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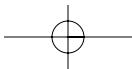
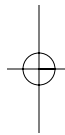
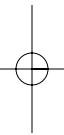
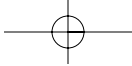
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Contents

About the Author	vii
Contributors	vii
Foreword <i>Dick Sobsey, Ed.D.</i>	ix
Preface	xiii
Acknowledgments	xix
1 Guiding Principles for Combating Violence and Abuse	1
2 The Relationship Between Disability and Abuse	13
3 Recognizing and Responding to Violence and Abuse	35
4 Systemic Barriers to Preventing Violence and Abuse	63
5 Personal Barriers to Preventing Violence and Abuse	89
6 Understanding the System	105
7 Empowering People with Disabilities to Prevent Violence and Abuse	127
<i>with Dorothy Bell Wagner</i>	
8 Principles in Practice: The Advocacy and Empowerment Project	163
<i>with Willi Horner-Johnson and Charles E. Drum</i>	
Appendix A My Safety Network Resources Worksheet	179
Appendix B Learning Activity Answers	183
References	189
Glossary of Terms	199
Index	213



About the Author

Nancy M. Fitzsimons, MSW, Ph.D., Associate Professor, Master of Social Work Program Director, Department of Social Work, Minnesota State University, Mankato, 358 Trafton Science Center North, Mankato, MN 56001

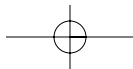
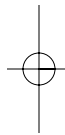
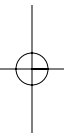
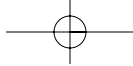
Nancy M. Fitzsimons graduated from Jane Addams College of Social Work, University of Illinois, where she earned a Master of Social Work and a doctoral degree in social work. She is currently Associate Professor and Master of Social Work Program Director in the Department of Social Work at Minnesota State University, Mankato. She worked as a licensed social worker in the Chicago metropolitan area for more than 10 years, providing supports and services to children and adults with intellectual disabilities and their families. She was Research Assistant Professor in the Department of Disability and Human Development, University of Illinois at Chicago, where she assumed the duties of principal investigator and project director on two federally funded projects to combat abuse of people with disabilities. She also developed the abuse prevention training for the Illinois Department of Human Services, Office of Developmental Disabilities. Most recently she was the principal investigator and project director of a U.S. Department of Justice, Office of Violence Against Women grant where she co-authored and created *Shadow Victims: Crimes Against People with Disabilities*, an online training program for law enforcement officers in Minnesota. In addition to serving as the Master of Social Work Program Director, Dr. Fitzsimons teaches courses in social welfare policy and social work practice with people with disabilities.

Also Contributing to This Volume

Charles E. Drum, J.D., Ph.D., Associate Professor, Oregon Health & Science University, 707 SW Gaines Street, Portland, OR 97239

Willi Horner-Johnson, Ph.D., Research Assistant Professor, Oregon Health & Science University, 707 SW Gaines Street, Portland, OR 97239

Dorothy Bell Wagner, B.A., Department of Social Work, Minnesota State University, Mankato, 358 Trafton Science Center North, Mankato, MN 56001



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.

Dick Sobsey, Ed.D.

Professor and Director

JP Das Developmental Disabilities Centre
and the John Dossetor Health Ethics Centre
University of Alberta
Canada

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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

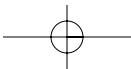
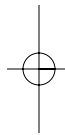
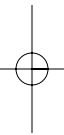
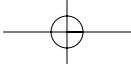
As a social worker who has supported and collaborated with people with disabilities for more than 20 years, I know how important the principles of empowerment, self-advocacy, self-determination, strengths perspective, and collaboration are to people with disabilities. I have come to learn the difference 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.

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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*.

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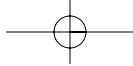
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*For my social work mentor and dear friend
Paula Braghetta,
a tireless advocate for people with disabilities.
You are dearly missed by me
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