence and abuse of people with disabilities. The experience working on the Advocacy and Empowerment Project had a profound impact on all of us. None of us will forget the wonderful people that we had the privilege to collaborate with or the valuable lessons that we learned about *Taking Charge* and combating violence and abuse of people with disabilities.

Tips for keeping people involved

- Pay extra attention to newcomers to your group to make sure they feel included.
- Give people something to do right away.
- Be on the lookout for what people can do and then ask them when the opportunity arises.
- Offer people a range of ways they can participate. Match tasks to people's talents and interests.
- Give people clear directions and adequate preparation to perform their assigned tasks.
- Give people the opportunity to say "no" to some tasks.
- Find ways for people to work together on specific tasks. This might increase the chances that some people who often say "no" will say "yes."
- Help people to feel a part of the group. Avoid inside jokes or stories or other actions that make some people feel like an outsider.
- Spend some time getting to know people on a personal level. "Personal relationships are the glue that holds the [group] together" (p. 249).
- Ask for everyone's ideas and opinions on a regular basis. Incorporate the ideas into the work of the group, as appropriate.
- Keep in regular contact. "Out of sight, out of mind—out of action" (p. 250).

Source: Homan (2004, pp. 247–252).

FINAL THOUGHTS

Now it's time for you to think about how you can combat violence and abuse in your community.



Ask Yourself...

What kind of approach to combating violence and abuse of people with disabilities would work well in my community?

Who are the stakeholders in my community? Who should be included, considering both individual people and organizations?

Who would I want to collaborate with on a project to combat violence and abuse?

What strengths can I contribute to a project to combat violence and abuse?

What can I do to create the right mind-set or way of thinking needed to combat violence and abuse?

These and many more questions are for you to answer. You have been given many of the tools (information and resources to learn more) that you need to

- Prevent violence and abuse in your own life
- Empower people with disabilities whom you know
- Educate others, including family members, friends, professionals, community leaders, and legislators
- Begin to change systems (disability services, victims services, vulnerable adult advocacy and protection, and criminal justice)

Learn about the supports and services for crime victims in your community. Find out how responsive these systems are to people with disabilities. Identify the systemic barriers and take action to eliminate these barriers. Read your local newspaper on a regular basis to discover what is being written about people with disabilities. In a recent edition of the author's local newspaper there was a story about people with autism who engage in disruptive behavior while in a public setting. A man in the story was quoted as saying, "When we got away from the concept of institutionalization in America, we lost an important element of trying to maintain civility. There is a place for mental institutions" (Associated Press, 2008, p. B3). The horrors of institutional abuse have been well documented. Yet segregating some people with disabilities, the ultimate form of abuse, is an acceptable practice in the minds of some people in our society. Institutionalization of people with disabilities is *not* reflective of a civilized society. Violence and abuse in all of its many forms must not be tolerated.

We must be steadfast in our efforts to combat violence and abuse of people with disabilities. No one should have to suffer in silence. No one should have to live with violence and abuse because they do not know where to get help or because people and systems are unwilling to help. Each action, no matter how big or small, can make a difference. I hope that this book has inspired and empowered

you to take individual and collective action to break the silence and stop the violence and abuse of people with disabilities in your community.

RESOURCES

Web Sites

Judge David L. Bazelon Center for Mental Health and Disability Law, <http://www.bazelon.org>. Click on *About* and then click on *links* to connect to many helpful advocacy and activism resources.

Partners in Policy Making, Minnesota Governor's Council on Developmental Disabilities, <http://www.partnersinpolicymaking.com>

The Center for Capacity Building on Minorities with Disabilities Research, Institute on Disability and Human Development, University of Illinois at Chicago, <http://www.disabilityempowerment.org>

The Community Toolbox, University of Kansas, <http://ctb.ku.edu/en>

The Institute of Cultural Affairs USA, <http://www.ica-usa.org>

For more information about the Project or to request a copy of the *Advocacy and Empowerment Final Report*, contact Nancy M. Fitzsimons at nancy.fitzsimons@mnsu.edu or 507-389-1287/800-627-3529 (MRS/TTY) or send a written request to Nancy M. Fitzsimons, Ph.D., MSW, Department of Social Work, Minnesota State University, Mankato, 358 Trafton Science Center North, Mankato, MN 56001.

Curriculum

Blue Tower Training Center. (2007). *Speaking in front of groups*. Decatur, IL: Blue Tower Training, <http://www.bluetowertraining.com>

Suggested Reading

Homan, M.S. (2004). *Promoting community change: Making it happen in the real world*, <http://www.brookescole.com>

My Safety Network Resources Worksheet

CALL THE POLICE BY DIALING 911 IF YOUR SAFETY IS AT RISK.

Call 711 to access telecommunications relay services anywhere in the United States.

STATEWIDE RESOURCES

Attorney General's Office

Phone: _____

E-mail: _____

Web address: _____

Crime Victim Compensation Office

Phone: _____

E-mail: _____

Web address: _____

Long Term Care Ombudsman Program

Phone: _____

E-mail: _____

Web address: _____

Protection and Advocacy Agency (for Individuals with Disabilities)

Phone: _____

E-mail: _____

Web address: _____

Other Statewide Resource

Name of agency: _____

Contact person: _____

Phone: _____

LOCAL RESOURCES

Adult Protection Services

Name of agency: _____

Contact person: _____

Phone: _____

Domestic Abuse Service Provider

Name of agency: _____

Contact person: _____

Phone: _____

Sexual Assault Service Provider

Name of agency: _____

Contact person: _____

Phone: _____

Center for Independent Living

Name of agency: _____

Contact person: _____

Phone: _____

Legal Aid

Name of agency: _____

Contact person: _____

Phone: _____

OTHER RESOURCES

Name of agency: _____

Contact person: _____

Phone: _____

Name of agency: _____

Contact person: _____

Phone: _____

PERSONAL RESOURCES

Name of person: _____

Phone: _____

E-mail: _____

Name of person: _____

Phone: _____

E-mail: _____

Name of person: _____

Phone: _____

E-mail: _____

Name of person: _____

Phone: _____

E-mail: _____

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Learning Activity Answers

LEARNING ACTIVITY: IDENTIFYING SYSTEMIC BARRIERS (FROM CHAPTER 4)

Joyce's Story

This information was given to me by Joyce on how the systemic barriers affected her.

_X_ Physical Barriers: Joyce encountered inaccessible buildings and unavailable or unreliable public transportation services that affected her ability to leave her abusers and receive needed supports and services. Joyce reported that there were times when she was unable to drive, so getting to court and other places she needed to go was a problem. Reaching a bus stop on snowy days in a wheelchair and limited paratransit hours were barriers.

_X_ Economic Barriers: Economic barriers affected Joyce's decision to leave her abuser and her options. We know that people with disabilities, particularly women, are more likely to be unemployed, have lower levels of education, get paid lower wages, and experience poverty than people without disabilities.

_X_ Communication Barriers: While Joyce had no difficulty speaking, at times writing was difficult. Joyce had a hard time writing out the complaint to get an Order for Protection. An accommodation was not offered.

_X_ Domestic Violence/Sexual Violence Service Barriers: Joyce experienced problems accessing support and services through her local domestic violence shelter due to inaccessibility and/or an inability to meet her personal care needs.

___ Overprotection (Disability Services Barrier): Joyce acquired her disability as an adult. She did not experience the overprotection many people with disabilities experience as they are growing up.

___ Failure to recognize abusive situations (Disability Services Barrier): Joyce did not receive any services from disability service provider agencies.

_X_ Disbelief when reports are made (Disability Services Barrier): Joyce's abuser was viewed by others as a kind and caring man, which resulted in some people discounting her reports of violence and abuse.

___ Attributing the claim of abuse to the disability (Disability Services Barrier): This systemic barrier didn't apply.

_X_ Criminal Justice System Barriers: Joyce experienced barriers when trying to access the services and protection of the criminal justice system. Joyce reported that the day she arrived at the courthouse for her OFP, the clerk asked her to write out her statement. Due to the MS, Joyce's handwriting can be very bad and difficult to complete, especially under stress. Joyce reported that she felt very intimidated with her struggle to write out her complaint.

___ Adult Protection Services Barriers : Joyce was not considered a *vulnerable adult* under state law and was not involved with APS.

_X_ Dehumanization Myth (Attitudinal Barrier): Because Joyce has a disability that affects her physical abilities, she felt that her abuser and others saw her as "less than a complete" human being.

___ Myth of Insensitivity to Pain (Attitudinal Barrier): This systemic barrier doesn't apply.

_X_ Lesser Quality of Life Myth (Attitudinal Barrier): Joyce's abuser and others believed and treated her as if she had a "lesser quality of life" because of her disability.

_X_ Helpless Myth (Attitudinal Barrier): People with disabilities are often treated as helpless. Joyce's abuser thought that she was "helpless" and could not live without him.

_X_ Asexual, Sexually Unattractive or Sexually Promiscuous Myths (Attitudinal Barrier): Joyce's abuser told her that she was unattractive. Joyce came to believe her abuser's claims, which contributed to her putting up with the abuse because she believed no one else would be attracted to her.

_X_ Lack of Credibility Myth (Attitudinal Barrier): Joyce's credibility was questioned. This is especially a problem when the abuser is someone well-known, respected, or in a position of authority in the community.

LEARNING ACTIVITY: IDENTIFYING PERSONAL BARRIERS (FROM CHAPTER 5)

Joyce's Story

This information was given to me by Joyce on how the personal barriers affected her.

_X_ Learned helplessness: After many years of abuse, Joyce learned that no matter what she did she couldn't please her abuser and couldn't prevent his verbal and physical attacks.

_X_ Low self-esteem: After years of abuse, Joyce came to believe all of the negative and destructive things her abuser told her, resulting in low self-esteem.

_X_ Self-blame: Joyce felt that she was a burden to her husband and assumed some (if not all) of the responsibility for the abuse.

_X_ Denial: Joyce was in denial about the abuse, especially early in the relationship. She initially thought that his jealousy and controlling behaviors were acts of love.

_X_ Sense of responsibility to others: Joyce chose to stay in the relationship for the sake of her children. The stigma of divorce kept Joyce from leaving sooner. When her children faced the brunt of the abuse, Joyce decided she and her children had to get out.

_X_ Fear of retaliation: Joyce knew that leaving her abuser would be very dangerous for her and her children. One night very close to the end of the relationship, Joyce's abuser arrived home after an evening of drinking; her daughters were not home. She was verbally and emotionally assaulted before being pushed to the floor. Her abuser stood over her telling her how clumsy and stupid she was. Joyce knew if she moved she was in even deeper trouble, physically. He went into the bathroom. Joyce managed to get up and out of the house. As she went for her van, her abuser reached it before her and Joyce headed off down the street in the other direction. Fortunately she only had gone a few steps before he returned to the house. Joyce got into her accessible van and drove away. Her abuser came out of the house and began to chase her around town in his truck, which led to him being arrested for drunk driving, but not before a scary chase ensued.

_X_ Fear of the unknown: Joyce was concerned about how she would be able to provide for herself and her children. While she had a lot of family support, Joyce was afraid that she would have to make even greater demands on her family because she was unable to take care of herself.

_X_ Fear of losing custody of children: Joyce's abuser used threats of getting custody of their children as a way to keep her from leaving.

___ Lack of knowledge and skills: Joyce acquired her disability as an adult. She had the knowledge and skills to protect herself and to get help, but the other barriers greatly influenced her decision to leave her abuser.

_X_ Poverty: Joyce was concerned about being able to financially support herself and her children. Women and children are typically less well off financially after a divorce than are men.

LEARNING ACTIVITY: USING THE SYSTEMS (FROM CHAPTER 6)

Joyce's Story

_X_ Crime victim advocate: Joyce benefited from getting a crime victim advocate to help her learn about her rights as a crime victim and to assist her as the case against her abuser was prosecuted in the criminal justice system.

_X_ Domestic violence shelter: Joyce received supports from a local domestic violence center to rebuild her life. However, finding accessible services was a barrier.

___ Sexual assault service provider: Doesn't apply.

☒ Crime victim compensation program reparation agency: Joyce was eligible for compensation for crime-related expenses, possibly for mental health counseling, medical costs, loss of support, and loss of wages.

☐ Adult Protection Services: Doesn't apply.

☐ Long Term Care Ombudsman: Doesn't apply.

☐ Protection & Advocacy agency: Doesn't apply.

☒ Criminal Justice services: Joyce eventually called the police when her safety and the safety of her children were at risk. Joyce eventually called the police to report the domestic violence. Her abuser was charged with a crime by the prosecutor's office and the case was prosecuted. Joyce obtained an OFP through the courts and knew that she could call the police to report any violation of the OFP.

☒ Civil Justice services: Joyce could have sued her abuser for financial compensation for the abuse.

Henry's Story

☒ Crime victim advocate: Henry would benefit from getting a crime victim advocate to help him learn about his rights as a crime victim and to assist him as the case against his abuser proceeds through the criminal justice system.

☐ Domestic violence shelter: Not the best option because most domestic violence shelters are not well equipped to serve men.

☐ Sexual assault service provider: Doesn't seem to apply.

☐ Crime victim compensation program: Need to know more to determine if Henry is eligible.

☒ Adult Protection Services: If Henry is considered a *vulnerable adult* under state law, APS could get involved to ensure Henry's safety and recommend/provide needed supports and services.

☐ Long Term Care Ombudsman: Does not apply.

☐ Protection & Advocacy agency: Does not apply.

☒ Criminal Justice services: Henry could call the police if his safety were at risk. Henry could call the police to report the domestic violence and possible financial exploitation. The police would work with APS to investigate the abuse. His abuser could be charged with a crime(s) by the prosecutor's office and the case prosecuted. Henry could obtain an OFP through the courts. Henry should call the police to report a violation of the OFP. Henry could testify if the case goes to trial.

☒ Civil Justice services: Henry could sue his abuser for financial compensation for the abuse.

June's Story

☒ Crime victim advocate: June and her parents would benefit from getting a crime victim advocate to help them learn about June's rights as a crime victim and to assist them as the case against June's abuser proceeded through the criminal justice system.

☐ Domestic violence shelter: Does not apply.

☒ Sexual assault service provider: June would benefit from services to help her heal from the trauma of the sexual assault.

☒ Crime victim compensation program: June is most likely eligible for compensation for crime-related expenses to pay for her mental health counseling and any crime-related medical costs.

☒ Adult Protection Services: June is most certainly considered a *vulnerable adult* under state law. Depending upon the role of APS in an institutional setting in June's state, APS might get involved to ensure June's safety and recommend or provide needed supports and services.

☒ Long-Term Care Ombudsman: The LTCO should be called to conduct an investigation into the abuse and the failure of the administration to protect June and other residents at the institution.

☒ Protection & Advocacy agency: The P & A should be called to investigate and attempt to get fixed the poor quality of care at the institution.

☒ Criminal Justice services: The police should have been called to report the sexual assault. The police would work with APS to investigate the sexual assault. Her abuser should be (and was) criminally charged by the prosecutor's office and the case prosecuted. June could obtain a harassment restraining order through the courts. The police should be called to report a violation of the protective order. It is possible that June could testify if the case went to trial. June's parents and sister could also testify at a trial.

☒ Civil Justice services: June's parents could help June sue her abuser and the institution for financial compensation for the abuse on her behalf.

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Combating Violence and Abuse

Glossary of Terms

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abuse A broad term used to refer to all forms of violence and abuse, including physical assault, sexual assault, financial exploitation, neglect, and psychological abuse. The use of the term *abuse* should not be interpreted to minimize the seriousness of the offenses, many of which are crimes under federal and state laws.

Abuse of People with Disabilities Caregiver Power and Control Model A theory explaining why people with disabilities are abused by care providers. Violence and abuse by care providers is an issue of power and control. Power is used by care providers to obtain control over people with disabilities.

abuser Also called *offender*. Refers to any person who commits acts of violence and abuse.

active listening Also called *assertive listening* or *empathic listening*. A specific type of listening that involves tuning in and focusing all your attention on the other person, paying close attention to the other person's message, and "actively attempting to understand before responding" (Alberti & Emmons, 2001, p. 62).

activities of daily living (ADL) Personal care such as bathing, toileting, dressing, and feeding.

Adult Protection Services (APS) Responds to reports of abuse and "works to insure the safety and well-being of elders and adults with disabilities who are or are in danger of being abused, are unable to take care of themselves or protect themselves from harm, and have no one to assist them" (NCEA, 2005, para. 1). Services are typically provided by state or county social services.

advocacy "The process of doing something for or speaking on behalf of some person or cause" (Stroman, 2003, p. 46).

Americans with Disabilities Act Public Law 101-336. Federal civil rights legislation passed in 1990 to prohibit discrimination against people with disabilities and to guarantee them equal access to employment, public services, transportation, public accommodations, and telecommunications.

American Sign Language (ASL) A complex language that uses “signs made with the hands and other movements, including facial expression and postures of the body” (NIDCD, 2000, para. 1). The fourth most common language used in the United States.

answer “The pleading by the defendant to respond to the plaintiff’s complaint” in a civil lawsuit (Hames & Ekern, 2006, p. 617).

arraignment “A hearing where the criminal defendant comes before the court to enter a plea” (Hames & Ekern, 2006, p. 617).

asexual myth An attitudinal barrier that is a systemic barrier. The belief that people with disabilities are not sexual beings; the belief that they are not interested in, should not engage in, or are not capable of engaging in sexual activity.

assertive behavior “To act on your own best interest, to stand up for yourself without too much anxiety, to express feelings comfortably, and to exercise your personal rights without denying the rights of others” (Alberti & Emmons, 2001, p. 6).

attitudinal barriers A type of systemic barrier. The myths (false beliefs), negative views, and stereotypes about people with disabilities that result in the denial of equal opportunity, equal protection under the law, and equal participation in all aspects of community life.

auxiliary communication aids Also called *augmentative and alternative communication*. Assistive devices to help people with disabilities communicate. Low-tech assistive devices include letter boards, communication charts, and books with pictures, symbols, or words. High-tech communication devices are battery-powered or electronic devices that have speaking functions.

background check A way to verify information provided by a potential care provider. A way to determine if a care provider has a history of criminal behavior or a history of abuse toward someone who is considered vulnerable under the law. Types of background checks include state criminal background, federal criminal background, state nursing assistant/care provider registry, sex offender registry, verification of academic credentials, verification of prior employers.

battered woman syndrome (BWS) A syndrome first proposed by Lenore Walker in the 1970s to explain why some women stay in abusive relationships. BWS is a pattern of signs and symptoms, including fear, self-blame, and a feeling of helplessness, that occur in women who have been abused over an extended period of time by their male partner.

behavior management program A formal plan to modify challenging behaviors by teaching and reinforcing wanted behaviors and inhibiting unwanted behaviors. The programs is typically developed by a behavior analyst in consultation with an interdisciplinary team, family members, and the person who is the target of the program. Most program today focus on learning the reasons for the behavior, teaching adaptive alternative behaviors, and modifying the environment.

beyond a reasonable doubt The burden of proof in a criminal trial. In order to issue a guilty verdict, the jury must be convinced (no reasonable doubt) that the defendant committed the crime(s) charged at a 99% or greater certainty.

burden of proof The duty of Adult Protection Services, prosecuting attorneys in criminal cases, or attorneys in civil cases to prove that the alleged offender or defendant committed the acts for which he or she is accused.

care provider Term used in this book to refer to family, friends, professionals, and others who provide paid or unpaid support and services to people with disabilities.

case advocacy “Actions by professionals on behalf of a client or client group to obtain needed services, resources, and entitlement, or to ensure clients’ rights are upheld” (Ezell, 2001, p. 27).

Centers for Independent Living (CILs) A national network of consumer-directed CILs were created and funded under the federal Rehabilitation Act for the purpose of empowering people with disabilities and to promote and support independence and community inclusion. The first CIL was formed in Berkley, California, in 1972. The National Council on Independent Living is the national association of CILs. <http://www.ncil.org/>

chemical restraint “The use of drugs to control behavior or restrict a person’s freedom of movement. In such instances the drugs are not considered a part of standard medical or psychiatric treatment for the patient” (U.S. DHHS, 2000, p. 4).

civil justice system The system of courts and processes created to enforce and protect private, personal, and property rights and to hold violators of personal rights accountable through the awarding of monetary damages.

civil lawsuit A noncriminal lawsuit involving violation of private, personal, and property rights. Cases are heard by a jury or judge. A verdict of *liable* is awarded when there is a preponderance of evidence (enough evidence) presented to conclude that the plaintiff’s claims are true.

Client Assistance Program (CAP) A national network of agencies that provide information and help to people seeking or receiving vocational rehabilitation services under the federal Rehabilitation Act (NDRN, 2006, para. 1).

coalition A large organization made up of many smaller organizations to create greater power to enhance their advocacy efforts on behalf of the organizations and their constituents (e.g., clients, consumers, customers, members).

coded disclosure Hinting about abuse, rather than making a direct statement, to see how others will react (Ramsey-Klawnsnik, 1993).

cognitive Having to do with the functioning of the brain or the mind in relationship to thinking, understanding, knowing, remembering, and learning.

consumer-directed services Services that empower people with disabilities to make their own decisions about recruiting, hiring, managing, and terminating the people who assist them on a day-to-day basis.

collaboration Working together or working in partnership with other people or organizations.

communication barriers A type of systemic barrier. Inaccessible public and private sector services caused by the lack of readily available ways to engage in effective communication.

community-based victim assistance programs Community-based programs that provide many types of services to crime victims including providing emotional support to victims, making appropriate referrals for services, and ensuring that the victim's legal rights are upheld (NOVA, 2005). Examples include domestic violence shelters and sexual assault service providers.

compensatory damages Money awarded by a judge or jury to a plaintiff in a civil lawsuit to be paid by a liable defendant to compensate for actual loss, injury, or harm suffered.

competence to consent The ability of a person to legally give informed consent, free from undue influence by others and with knowledge of the important aspects of the issue, including benefits and risks, in matters pertaining to a person's life, including sexual relations, medical, and financial decisions.

complaint "A document filed in a criminal or civil lawsuit that describes the allegations of the plaintiff and the basis for the lawsuit" (Hames & Ekern, 2006, p. 619).

contingency fee basis An attorney is only paid if the victim in a civil lawsuit is awarded monetary damages (NCVBA, 2007).

continuum from subtle to obvious Continuum refers to a series of small steps between two extremes. Abuse varies in intensity and can escalate along a continuum from subtle to obvious abuse (Fitzsimons-Cova et al., 2000).

crime "A type of behavior that society has declared illegal and has decided to punish" (Hames & Ekern, 2006, p. 121).

crime victim compensation State programs that provide direct payment to or on behalf of victims of criminal offenses occurring in the state (including victims of federal crimes) for crime-related expenses.

criminal complaint "A written statement explaining the significant facts of the case" (Hames & Ekern, 2006, p. 410).

criminal justice system The system of agencies, courts, and procedures created to enforce criminal law. The four parts of the system are: law enforcement (commonly referred to as the police), prosecution, judiciary (the courts), and corrections.

culture of abuse The attitudes, values, beliefs, practices, and policies that are shared by a family, organization, community, or the broader society that knowingly or unknowingly tolerate, reinforce, and perpetuate violence and abuse of people with disabilities.

defendant In a criminal case, the offender; the person who allegedly committed the crime. In a civil lawsuit the person who is being sued.

dehumanization myth An attitudinal barrier that is a systemic barrier. This myth implies that people with disabilities are less than full members of human society.

denial A type of personal barrier. The refusal to face the reality of a painful event or life situation. Short-term denial can be something victims use to cope with the abuse.

Dependency-Stress Model A theory explaining why people with disabilities are abused by care providers. In this model, care providers engage in abusive behavior because of the stress they are under due to the demands of caregiving. When the demands of

caregiving outweigh coping abilities of care providers, they lash out to temporarily relieve the stress (also referred to as *caregiver* or *care provider stress*).

deposition “The testimony of a witness, given under oath, outside the courtroom and taken before a court reporter” (Hames & Ekern, 2006, p. 620).

disability A generic definition of disability is “the outcome or result of a complex relationship between an individual’s health condition and personal factors, and of the external factors that represent the circumstances in which the individual lives” (WHO, 2001, p. 17). In the United States the federal government uses different definitions of disability to determine eligibility for programs and protection under federal law. States also have their own definitions to determine eligibility for programs and protections under state laws.

discovery A pretrial process in criminal and civil cases in which attorneys gather the facts, including interviewing witnesses, obtaining documentary evidence, and obtaining depositions under oath from victims, witnesses, and defendants.

domestic violence Also called *domestic abuse*. Abuse in a private home or residence typically perpetrated by a family member or someone with whom the victim has a close or intimate relationship.

domestic violence programs Community-based programs that provide many services to victims of domestic violence (most typically women and their children), including: “counseling and support groups; information about legal options, the criminal justice system, and social services; shelter; attorney referral; vocational counseling; safety planning; and case advocacy” (NCVC, 2008a, p. 3).

economic barriers Also called *financial barriers*. A type of systemic barrier. Obstacles people with disabilities experience in education and employment that limit their ability to become financially independent and secure.

emotional abuse Also called *psychological abuse*. Acts, physical or verbal, intended to hurt a person’s feelings, harm a person emotionally, or to humiliate, demean, intimidate, produce harm, or threaten harm.

empathy Understanding and identifying with the feelings, viewpoint, and experiences of another person. In assertive communication it refers to paying attention to how someone else is feeling and communicating that understanding to them.

empowerment A value or a principle that guides how professionals and family members support and work with people with disabilities. A process of increasing power so that individuals and groups can take action to improve their lives. An outcome of the empowerment process whereby people become empowered.

empowerment practice “The process of helping individuals, families, groups, and communities to increase their personal, interpersonal, socioeconomic, and political strength and develop influence toward improving their circumstances” (Barker, 2003, p. 142).

evidence Information used to show whether a defendant in a criminal trial is guilty or innocent, or in a civil suit liable or not liable. The four main types of evidence are testimony, actual, documentary, and demonstrative.

facilitated (or focused) conversation method A highly collaborative process designed to maximize input and participation of all group members, obtain a diverse array of ideas and opinions, and achieve group consensus on the issue being addressed by the group.

fear of retaliation A type of personal barrier that is directly caused by the abuser and others who enable the abuser. Being afraid that the abuser or someone trying to protect the abuser will purposely hurt you in order to get back at you for reporting the abuse.

fear of the unknown A type of personal barrier. Being afraid of what is not known to you; feeling uncertain about your future.

financial exploitation Also called *financial abuse*. The improper or illegal use of another person's money, property, and other assets (material goods) without their informed consent or when consent is obtained by bullying or fraud (BITS, 2005).

fiscal agent A person or an organization that handles financial matters for a person with a disability. A fiscal agent may take care of all payroll functions pertaining to hiring, paying, and terminating a personal assistant.

grand jury "A jury that is called upon to receive and review accusations [charges] and complaints in criminal matters" (Hames & Ekern, 2006, p. 621).

guiding principles The values that need to be put into action to combat violence and abuse: empowerment, advocacy, self-advocacy, self-determination, strengths perspective, and collaboration.

handicap A term once commonly used to refer to "a disadvantage resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal...for an individual" (WHO, 1980, p. 183).

hands-off behavior Sexual assault that does not involve the abuser physically touching another person for sexual or other pleasure.

hands-on behavior Sexual assault that involves the abuser physically touching another person for sexual or other pleasure.

harassment restraining order A type of protective order that may be granted by the court for nondomestic relationships ordering offenders to refrain from specified conduct. Nondomestic relationships are relationships with people who are not related or who are not currently or have been in the past in an intimate relationship.

harmful genital practice Unwanted, intrusive, and/or painful procedures in caring for a person's genitals or rectum (Ramsey-Klawnsnik, 2003).

hate crime "A criminal offense against a person or property motivated in whole or in part by an offender's bias against a race, religion, disability, ethnic origin or sexual orientation" (U.S. FBI, n.d.a, para. 2).

helpless myth An attitudinal barrier that is a systemic barrier. The belief that all people with disabilities are helpless. The myth implies that helplessness is an automatic outcome of disability.

hung jury "A jury that cannot attain the necessary consensus or majority to reach a verdict" (Hames & Ekern, 2006, p. 621).

impairment “A problem in body function or structure such as significant deviation or loss” (WHO, 2001, p. 12).

Independent Living Movement Began in the late 1960s. Ed Roberts, a student at the University of California, Berkley, is considered the founder of the movement in the United States. Advocates for people with disabilities to live in the community and to remove the systemic barriers to independent living and inclusion in the community. The first Center for Independent Living (CIL) was formed in Berkley, California, in 1972.

indicators Warning signs of abuse.

indictment “A written accusation given by a grand jury to the court”, “a criminal charge against a defendant that must be proved at trial” (Hames & Ekern, 2006, p. 621).

Individual Model of Disability This broad perspective on disability locates the problem of disability within the individual. Problems are seen as coming from the physical, sensory, or mental limitations that are caused by the impairment. Disability is viewed as an individual problem requiring the services of professionals to change, cure, or “fix” the person.

information “An accusation made by a prosecutor against a criminal defendant that does not involve a grand jury” (Hames & Ekern, 2006, p. 622).

institutional abuse Abuse in long-term care facilities such as nursing homes, state institutions, assisted-living facilities, and group homes.

instrumental activities of daily living (IADL) Activities related to independent living such as grocery shopping, managing money, cleaning, cooking, and laundry.

interdisciplinary collaboration People who are from different professional disciplines working together as a team to create a plan for and deliver services that meet the needs of client systems (individuals, agencies, and communities) in order to achieve agreed-upon goals.

Integrated Ecological Theory of Abuse A theory explaining why people with disabilities are abused by care providers. The theory that focuses on the interaction between four systems: 1) characteristics of the potential victim, 2) characteristics of the potential offender, 3) characteristics of the immediate environment, and 4) characteristics of the broader society or culture (Sobsey, 1994).

interpersonal Refers to relationships between people.

intimate relationships A type of interpersonal relationship. Relationships between people of a “very personal or private nature” and involving “very close association, contact or familiarity” (Merriam-Webster On-Line, 2006–2007). Intimate relationships occur with spouses or partners, family members, close friends, and paid and unpaid care providers.

lack of credibility myth An attitudinal barrier that is a systemic barrier. The belief that when people with disabilities report abuse they are not telling the truth or are exaggerating what happened.

lack of knowledge and skills A type of personal barrier that is directly caused by other people and the broader society. Not having the information and skills needed to prevent and stop abuse.

learned compliance Learned helplessness that is reinforced by compliance training.

learned helplessness “The belief that one’s actions have no influence on future outcomes” (Sobsey, 1994, p. 164). A type of personal barrier. Learned helplessness happens when people learn that their efforts to assert themselves fail over and over again. As a result, they give up and let others have power and control over their lives. It is one of the theories used to explain why women stay in abusive relationships.

lesser quality of life myth An attitudinal barrier that is a systemic barrier. Implies that because individuals are “damaged” they have a lesser quality of life, are lesser human beings, and in some cases are better off dead.

liable The verdict in a civil case in which the defendant is determined to be responsible for personal harm and/or property damages.

Long Term Care Ombudsman Program (LTCOP) A national network of agencies that provide advocacy on behalf of residents of long-term care facilities, such as nursing homes, board and care homes, and assisted living environments, “who experience abuse, violation of their rights, or problems” (ABA, 2005, p. 2).

low self-esteem A type of personal barrier that is made worse by an abuser. Refers to a poor self-concept and negative feeling about one’s own worth and abilities.

mechanical restraint “Use of an external device, such as straps, belts, or cuffs to restrict a person’s freedom of movement” (U.S. DHHS, 2000, p. 4).

mercy killing Intentionally taking another person’s life in order to relieve their pain and suffering (real or perceived by the perpetrator) caused by incurable disease, chronic illness, or severe disability. Mercy killings occur with and without the consent of the person being killed. The perpetrator may perceive that he or she is performing an act of compassion.

myth of insensitivity to pain An attitudinal barrier that is a systemic barrier. The belief that people with disabilities do not have feelings or feel pain in the same way as people without disabilities.

neglect The failure to fulfill one’s responsibility to help, provide reasonable care, fulfill basic physical, medical, and emotional needs, or protect another person (BITS, 2005).

nolo contendere plea A criminal plea in which the defendant does not admit or deny the charges. The plea means “I will not contest it” (Hames & Ekern, 2006, p. 623).

obvious abuse Forms of abuse that are easy to see and in which there is little, if any, disagreement that the behavior is harmful, abusive, and wrong (if not illegal).

offender A person who commits acts of abuse. Offenders or abusers are often known to people with the disabilities, particularly spouses, partners, family members, and paid care providers.

Older Americans Act Public Law 89-73; 2006 amendments P. L. 109-365. A federal law passed in 1965 that created the Administration on Aging to oversee the development and implementation of a system of community-based services to support older adults. Each state has a network of Area Agencies on Aging that deliver services funded by the Act. In

the 1978 amendments to the Older Americans Act (P.L. 95-478) the Long-Term Care Ombudsman Program was created.

ombudsman An advocate.

order for protection (OFP) Court-issued order that directs individuals (abusers or offenders) to refrain from specified conduct. A person who is a victim of domestic violence may petition the court to obtain an OFP in order to prevent the abuser from threatening or causing further harm.

overprotection A type of systemic barrier commonly associated with the disability service system. The failure of parents and other care providers to provide people with disabilities with the information, skills, resources, and opportunities to practice ways to protect themselves from abusive relationships and situations and to reduce or minimize their risk for violence and abuse. The overprotection of parents and other care providers increases the risk for harm.

passive euthanasia *Euthanasia* means death. Hastening a person's death by removing supports that sustain life, such as food and water, medical treatment (e.g., stopping medication, turning off a respirator), and not performing emergency life saving measures (e.g. CPR).

People First language The preferred language to use when referring to people with disabilities. People first language recognizes the person first and then the disability.

People First Movement An empowerment movement begun by people with intellectual disabilities that focuses on people with disabilities being seen as "people," not as "disabled people."

personal barriers The lack of knowledge and skills and the negative thoughts, feelings, beliefs, and fears within a person that result in disempowerment.

personal boundaries The invisible parameters or limitations that a person establishes to keep other people away or to prevent others from touching his or her body or personal property. Personal boundaries protect a person's physical space, emotional space, social space (interaction with others), and personal property.

personal safety network A specific person or people that a person trusts who can be called when a person is feeling unsafe.

physical assault Deliberate physical acts that cause pain, injury, or other physical suffering or harm (also referred to as *physical abuse*).

physical barriers A type of systemic barrier. Architectural and structural barriers that physically prevent people from taking part in all aspects of community life.

physical restraint "Restricting a person's movement by physical force" (U.S. DHHS, 2000, p. 4).

plaintiff The victim in a civil lawsuit. The state (some governmental representative) in a criminal case.

plea The defendant's response to the charges in a criminal (guilty, not guilty, nolo contendere) or civil (liable, not liable) case.

plea bargain The process of a defendant pleading guilty to a lesser charge and a prosecuting attorney dropping charges of more serious offenses.

Power and Control Model A theory of domestic violence typically used to explain violence perpetrated by men against their female partners. In this model, the abuser wants to dominate the victim and wants all the power in the relationship. The abuser uses violence in order to establish and maintain power and control over a victim.

posttraumatic stress disorder (PTSD) A type of mental health condition that develops after a person has experienced, witnessed, or learned about a traumatic life event. The debilitating effects include re-experiencing the traumatic event, avoidance of situations associated with the traumatic event, and an ongoing intense feeling of fear.

preliminary hearing “A defendant’s second appearance before the court; the purpose is to establish that probable cause exists” (Hames & Ekern, 2006, p. 624).

preponderance of evidence The amount of proof required in civil cases to find the defendant is liable. The amount of proof needed in Adult Protection System cases to confirm that an abuser committed the acts of abuse for which they are accused.

prevention Reducing or minimizing the risk for violence and abuse. Also refers to stopping abuse from happening again once a person has been abused. Also referred to as *risk reduction*.

privacy awareness An important component of abuse prevention and personal safety. Understanding the difference between personal information versus public information; private places versus public places; and that your body is private and you have the right to control when, where, and how you are touched.

probable cause “When an officer has a reasonable basis for the belief that a person should be searched or arrested” (Hames, & Ekern, 2006, p. 394).

probation A defendant who is found guilty is released to the community with conditions instead of being incarcerated (sent to jail or prison) (Hames, & Ekren, 2006, p. 133).

professional In this book it refers to anyone who gets paid to provide services to people with disabilities or to victims of violence and abuse.

protection and advocacy (P & A) An agency that provides legal representation and other advocacy services, under all federal and state laws, to all people with disabilities (NDRN, 2006, para. 1). Each state has a P & A. P & As are authorized and funded by several federal laws, including the Developmental Disabilities Assistance and Bill of Rights Act, Rehabilitation Act, and Protection and Advocacy for People with Mental Illness (PAMI) Act.

psychological abuse Also referred to as *emotional abuse*. Acts, physical or verbal, intended to hurt a person’s feelings, harm a person emotionally, or to humiliate, demean, intimidate, produce harm, or threaten harm.

punitive damages Money awarded by a judge or jury to a plaintiff in a civil lawsuit to be paid by a liable defendant to punish the defendant and deter others from engaging in actions similar to the defendants. Typically awarded for conduct that is perceived as intentional or especially malicious (mean, cruel).

rape kit An examination that is typically done by a sexual assault nurse examiner (SANE) or a sexual assault forensic examiner (SAFE) in a hospital setting to collect forensic (crime-solving) evidence that can help in the successful prosecution of a criminal sexual assault case against the offender.

restitution Money to compensate for loss or injury of a victim or to compensate persons who have become responsible for the care and support of a victim as a result of a crime.

restraint “Methods of restricting a person’s freedom of movement” (U.S. DHHS, 2000, p. 4).

retainer fee Money paid to obtain a lawyer that is put in a special account to cover costs related to the case.

Ring of Safety “A set of skills that give [people] the ability to repel unwanted advances or to report advances immediately [when they happen]” (Hingsburger, 1994, p. 73).

safe Free from danger or risk from violence and abuse.

safe secret A secret that when kept causes no physical, financial, or psychological harm or potential for harm to the person or people asked to keep the secret.

safety The condition of being safe or actually being safe.

safety planning A plan of action to take in situations involving abuse, threats of abuse, or feelings of danger.

seclusion “Involuntarily confining a person alone in a room from which the person is physically prevented from leaving” (U.S. DHHS, 2000, p. 4).

secret word Also referred to as a *secret code*. A secret word that a person can use in front of an abuser to tell someone that they trust to call the police.

self-advocacy “A process in which an individual or group of people speak or act on their own behalf to obtain needed services, resources, and entitlements or to ensure that their rights are upheld” (Ezell, 2001, p. 27).

Self Advocates Becoming Empowered (SABE) A national coalition of all state and local self-advocacy organizations for people with intellectual disabilities (<http://www.sabeusa.org/>).

self-blame A type of personal barrier that is made worse by an abuser. Refers to blaming one’s self for the abuse.

self-determination “The ability to control your own life, reach goals and participate fully in your environment” (The Center on Self-Determination, n.d.).

self-esteem A person’s own sense of worth.

Self-Help Movement The empowerment movement for recipients or consumers of mental health services that began in the 1980s. The National Alliance for the Mentally Ill (NAMI) was formed and the National Mental Health Consumers’ Self-Help Clearinghouse was created as a result of the movement.

sense of responsibility to others A type of personal barrier. Victims willingly or through intimidation put up with the abuse for the greater good of their family or others.

service system barriers A type of systemic barrier. Limitations in the service delivery system that prevent people with disabilities from obtaining the protection, services, and supports they need to prevent and stop abuse.

sexual assault Forcing or bullying another person to engage in or observe sexual acts (also referred to as *sexual abuse*).

Sexual Assault Forensic Examiner (SAFE) A member of the Sexual Assault Response Team (SART) who responds after a sexual assault and collects forensic data.

Sexual Assault Nurse Examiner (SANE) A member of the Sexual Assault Response Team (SART) who works with the victim immediately after a sexual assault.

sexual assault programs Provide support and services to victims of sexual assault regardless of whether or not the victim chooses to report the assault.

Sexual Assault Response Team (SART) A team that consists of a police officer, advocate, Sexual Assault Nurse Examiner who respond at crime scenes, hospitals, and police stations to serve the immediate needs of victims.

sexually promiscuous Term used to refer to a person who has an overactive desire to engage in sexual activity.

sexually unattractive myth An attitudinal barrier that is a systemic barrier. Implies that individuals with a disability are sexually unattractive and therefore are immune or protected from sexual assault.

Social Model of Disability This model for understanding disability focuses on the role of society (the environment) in creating and maintaining disability.

stakeholder A person or group who has a stake or interest or involvement in an issue.

strengths perspective A way of working with and supporting people with disabilities that aims to help people with disabilities discover and enhance their strengths in order to achieve their goals.

subtle abuse Behavior that is difficult to see or identify as abuse. There may be disagreement or uncertainty that the behavior is abusive.

survivor's pride Refers to the growth and dignity (self-respect or pride) that can come from overcoming obstacles.

system advocacy Sometimes referred to as *class* or *cause advocacy*. Actions taken to effect changes in policies and practices affecting all persons in a certain group or class.

system-based assistance programs Programs run out of local police or prosecutor's offices that provide advocacy services within the criminal justice system.

systemic barriers Organizational and societal obstacles that perpetuate (carry on) violence and abuse of people with disabilities and make it difficult to end abusive relationships and situations.

teamwork Working cooperatively with a group or team to achieve an agreed-upon outcome or goal.

Telecommunications Relay Service (TRS) A telephone service that allows people with hearing or speech disabilities to place and receive telephone calls.

- tort** “A term used in civil cases used to refer to the ‘wrongful act’” (NCVBA, 2007, p. 9).
- understanding the system** Knowing the laws, rights, agencies, programs, and services that protect and support victims and promote justice.
- unsafe feelings** Also called a *sixth sense*, *gut feeling*, or *intuition*. The physical or bodily feelings that a person has when they think that they might be in danger or their safety might be at risk.
- unsafe secret** A secret in which the person or people being asked to keep the secret are being or are at risk for being physically, financially, or psychologically harmed.
- values** Refers to the ideals or principles that are very important to a person such as freedom, independence, equality, family. A person’s way of thinking and acting is influenced by their values.
- verdict** The decision of a jury in a criminal or civil case. In criminal cases the verdict can be guilty or not guilty (sometimes referred to as an acquittal). In civil cases the verdict can be liable or not liable.
- victim** A person who is victimized (e.g., abused, assaulted, exploited) by another person. A person is a victim because of the abusive actions of the abuser (offender).
- victims’ bill of rights** Stipulates the legal rights of crime victims. Each state has a set of legal rights that are often called a “victims’ bill of rights.”
- victim services** The array of federal, state, and local services to help victims obtain justice and heal from their victimization.
- Victims of Crime Act of 1984 (VOCA)** (PL 98-473) A federal law that authorizes funding for a broad array of services and resources to aid victims and ensure that their rights are not violated. VOCA funds are administered by the Office for Victims of Crime, U.S. Department of Justice.
- vulnerable adult** “A person who is being mistreated or is in danger of mistreatment and who, due to age and/or disability, is unable to protect himself or herself” (NCEA, 2005, para. 3). Each state has its own legal definition of who is considered a vulnerable adult.
- vulnerable adult advocacy and protection services** The system of services designed to protect and advocate on behalf of vulnerable adults. Services within the system include 1) adult protection services, 2) long-term care ombudsman program, and 3) protection and advocacy for individuals with disabilities.
- Walker Cycle Theory of Violence** This theory is used to explain the phases of abusive episodes perpetrated against women by their partners. There are three distinct phases: 1) the tension building phase, 2) the abusive episode, and 3) the honeymoon or loving-contrition (apology, regret) phase (Walker, 2000).
- Web of Power and Control** Illustrates how the power and control of an abuser, along with systemic and personal barriers, make it difficult for a victim to break free from violence and abuse.
- whistle blowing** An employee publicly reporting illegal activity going on inside an organization. A paid care provider reporting the abusive actions of a co-worker, supervisor, or administrator at their place of employment.

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PL 99-435, *see* Air Carrier Access Act of 1986

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PL 101-336, *see* Americans with Disabilities Act

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Violence and abuse of people with disabilities

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- skillfully recognize the indicators of physical assault, sexual assault, neglect, psychological abuse, and financial exploitation
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- make the most of supportive services and systems
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Help people with disabilities prevent violence and abuse by

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