Curriculum on Abuse Prevention and Empowerment

A CAPE of Self-Protection for People with Disabilities and Elders Living Independently

The World Institute on Disability
Curriculum on Abuse Prevention and Empowerment
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Curriculum on Abuse Prevention and Empowerment

## Contents

**Part I Abuse and Empowerment**

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Introduction to CAPE</td>
<td>12</td>
</tr>
<tr>
<td>2</td>
<td>What Is Abuse?</td>
<td>20</td>
</tr>
<tr>
<td>3</td>
<td>Assistance, Interdependence, and “Vulnerability”</td>
<td>29</td>
</tr>
<tr>
<td>4</td>
<td>Empowerment Skills</td>
<td>40</td>
</tr>
</tbody>
</table>

**Part II Key Issues**

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>The People Who Help</td>
<td>63</td>
</tr>
<tr>
<td>5</td>
<td>Sexual Abuse Prevention</td>
<td>72</td>
</tr>
<tr>
<td>6</td>
<td>Handling Anger</td>
<td>84</td>
</tr>
<tr>
<td>7</td>
<td>Confronting Violence</td>
<td>94</td>
</tr>
<tr>
<td>8</td>
<td>Peer Counseling for Assault Survivors</td>
<td>103</td>
</tr>
<tr>
<td>9</td>
<td>Populations</td>
<td>111</td>
</tr>
<tr>
<td>10</td>
<td>Tips for Multicultural Inclusion</td>
<td>129</td>
</tr>
</tbody>
</table>

**Part III Training Tools**

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>Empowerment Training Sessions and Events</td>
<td>136</td>
</tr>
</tbody>
</table>
## CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>12</td>
<td>Facilitating Support Groups</td>
<td>144</td>
</tr>
<tr>
<td>13</td>
<td>Movies For Empowerment</td>
<td>167</td>
</tr>
<tr>
<td>14</td>
<td>PAS Scenarios for Men about Handling Abuse</td>
<td>183</td>
</tr>
<tr>
<td>15</td>
<td>Frequently Asked Questions</td>
<td>187</td>
</tr>
<tr>
<td>16</td>
<td>Safety and Abuse-Prevention Tips</td>
<td>194</td>
</tr>
</tbody>
</table>
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Part I
Abuse and Empowerment
Introduction to CAPE

A focus on abuse prevention affirms a fundamental right of people with disabilities and seniors to live in safety and with respect. Sadly, people with disabilities get abused, sometimes at the hands of people who help or care for them. Care providers and personal assistants, including family members and service providers (paid or unpaid), can be abusive. When abuse occurs, the person’s health, safety, and emotional well-being may be at risk, along with their ability to engage in daily life activities. Public disability agencies, public officials, and people with disabilities have identified prevention of abuse of people with disabilities and seniors as a high priority.

It is widely recognized that women with disabilities are abused and mistreated at much higher rates than women without disabilities. Newer studies are indicating similar trends for men with disabilities.\(^1\) Statistics on the prevalence of abuse vary by study because abuse is difficult to define and document and underreporting is likely. In this text, we define abuse as any unwanted, hurtful, inappropriate, frightening, insulting, oppressive, or demeaning behavior directed at a person with a disability. It can include physical, verbal, emotional, sexual, or financial mistreatment, such as theft, or the violation of privacy or autonomy by anyone in a helping role, including informal or paid assistants, associates, family members, or services providers. It can include violent mistreatment or subtle forms of abuse which undermine self-esteem, confidence, and independence. Abuse can be directed at people of all ages who possess any kind of physical, sensory, cognitive, or emotional impairment or disability.

Our goal is to end the abuse of people with disabilities, particularly abuse by care providers, by empowering people to learn abuse prevention skills and strategies. Our focus is to reach disabled people directly with these skills, based on the assumption that disabled people can and must be in charge of their own lives. People with disabilities and seniors living independently are able to learn to recognize and minimize abuse factors, resist abuse if it arises, disclose abuse

if it happens, and get the help they need to stop further abuse. We offer help in acquiring and reinforcing seven key skills, which we call the “CAPE-abilities.” These skills nurture confidence and self-esteem, assertiveness, the ability to get help, responsibility (as directors of their own assistance), resilience, community participation, and a sense of entitlement that disabled people need to self-protect from abuse. Together, these skills can aid disabled individuals who were abused to recover and go on to enjoy strong lives. We enlist disabled and non-disabled peers, educators, services providers, and family members to help facilitate this empowerment of the disabled people they care about. Not all people with developmental disabilities and disabled adolescents and seniors are able to live fully independently, but they can be included as central members of the team of people concerned with their safety and well-being.

CAPE is comprised of four parts: the first three, “Abuse and Empowerment,” “Key Issues,” and “Training Tools,” are available both in print versions and on our multimedia CD, while the fourth part, “Multimedia Tools,” is only available on the CD. The first three parts include a series of informational chapters on abuse and abuse prevention for people with disabilities, family members, teachers, and providers, while the fourth offers learning tools and resources. The curriculum explores fundamental issues of abuse, violence, and disability. It offers approaches to empowering people with disabilities, their families, and services providers to help prevent and address abuse. We present best-practices training approaches and personal narratives of abuse experiences and successful abuse interventions. The CAPE multimedia CD offers a selection of “hands-on” learning activities and resources for people with disabilities. It also offers learning tools for individuals and resources for teachers and facilitators to implement abuse-prevention activities for their constituents. These activities can be adapted for use at various disability community events, such as rehabilitation sessions, independent living training events, disability advocacy meetings, and social gatherings. The multimedia CD includes a series of brief movies, motivational games, workshop activities, quizzes, comic book scenarios, and PowerPoint presentations that engage people with disabilities, either alone or in groups, to learn and reflect on the skills that help identify and prevent abuse. For easy dissemination in the community, the multimedia CD also includes printable pamphlets, brochures,
INTRODUCTION TO CAPE

Figure 1: An example of a CAPE Comic Book Scene

and bookmarks, which explain and explore abuse prevention.

Multimedia tools enhance the learning experience, and they are fun and familiar modes of information and entertainment. Some tools are similar to the web and online resources that adolescents and adults are spending more and more time with. Bear in mind, though, that there is no substitute for face-to-face interaction, an essential part of empowering people to navigate safely and securely through the rough terrain of our disability unfriendly society. Handing disabled people CDs or sending them to websites will not adequately empower them to resist abuse. Disabled people need regular and meaningful contact with peers and mentors to allow them to exercise and expand their confidence and interpersonal skills. CAPE offers coaching in leading support groups and training events where disabled people can interact and learn together. CAPE does not attempt to reinvent the wheel of abuse prevention education; there are already many high-quality resources and training curricula available from a wide range of sources. Nor does CAPE attempt to meet all the abuse-awareness needs of all populations of disabled people. We do intend to offer a unique model and approach in order to inspire readers to develop their own additional materials to meet specific needs.

Many researchers have explored abuse of people with disabilities. Sobsey and Doe, in 1991, were among the first to report the patterns of abuse, including sexual abuse and assault among children and adults with developmental disabilities. Many other researchers and advocates have pursued and expanded this work. Researchers from the World Institute on Disability and Portland State University have collaborated for several years to investigate issues of abuse and

disability. Our studies on women (1999-2002) and men (2003-2007) with disabilities explored the specific perceptions and experiences of people with physical and cognitive disabilities in relation to abuse by personal assistance providers and others. We wanted to understand how women and men with disabilities define abuse and how they respond to abusive situations. We also sought to uncover the strategies they employed to prevent and reduce abuse in their own lives. Since the 1980s, an increasing number of useful training materials for domestic violence services providers have emerged that focus on abuse and violence prevention and how to address disability issues and serve women with disabilities. We list many of these in our reference sections throughout the text.

In reviewing the growing literature about safety and abuse prevention, we identified some significant gaps, which we have tried to address with CAPE. These include the following:

1. **Advice is not enough.** The vast majority of the abuse-prevention material is advice, usually in the form of so-called tips. Yet educational principles do not support the usefulness of offering advice as the primary source of learning for any population, especially not for educating marginalized groups about charged emotional and social conflicts. However, educational principles do support motivational, interactive games, movies, cartoons, personal success stories, question-answer formats, and other colorful, attention-getting formats.

2. **A serious and somber tone does not motivate, inspire, or engage.** Not surprisingly, the tone of virtually all the abuse-prevention material is intense and serious. Abuse is serious and its consequences are devastating. However, the somber viewpoint adopted by most teaching materials not only detracts from their messages, but may also potentially repel users. Comic books and cartoons, computer games, and the Internet have shown that innovative approaches better engage people of all ages and interests.

3. **Crucial populations were missing in development of educational materials.** While many new materials have emerged for disabled women, there have been virtually no resources designed for the unique needs of men with disabilities and few for adolescents with disabilities, which are critical populations. The Spanish-speaking community, our largest language minority in the United States, has even less access to these essential materials. Currently available
educational materials are generally targeted at professionals, parents, and caregivers, rather than at people with disabilities themselves. The assumption is clear: Disabled people are passive, helpless targets of victimization and have little or no role in their own protection.

4. People with disabilities are not “victims.” Many abuse-prevention programs still use this language, emphasizing fear-based or victim-based perspectives. Consistent with the contemporary shift in language away from terms like “victims,” “afflicted,” and “suffering,” the disability community is seeking approaches to empowerment that transcend stereotypical views. From a legal or criminal justice standpoint, instances of abuse create “victims,” but many people with disabilities, parents, teachers, and providers now flinch at the disabled-person-as-victim model. People who have been hurt by abuse are survivors and can move from there to become peers and leaders.

The two studies cited above document that people with disabilities can change their relationship with abuse. The cycle of abuse, well documented in domestic violence research, can be overcome. This point is illustrated by a comment from one man in our study who spoke of re-evaluating lifelong patterns of male power-dynamics:

We can’t retaliate by punching somebody out. . . That avenue is no longer available. When you are disabled and you have been abused or insulted, you have to find other ways to respond.\footnote{Ibid.}

This is what CAPE aims to do: help disabled people, their friends and families, services providers, and others find positive ways to prevent and, if necessary, respond to abuse.

**For Whom Is This Curriculum?**

Our primary target population is people with disabilities living independently who rely on personal assistance services. This can include the following constituencies (and their families and allies): people with mobility impairments, such as spinal-cord injury, cerebral palsy, or multiple sclerosis; people with brain injury, autism, cognitive impairments, or dementia; and people with multiple disabilities, including visual and/or hearing loss, people with developmental disabilities, and people with complex medical needs related to chronic illness such as AIDS, rheumatoid arthritis, or diabetes. There are approximately 10 million people using personal assistance, defined as being "one or more persons assisting another person with tasks which the individual would typically do if they did not have a disability.”\footnote{Litvak, S., & Kennedy, J. (1991). Policy issues and questions affecting the Medicaid personal care services optional benefit (Contract No. HHS-100-89-0025). Oakland, CA: World Institute on Disability.}

About 79% of community-based personal assistance services are provided by unpaid,
informal providers, while approximately 11% of attendant users receive a combination of paid, formal services and informal services, and only 10% receive exclusively formal, paid services. 7

Studies also document considerable abuse of elders in nursing homes 8 as well as people with disabilities of all ages in institutional settings. This abuse is crucial to challenge, yet outside the scope of this project. CAPE focuses on reaching people with disabilities and elders living in the community, where they have self-determination and potential access to educational resources, materials, and independent living advocacy, which institutionalized people don’t have. Several of our stories and chapters refer to the Olmstead Decision, handed down by the Supreme Court in July of 1999, requiring states to administer their services, programs, and activities "in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 9 Olmstead will eventually create state level resources for more and more severely disabled people of all ages so they can choose to live in the community. This decision will have enormous positive impact on the lives of disabled and elderly people, shifting the bias in allocation of Medicaid funding away from nursing-home placement. But it will likely take years to get the regulations in place to implement the decision, and will require an ongoing fight for funds and priority. The World Institute on Disability joins many other organizations in the United States, particularly ADAPT, in leading the cause to end abusive and unnecessary institutionalization of people with disabilities. 10

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7 Rutgers University, Bureau of Economic Research. (1990). The need for personal assistance (in coordination with the World Institute on Disability, Grant No. G0098200134).
10 ADAPT is an organization based in Colorado, originally named Americans Disabled for Accessible Public Transit. They were successful in achieving their first mission, the strong transportation component of the Americans with Disabilities Act. They then changed their focus and their name to Americans Disabled for Attendant Programs Today. They are working on reallocating Medicaid funds from institutional programs, such as nursing homes, to consumer controlled community-based housing for disabled people.
A Note on Language

Because attitudes, practices, and policies about disability are changing, the terms we use are also changing. The term disability is often used in the United States to mean both the individual’s condition and the limitations imposed by society’s negative attitudes. British advocates recommend the use of the word impairment to connote the personal physical or psychological condition, and disability to refer to activity limitations as a result of the impairment, including those imposed by society’s bias. For example, the weakened muscles of spina bifida would be considered the impairment, and might contribute to a walking disability, as well as an increased likelihood of unemployment, a socially imposed disability.

People first language places the personal noun before the disability-related adjective, i.e., woman with a disability. This was introduced in the 1970s as a way to challenge objectifying phrases, such as the disabled, and old-fashioned terms, such as the handicapped, afflicted with, or crippled by arthritis. Since then, disability advocates and scholars have grappled with, and argued about, the complex issues of language, identity, and pride. Some authors now prefer disabled person rather than person with a disability because they wish to claim disabled as their primary positive identifier, and emphasize the continued existence of this oppression. To acknowledge this ongoing debate and to infuse stylistic variation, CAPE texts and learning tools alternate between both linguistic formats.

How to Use This Book

This curriculum can be used by individuals with disabilities and by people working in agencies serving people with disabilities. These would include Independent Living Center staff, trainers, peer counselors, rehabilitation professionals and other assistance providers who serve people with disabilities, along with parents of people with disabilities.

CAPE offers a range of learning tools. These will be adequate for the learning needs of many, but not all, learners. We offer suggestions and resources to help teachers and facilitators assess learning needs, and then develop their own learning tools and activities, tailor-made for specific populations. We hope the people reading and using this curriculum will be inspired to develop more tools and to share them. Help us expand this work with your own good ideas.

To get started with CAPE, we suggest browsing through the introductory chapters to get a sense of the range of issues involved in abuse prevention and empowerment. (You may have also seen our accompanying book, Sticks and Stones: Disabled People's Stories of Abuse, Defiance and Resilience, a collec-
tion of over fifty stories of disabled people confronting abuse as well as a teaching guide.) Then visit some of the multimedia CD sections, view the videos, and/or try out the personal assistance quiz. Check out the Disability Awareness Workshop activities. Browse through the Movie Guide and reflect on movies you’ve seen that feature disability or abuse themes. Then study the chapters which focus on abuse and approaches to ending it. Consider the people you want to reach with this information. Begin to make a plan.

If you are a disabled individual concerned with your own safety, protection, and empowerment, think about others who might join you in exploring these materials together. You might also want to consider setting goals with a group of peers to increase your support system. If you are a teacher, parent, or services provider, you are also encouraged to get support in thinking through the process of becoming an abuse-prevention and empowerment resource person. Plan a get-together with some friends or co-workers and explore the materials, beginning to formulate educational events with the individuals or groups you care about. Remember to include people with disabilities at every step of the way, which is central to the concept of empowerment. We have come to realize that “doing for” people with disabilities, without empowering them to take the lead, is self-defeating and discriminatory, and ultimately, a kind of abuse in itself. The disability community’s slogan, “Nothing about us without us,” is particularly true of abuse-prevention and empowerment activities.

As you will see in our CAPE materials, we greatly emphasize finding and strengthening person to person community connections. Make sure to consider training events and support groups which bring together people with disabilities, their peers, friends, and allies for fun as well as learning. Each of us belonging to, and participating in, the community is essential to ending abuse and empowering people with disabilities to lead and enjoy the good, strong lives we know are possible. Thank you for your interest in this crucial issue. With your help we can end abuse of people with disabilities!
CHAPTER 1

What Is Abuse?

We define disability-related abuse as any hurtful, inappropriate, unwanted, frightening, insulting, oppressive, or demeaning behavior directed at a person or persons with disabilities. It includes physical abuse, such as rough handling, pushing, hitting, slapping or other violence, with or without weapons, or throwing things. It can include verbal or emotional mistreatment, such as making threats, putting someone down, calling names, or keeping someone isolated or limited by jealousy or suspicion.

Abuse may occur as forced or pressured sexual activity, financial mistreatment, including theft of medication or material possessions, or inappropriate control of adaptive equipment. It can involve withholding needed assistance, medication, provision of and access to necessary equipment or communication facilitation or other resources. It can include violation of privacy or autonomy. It can be perpetuated by anyone: strangers, family members, spouses, informal or paid assistants, associates, or services providers.

Abuse of disabled people may be manifested not only by doing something, but also by not doing something. Because of many disabled people’s need for assistance or other kinds of resources, withholding or ignoring needed resources can result in harm. Abuse of disabled individuals may not be easily apparent. The degree of need for assistance from others, as well as the availability of help, adaptive equipment or other resources, is crucial and varies widely. The expectations of disabled individuals and of others who may provide help vary enormously. The lines, boundaries, and levels of tolerance of abuse result from varied personal histories and backgrounds. One individual might consider rough handling by an assistant as abuse. Another might consider rough handling as abuse, only if harm were intended. Another might consider rough handling, even
Abuse of people with disabilities can create a significant barrier to independent living, integration, and inclusion in the community. Violence can be devastating to people with disabilities. Violence can kill or injure. But nonphysical abuse, such as threats or verbal abuse, can be damaging as well. It can destroy confidence, prevent learning and emotional growth, and keep disabled people living in fear and isolation. Abuse can be directed against people with disabilities of all ages, with all kinds of physical, sensory, cognitive, or emotional impairments and disabilities or chronic health conditions. Abuse can cause disabilities or further injure people already disabled.

Caregivers or guardians may prioritize concerns for the safety of disabled individuals while disregarding individual autonomy. Disabled people need and are entitled to autonomy in directing their own lives, and need and deserve respect and a reasonable right to risk. Those with legal guardians still deserve the maximum possible degree of autonomy in decision-making about their lives. The denial of these rights and the imposition of patronizing control or decision-making also may be considered abuse.

Defining disability-related abuse, while simultaneously ensuring disabled individuals’ autonomy, proves to be particularly challenging. Notions of who controls the lives of disabled people and from where spring the necessary resources to support autonomy are in transition. There is distinct variation from culture to culture and family to family.

The CAPE definition of abuse rejects the notion that incidents of mistreatment can be considered discrete “bad things” that happened to that individual disabled person at one particular time or series of times. We regard abuse as part of a continuum of systematic mistreatment. It may be extreme or subtle; it is the visible manifestation of disability oppression. Ending abuse can only happen in concert with substantial forward progress in ensuring disability rights and adequate and appropriate community resources for all constituencies.

**Why Does Abuse Happen?**

Everyday we read news stories of crime and violence. We may feel pain and horror about war, but we know that society sanctions violence in war as necessary, unavoidable and justifiable. Violence in our cities is horrible, but we are jaded; we’ve gotten used to hearing about it. Violence on television and movies has become so common that we are hardly surprised by it.

But most of us feel outraged when we hear of violence directed at disabled people. It is particularly shocking when the abuser is someone who was supposed to help, to care. Why would someone in a helping role, a family member or a paid caregiver or services provider, abuse a disabled person? What could explain such behavior directed against someone who, in many cases, couldn’t possibly resist or fight back? Society may have condoned violence
against disabled people in the past. But are we not now a more civilized world?

We see disturbing evidence of tolerance in our society for certain kinds of violence directed at people with disabilities. When mercy killing of disabled people occurs in families, including killing young people with disabilities, courts are sometimes more lenient about sentencing, and the media debates reveal that segments of the public condone the killing of disabled people—euthanasia—as the right thing to do to end suffering. This attitude is part of the continuum of oppressive assumptions about people with disabilities.

Factors in Abuse of Disabled People

Violence and abuse directed at disabled people, as in domestic violence, child and elder abuse, is caused by a complex interaction of factors.

- The abuser’s personal history of violence and mistreatment, including being targeted with, as well as witnessing, abuse in his or her family, the neighborhood, and community.
- The abuser’s deeply held attitudes about disabled people as burdens, unworthy, and inferior, and that they should be blamed for their or their family’s difficulties.
- The abuser’s (as well as the community’s) values about who should be in charge in relationships with disabled people.

Some abusers appear to specifically target those disabled people who appear weakest or those unable to disclose mistreatment because of communication impairment or low credibility due to cognitive, emotional, or physical impairment.

Anne Finger, in her memoir of childhood polio, tells of her father directing physical abuse at her:

I was the one who bore the brunt of his physical rage. Sometimes when I tell people this, they think he went after me because I was the weakest one, but I don’t think that had anything to do with it. We were all scared of him, scared to fight back or even resist. His anger toward me was physical, rage at that body of mine that persisted, despite all the promises that had been made to us, despite all that had been done for it, despite all that had been done to it, in remaining crippled. His daughter’s body—and for him, the operative word in that phrase was "his"—which walked up and down Hope Street leaning heavily on its crutches, drawing stares, some curious, some sympathetic. Out there for all the world to see, the physical manifestation of the
CHAPTER 1. WHAT IS ABUSE?

inner state of our family—broken, bent, crippled, wrong (p. 102).

Finger shows how her father ascribed meaning to her disability. To him, her impairments represented the dysfunction in the family that he and society needed to hide at all cost.

Additional stressors, which exacerbate difficulties in interpersonal interactions, may contribute to abuse. These include alcohol and drug use, poverty, physical exhaustion, time pressure, job pressure, needs of other family members, etc.

Some contributing factors in abuse have to do with limited resources of families and communities to meet the real needs of disabled people. Inadequate services and resources increase the stress on disabled people and their care providers. Some state and county agencies and personal assistance services systems give disabled people no choice in who provides their care. Low wages for personal assistance workers reduce the pool and limit the retention of qualified workers. Architectural barriers, such as stairs, increase stress in the home of a mobility-impaired person. Lack of appropriate accommodations and services increase the stress levels of all involved, which contributes to the likelihood of abuse.

Most services providers and researchers believe that caregiver stress, drunkenness, and limited resources don't cause violence or abuse. Abuse and violence are caused by the complex interplay of social attitudes and values and individual attitudes and actions. But these additional factors exacerbate or increase the likelihood of difficulties.

In a guest lecture to my university class, Barbara Waxman, a longtime disability activist, said,

People that are devalued as cripples, burdens, or defectives will be abused. If you like somebody, respect somebody, you're not going to kick them. You're not going to leave them in bed and not get them up...You’re not going to withhold medications that they need or give them too many to tranquilize them and shut them up...Even though a care provider might feel frustrated and stressed about the whole situation, they’re going to take care of that person. (guest lecture, 10/14/1998)

CHAPTER 1. WHAT IS ABUSE?

When Abuse Becomes Criminal

When mistreatment of a disabled person crosses the line into criminal abuse, law enforcement professionals and agencies may be crucial in addressing the situation. But well-meaning advocates, family members, and friends must consider the implications of this step carefully. If an individual’s life is in imminent danger, of course the police should be contacted. However, when criminal abuse of a disabled person (physical mistreatment, financial abuse, or extreme emotional abuse) is discovered by a friend or services provider, the disabled individual is the one, ideally, who should be supported to make the decision to involve the police. Forcing someone to submit to involvement in the legal system can sometimes backfire for people with disabilities. For example, legally enacting protection against abusive family caregivers sometimes results in the disabled individual being placed in a restrictive setting. Disabled people should not be removed from an abusive home situation only to face restrictive institutional care. The option to support and educate disabled individuals to address abuse and change their living situations must first be considered.

There are several national organizations that address criminal abuse and mistreatment of disabled people, mentioned in Chapter 7. New areas of research are being conducted in many areas of disability law, hate crime, mistreatment of disabled people within the criminal justice system, and disabled people in prison.

What Is Abuse and Violence Prevention?

Abuse prevention includes any and all programs and activities which help people with disabilities live safely and free from the threat or the realities of abuse and violence. A range of organizations and communities are involved in this effort across the United States and the world. The Domestic Violence Prevention community is working to make its programs and services more accessible to women with disabilities. The Independent Living community, which includes Centers for Independent Living, developmental disabilities organizations, and support and self-help organizations of all kinds, seeks to educate disabled individuals, services providers, family members, and the general public about safety and abuse-awareness. Rehabilitation organizations are building safety and abuse-awareness education into their programs. Violence prevention organizations are working to address inclusion of people with disabilities in their programs. Programs for elders and youth are developing educational materials specifically for these populations. Criminal Justice agencies are working to address the specific needs of people with disabilities in disability, gender, sexual orientation, nationality, or affiliation with someone else with one of these traits. Acts of hate crime could include physical assault, threats, vandalism, hate mail, destruction of property, and fire bombings.
We must shift from protection-focused approaches that aim most of the resources toward building professional’s knowledge and intervention capacities to empowerment-focused approaches that direct substantial resources toward (a) providing individuals with disabilities with information and tools that they need to prevent and stop abuse, (b) linking them to support from peers, advocates and professionals that they can trust to assist them; and (c) proactively communicating that persons with disabilities have a right to be safe, that experiencing violence or abuse is neither their fault nor a sign of incompetence, and that they can manage abuse in their lives by trusting themselves and using their tools and supports.

To implement approaches focusing on the empowerment of disabled individuals, Laurie Powers and Mary Oschwald recommend a range of specific strategies:

1. Allowing disabled people to choose who provides their personal assistance services (PAS) and the option of multiple providers, with back-up services available;
2. Establishing competitive wages for PAS to enable choice and quality care;
3. Providing abuse screening tools to providers;
4. Offering cross training for victim’s services and police to learn about programmatic access, build capacity to include people with disabilities, and increase linkages between domestic violence, criminal justice, and community organizations, including independent living and survivors centers, shelters, and violence prevention groups;
5. Making information available and accessible about violence and sexual assault services and support groups;
6. Developing adequate community resources such that disabled people who disclose abuse will not be threatened with placement in restrictive group homes or institutions or risk losing their custody of children or pet;
7. Having 24-hour crisis hotlines with information about safety planning and victim services staffed with providers who understand disability issues;
8. Supplying emergency resources for disabled people, such as interpreter services and transportation;
9. Offering information, training, and community resources about all phases of self-directed PAS, including writing a job description, using effective communication skills, interviewing potential candidates, performing criminal background checks, and hiring, training, supervising, evaluating, and firing of personal assistants;
10. Supplying disability friendly systems for home security, financial management, and communication.

CHAPTER 1. WHAT IS ABUSE?

the law enforcement system, including the police and the court system. (See CAPE resources listings in Chapter [ ] for contact information.)

Many of these programs work with services providers and families to protect people with disabilities from abuse and violence by addressing policy issues and surveillance of quality of life and provision of care. The United Nations Convention on the Rights of People with Disabilities, signed in 2007 by over one hundred countries around the world, holds as one of its guiding principles freedom from exploitation, violence, and abuse, as well as “respect for the inherent dignity, individual autonomy of people with disabilities, including the freedom to make one’s own choices, and live independent lives.”

What Is Empowerment?

The idea of “Nothing about us without us” challenges patronizing assumptions and practices, and asserts the notion that disabled people must be, as much as possible, in charge of their own lives and choices. Empowerment activities assist and support people with disabilities to take greater control of their own lives, make their own choices, and become involved in and lead in arenas that are important to them.

Some researchers and services providers think that disabled people should not have
to participate in their own safety and protection. They believe that others should take care of that. Stereotyped views of disabled people regard them as helpless or as victims. The Independent Living Movement contends that disabled people living independently (and those who want to become independent) can and must be included in their own safety and protection from abuse. Independent Living does not have to mean “doing things by one’s self,” but it does mean choosing and directing one’s life priorities and activities.

Multicultural Tip #12: Including Culture in Disability Education

Individualize independent living and abuse-prevention planning for consumers to include cultural as well as health and disability accommodation needs. For more tips, see Chapter 10.

Everyone, including non-disabled people, at some point in their life may face the possibility of needing protection, appropriate services and help from family, mentors, police, and other community resources. With the issue of abuse and violence prevention, it is extremely important that disabled people are supported to become the directors and facilitators of their own safety and empowerment planning and implementation. Particularly for the independent living population, abuse-prevention activities must be done with, not for, people with disabilities.

Even though people may not be able to physically resist certain kinds of abuse due to impairment, empowered disabled individuals know they do not deserve mistreatment, know they have some degree of power through communication, such as the ability to communicate “no,” and know that they can disclose abuse and get help, if not immediately, then soon. Empowered people with disabilities are connected to others in their families and communities, and have high expectations that they are cared for and will be aided when they need help. Empowerment activities teach and reinforce these ideas and skills. An empowered disabled person is his or her own best resource in self-protection and safety. People with disabilities themselves must lead the abuse-prevention movement.
CHAPTER 1. WHAT IS ABUSE?

Barriers and Solutions to Integrating Abuse Prevention/Empowerment Activities into Existing Programs

Abuse prevention and empowerment are central to all other disability issues. But competing needs and tight budgets make it difficult to prioritize these issues. The chart below offers common barriers and possible solutions to integrating CAPE training in existing programs.

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Possible Solutions</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Many disability services programs are overwhelmed with current goals; organizations are understaffed. Abuse gets marginalized.</td>
<td>Set long-range goals to address abuse prevention in upcoming years. Include abuse awareness and resources on websites and newsletters. Explore one basic skill (see the Empowerment Wheel, Chapter 3) in every newsletter or event for clients and families.</td>
<td>The “taboo” hides its prevalence. Ending abuse is everyone’s issue.</td>
</tr>
<tr>
<td>Funding is tight for new goals or activities in current and future programs.</td>
<td>Build CAPE activities into the budget over time. Set modest goals for training. Distribute CAPE handouts; encourage all to attend other organizations’ empowerment activities.</td>
<td>Make the case that empowerment is cost beneficial in financial and human terms.</td>
</tr>
<tr>
<td>Staff may lack qualifications to present training or run support groups.</td>
<td>Partner with other organizations that offer complementary skills and resources. Invite guest trainers to present occasionally or provide leadership skills training for staff.</td>
<td>We are all qualified to support each other to set goals for safety and connection.</td>
</tr>
<tr>
<td>Parents, board, providers, or disabled people may feel threatened by topics of abuse, violence, or self-protection, or may assume only law enforcement should address these, not disabled individuals.</td>
<td>Frame and title info and training as “Self-direction,” “Empowerment,” or “Help Getting Good Help.” Present stories in Sticks and Stones; invite guest speakers; show CAPE videos. Remind all of the Independent Living goal: disabled people must participate in and lead abuse-prevention efforts along with other aspects of their lives.</td>
<td>Resistance to the topic is understandable. Give people time to reflect on these charged issues. Recruit guest speakers from domestic violence and Independent Living Centers and police.</td>
</tr>
<tr>
<td>Newly disabled people (of any age) already have so much to learn about living with a disability.</td>
<td>Make self-protection a matter-of-fact aspect of independent living. Frame the issues positively as self-direction and empowerment.</td>
<td>Elders with age-related disabilities are also “newly disabled” and need abuse prevention.</td>
</tr>
</tbody>
</table>
CHAPTER 2

Personal Assistance, Interdependence, and “Vulnerability”

This curriculum is designed for the population of people with disabilities who live independently or who want to live independently. CAPE is also for their providers, family members, friends, and educators. Our goal is to empower people with disabilities to resist abuse and violence, and find connection with and support of others. We want people with disabilities to live strong, full, active, self-directed lives.

Every human being needs help, but many disabled people depend on the provision of help for their survival, well-being, and enjoyment of life. Yet a helping relationship may become an arena for abuse. The power imbalance in a helping relationship can distort the help given to a disabled individual, resulting in a less than humane and empowering interaction. When abuse occurs in the context of these helping relationships, disabled people’s ability to engage in daily life activities is greatly threatened along with their personal health and safety. The systematic mistreatment of people with disabilities in helping relationships is a critical part of the oppression of disabled people.

The need for new views on the provision of assistance motivated a challenge to the previous models of charity and obligation that had existed for centuries. In the late 1960s a new movement arose, created by people with disabilities themselves. Known as the Independent Living Movement, it spread throughout the United States and the world. Irving Zola, the internationally known activist and writer on medical sociology and disability rights, pointed out that within this movement, independence is not measured by the quantity of tasks one can perform without assistance, but the quality of life one can have with help. People have often gotten help
from others, but it was given in the context of duty and charity. Help in the spirit of independent living is instead given within the framework of a civil right and a service under the control of the recipient—where, when, how and by whom (p. vi).

The Role of Personal Assistance Services

Personal assistance services (PAS) are a central resource developed by the movement for Independent Living. Personal assistance is a broad subset of support services that vary with the needs, abilities, desires, and circumstances of the individuals involved. Approximately 10 million people in the U.S. use PAS, defined as "one or more persons assisting another person with tasks which they would typically do if they did not have a disability." Candace Low, a deaf PAS consumer advocate from Oklahoma, stated, "The meaning of personal assistance is as unique as the individual who utilizes the service."

The tasks of PAS are varied: they can include personal maintenance for a mobility-impaired person, such as dressing, bathing, and catheter care, and transferring to and from the bed or wheelchair; household tasks such as cooking, cleaning, and childcare; or cognitive assistance, such as money handling and budget planning. A deaf person who uses sign language may use an interpreter to communicate with people who do not sign. A person with a psychiatric or developmental disability may use support services for decision-making, managing time, or planning, or for extra assistance during a personal crisis. A person may use an assistant to read printed mail or for shopping or transportation.

Access to quality assistance is an essential requirement for personal independence and community living. A range of organizations coordinate and fund formal PAS, primarily Independent Living Centers, which have spread to every state in the United States. Personal assistance services in the U.S. have enabled an enormous change in the

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lives of millions of people with disabilities. As Tony Young, a PAS user for over 20 years, said,

Before personal assistance services [PAS], I spent the majority of my time watching television and sleeping. There were days when I never got out of bed because my family did not have the time or energy to help me in both the mornings and the evenings, especially after working all day. Even though I never worried about getting my basic needs met, there wasn’t much more to my life than eating meals and watching television.

After PAS, I have a job, a career, an active social life and active advocacy life, and the reasonable expectation that they will continue. I find myself thinking of the future in terms of the next few years instead of the next few days. There is the potential of marriage, a home of my own, and a family of my own. I now live in a world of potential rather than a world of despondency. I no longer fear that I will inevitably spend many years in a nursing home or other institution.

Various models of PAS and other disability services exist around the world. Independence and self-reliance are strongly held values in the United States. Interestingly, the U.S. concept of “independence,” stemming from our frontier history, is being constructively criticized by people in some other countries. The names of many disability organizations around the world translate into English as “inter-dependent living” or “self-determined living,” which better emphasize the interconnectedness of families and communities, and elevate the contributions of people with disabilities in the interactions between “helper” and “recipient.”

“Vulnerability” to Abuse

It is assumed that people with disabilities are vulnerable to abuse because they have impairments that limit mobility, strength, or communication and may need assistance. This, it is thought, makes them attractive to abusers who are seeking a powerless target. But it is important to clarify that vulnerability does not cause mistreatment. Mistreatment is caused by the actions of abusing individuals and by society. Abuse is not caused by disability or by an individual’s need for assistance. This has important implications for empowering disabled people to protect themselves from abuse.

While disability or the need for assistance does not cause abuse, there are factors that may prevent some people with

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31
One evening, a male attendant raped Jill in the corner of the dayroom, seemingly unconcerned that Ron was witnessing this horrific incident as he did not fathom that Ron could ever explain what he had seen. Unfortunately, this attitude was widely held at the time by both professionals and laypeople... This event occurred almost 40 years ago at a time when most did not realize that individuals who are unable to speak possess the ability to comprehend and act according to what happens around them. Advances in technology, especially over the past two decades, along with paradigmatic shifts in social attitudes, have decreased the likelihood that this horrific crime, as well as the skepticism encountered by the crime’s sole witness, could be repeated today.

(Howard Shane and Christine Carlson in “Would It Be Different Today?”)

Micheline Mason, a British disability educator, succinctly describes one of those factors:

Disabled people suffer a form of violence which is unrecognized. Current interventions from nearly all professional and service providers have the effect of breaking natural relationships between disabled people and everyone else.5

This “breaking of natural relationships,” as Mason calls it, is the range of distortions that disability discrimination, including those imposed by certain services, creates in the lives of disabled people. These distortions isolate and disempower disabled people beyond the limitations of their impairments. Mistreatment becomes internalized in one’s self-image and belief system. It may distort a disabled person’s realization that abuse need not be endured, and that it can be stopped. This toleration of mistreatment can then limit a disabled individual’s ability to resist or to disclose abuse and get help. This is the crucial factor that CAPE empowerment tools intend to address: Disabled people can realize and act on the belief that no one ever deserves mistreatment. You, as a disabled person can resist abuse, disclose it, and get help.

To better understand disabled individuals’ susceptibility to internalizing mistreatment, we need to take a closer look at this “natural breaking of relationships.” We will

I will never forget how I learned about my son Rowen’s Down Syndrome. Right at his birth, they whisked him away to another room. Before I had been told, a nurse approached me with a pained look on her face and said, “The doctor must tell you something.” I said, “What? What are you talking about?” She said, “I can’t say anything.” I lay there for a half-hour, waiting in horror, afraid that my baby had died. My husband was in the Navy, so it was me and my sister, waiting. Finally the doctor came in pale as a ghost, and said with his eyes lowered, “Mrs. Johnson, your son is a Mongoloid idiot. It would be better for everyone concerned if he were put away in a home for people like him.” I said, “Bring me my son.” I took that baby home and loved him and taught him. He is forty-six now and he works in a grocery store, and is loved by everyone he meets. And he is no idiot. He is a joy. The idiot was that doctor.
(S. Johnson, personal communication, May 31, 2006)

explore some of the typical milestones and factors in the lives of people with disabilities, starting with early childhood, moving on to adolescence, and finally to adulthood.

Disclosure of Disability at Birth or in Adulthood

People with disabilities (and their parents) often have stories of the harsh ways they were informed of a diagnosis at birth or later in life. Medical providers lack the training and skills to inform parents in a thoughtful way about their new baby’s disabilities. Obstetricians expect and hope for positive outcomes, and fear negative ones. Few medical school programs offer training in delivering unwelcome news. Newer generations of medical educators are beginning to address this shortcoming. But still, doctors may sometimes blurt out complex medical language that parents cannot understand, or say that the baby is “defective.” Parents of many disabled adults now over the age of 30 were told when their babies were born that their newborns should be “put away” in an institution.

Of course parents need information that their baby may require medical intervention, but negative judgments communicated early in a child’s life begin the parent-child bond on an unstable footing. Like all parents, they need the chance to be pleased and proud of their precious new baby. If at all possible, providers should wait until the parents have had a chance to meet and welcome their baby before they are bombarded with medical information.

Prenatal Testing

For the last 30 years, parents have begun to be offered prenatal tests to detect disabling conditions in the fetus. If a “genetic flaw” is discovered, the mother is offered (and in some cases pressured) to have an abortion. This reproductive option ostensibly enables the mother a choice. A mother whose baby
was found to have spina bifida wrote about her experiences:

As I was examined and interviewed by several different professionals, I was left with the impression that continuing a pregnancy [of a baby with spina bifida] such as mine was an unusual thing to do. It seemed as though every time I turned around, another physician was asking me whether or not anyone had discussed my "options" with me. "Options" has clearly become a euphemism for abortion.

Women are increasingly pressured to use prenatal diagnostic testing as the "responsible thing to do." Strangers in the supermarket may ask a woman with a pregnant belly, "Did you get your amnio?" While the ostensible justification is reassurance that the baby is fine, the underlying communication to the mother is clear: screening for fetuses with undesired traits is the right thing, the healthy thing to do. This may leave parents feeling defensive or even embattled about deciding to raise a disabled child, rather than being proud of him or her.

**Alone in the Family**

Children with disabilities are typically the only ones with a disability in their family, and may even grow up being the only one with a disability in their school or their neighborhood. Thus disabled children do not have the experience of comradery with others in a marginalized subculture or group. The additional needs and services, as compared to other siblings and adults, contribute to the child’s experience of herself as different or as a burden. Siblings may resent the extra attention given to the disabled child, which creates tensions that can extend into adulthood.

**Special Education**

For children with disabilities, the experience of school is often one of separation. Sometimes they are physically isolated from the other children. The labels that are placed on disabled children by teachers stigmatize them. They may arrive and leave in separate busses. They may be teased or harassed by other children and targeted by bullies. They may have limited opportunity to learn and develop social skills through play, laughing, and hanging out with a wide range of peers, which is taken for granted by non-disabled children.

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CHAPTER 2. ASSISTANCE, INTERDEPENDENCE, AND “VULNERABILITY”

Handled by Strangers

Children who need medical treatments or hospitalizations can become recipients of objectifying help by medical providers and caregivers. Children may be told over and over that “this is for your own good,” or even that they should be grateful for a medical procedure. But the child may experience it as painful or frightening. Thus disabled children end up feeling that they cannot trust their own instincts that something painful isn’t okay. Even kindly or thoughtful providers don’t typically have the time in their high-pressure jobs to adequately introduce themselves, connect with the child, explain what they are going to do, and then allow the child to react in the natural way (such as cry or shake from fear). Children are often told to “be brave.” Children who get used to such procedures have adjusted to feeling disconnected from their own sensations and reactions. This may result in confusion about what kind of touching is harmful or objectionable in social relationships later in life.

Sent Away

Although institutionalization of disabled children and adults is less common than it used to be, it still exists. Many disabled adults who seek services from Centers for Independent Living were institutionalized in residential and hospital schools, nursing homes, long-term rehab programs, and other facilities. The impact of being sent away from their families and communities to live

When I was in ninth grade, I experienced abuse outside the home. I thought I had befriended a group of high school girls, but it turned out that they had other motives. They brought me to their houses when no adults were home and made me take off my pants and touched my private parts. They threatened that I would “get it” at school if I told anyone. I was used by them for an entire year; I was too scared to tell anyone.

(James Meadours in “James’s Story”)

the narrow and often abusive experience of an institution is devastating to self-esteem, to a sense of inclusion and entitlement, and to the process of learning to live and function in the world.

Adolescent Milestones

Typical milestones in the lives of adolescents include dating, learning to drive, staying overnight at friends’ houses, and becoming gradually more independent from families. Adolescents with disabilities may not be able to participate in these life phases and are left feeling on the outside.

Exclusion in Public and Social Institutions

Disabled children and adults must learn to put up with architectural and attitudinal barriers when they go out into the world. There may be no curb cuts, ramps, or elevators for individuals using wheelchairs. There
may be no materials on tape, large print, or Braille for blind people. Deaf children and adults must accept that few people in the hearing public use sign language, and individuals with adult-onset hearing loss discover that few public events are closed captioned. In the street passersby may stare or avert their eyes. Clerks and waiters may ask a non-disabled companion, “What does she want?” right in front of the disabled individual, as if she or he were invisible. Discrimination in employment and educational systems are being challenged by law, but these battles take years. Disabled people may seem “adjusted” to this exclusion, but each incident reinforces the feeling of being different and not wholly accepted as a welcome part of the community.

Inadequate Community Services to Meet Needs

Traditional helping networks, such as churches and neighborhood organizations, are insufficient to address long-term care needs. Disability services through governmental agencies are chronically under-funded. Formal personal assistance services through state and county agencies are often fraught with complex, time-consuming bureaucratic requirements, adding further frustration. Many services which the general public takes for granted, such as restaurants, shops, even schools and libraries, may be inaccessible to disabled people, leaving them relatively isolated from community activities.

Enforced Poverty and Unemployment

Many disabled people would like to work and are qualified to work, but laws persist in many states that jeopardize their state-funded medical benefits and personal assistance funding if they became employed. Since few employers offer benefits which cover personal assistance services or durable medical equipment, such as wheelchair repair, disabled people cannot afford to make the trade-off. These “dis-incentives to work” keep disabled people trapped in the unemployed role. They must live within near-poverty-level monthly benefits. This unemployment status, combined with low income, keeps people with disabilities relatively disconnected from mainstream community life, where people typically find their circle of friends, meet their spouses, and contribute to society.
CHAPTER 2. ASSISTANCE, INTERDEPENDENCE, AND “VULNERABILITY”

Abuse Using Communication Technologies

A new source of abuse has arisen out of the widespread use of popular communications technologies, including social networking websites like Facebook, digital cameras, and cell phones. These useful, accessible technologies have unfortunately become vehicles for abuse in ways not seen before, among teens as well as users of all ages. High priority concerns included threats of violence, harassment, and attempts to control dating partners via text messaging, electronic stalking, and spreading rumors via web and cell phone use. While technologies can be used for abuse, they can also be employed for solutions. Suggestions include changing passwords often, developing user protections and training in technical vigilance, and use of anti-virus software. Several groups have spearheaded a national dialogue enlisting parents, disability advocates, and technology experts, as well as teen leaders from the National Teen Dating Abuse Hotline and members of the National Domestic Violence Hotline. For more information contact:


Elders with Disabilities

Aging is an ordinary part of living, and indeed, it is a privilege to survive into our elder years. Yet older people may acquire physical limitations. Likewise, people disabled earlier in life will reach their older years. Thus many elders need personal assistance, and may require disability access and accommodation at home and in the community. The last link in the chain of lifelong misinformation about disability comes in our later years. The stereotypes of aging, of seniors being helpless and passive, or a burden to their families, are essentially also disability stereotypes. Gray hair and wrinkles are certainly stigmatized in our society. But when elders’ physical and cognitive limitations result in isolation and despair, it may be that elder individuals, families, and communities have succumbed to the stereotype that aging is a humiliating problem, rather than a natural part of the lifespan. Seniors, of course, may internalize these notions, which greatly adds to the confusion.
I grew up in Brooklyn, moved out to California in 1956. My wife, Judy, died in 1991 after forty-six years of marriage. I lived alone until I got rheumatoid arthritis really bad, and began to have a lot of pain. At 82, I couldn’t live on my own anymore. My background is Armenian and growing up, we expected to take care of the old folks. But that’s all changed now.

My son and my daughter both live within an hour’s drive. They made it clear that neither of them wanted to take me in. They argued about who would get stuck with me. They wanted to put me in a nursing home. I said I would rather die. The state takes everything away if you go into a home.

(David Dugigian in “Luke’s Granddad”)

How Do These Factors Affect Disabled People in Relation to Abuse?

This disruption of natural relationships can create disconnection and confusion that affect the disabled person’s relationships with others at subtle but critical levels. Typical social or sexual boundaries may be confusing. Disabled people may have low expectations for quality interaction and little experience with “reality checks” in what to expect. There may be limited opportunities to improve communication skills or learn about sexuality. Some disabled people may come to expect abuse, or even feel they deserve it, because they have been told their very existence is a burden. Some disabled people are lonely for contact, connection, physical affection, and love; they may settle for less than thoughtful, caring attention from others.

Again, it is not the existence of an impairment or the need for assistance that engenders abuse, a view which would “blame the victim” and further invalidate and disempower the disabled person. But when abusive interactions are initiated by others, including people in the helping role (or disabled peers), many disabled people are not adequately prepared to say no or realize how they might extricate themselves from an abusive interaction, or find another way to get their personal assistance needs met. A comment from a focus-group member, also quoted in the section on Youth with Disabilities in Chapter 9 illustrates this point:

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 hard 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. Because of that experience growing up, I feel more vulnerable to allowing it to happen now. Now I feel the power to say, "No, this isn’t going to be okay."

7Saxton, M., Curry, M. A., Powers, L. E., Maley, S., Eckels, K., & Gross, J. (2001). Bring my scooter so I can leave you: A study of disabled women
Multicultural Tip #11: Recruiting for Diversity

Actively recruit staff and volunteers who reflect clients’ or members’ diversity of racial, ethnic, cultural, and personal identities.
For more tips, see Chapter 10.

What Helps Improve Interpersonal Skills and Increase High Expectations for Quality Assistance?

People with disabilities need opportunities to learn new social skills and acquire skills related to personal assistance management. They need chances to practice and get reinforcement for these skills. They also need opportunities for positive interactions with peers in all kinds of relationships. There is no substitute for direct interaction with others in order for disabled people to learn to improve their independent living skills, gain confidence, and protect themselves from mistreatment. Our program offers many avenues and modalities for positive interactions, including support groups, training events, interactive games, stories, vignettes, movies, and empowering social activities.

These kinds of activities can help disabled people counteract the “vulnerabilities” to abuse created by the isolation of disability discrimination and mistreatment. The new skills and confidence gained from these

handling abuse by personal assistance providers. Violence Against Women, 7(4), 393-417.

activities can help people with disabilities protect themselves from mistreatment and live the fulfilling, interdependent lives they want and deserve to live.
Empowerment Skills

What enables people with disabilities to resist abuse, disclose abuse if it happens, get help, and recover from mistreatment? Empowerment. Empowerment is whatever helps people take more initiative in their own lives and act effectively on their own behalf. This idea is one of the most important ideas to emerge from the disability movement.

Empowerment, along with social connection, are the central tenets of abuse and violence prevention. People with disabilities can direct their own lives, exercise their own choices, and set their own boundaries. Many disabled people who are not able to live independently can still participate in a team effort which protects their safety and enables engagement with the community.

An empowered disabled person can learn that he or she deserves to be treated well, learn to communicate “no,” and learn to disclose abuse and get help, if not immediately, then soon. People with disabilities can increase their connections to others in their families and communities, and raise their expectations that others will respond when they request help. Our program is designed to provide hands-on training tools and resources to use directly with people with disabilities, enlisting them as the key resource-person in their own safety and empowerment.

No Magic, No Shortcuts

Effective empowerment for people with disabilities requires time for planning and coordinating; collaboration with other organizations and resources; rigorous skills development; and repeated opportunities to learn and reinforce skills. There is no magic and there are no shortcuts to empowerment. Disabled people and their teachers, rehabilitation counselors, facilitators, peer counselors, and parents must put in the time to create appropriate learning activities, with adequate reinforcement over time. The results of this rigorous planning and implementation are well worth it! The high cost of abuse, in human as well as economic terms,
will be well worth the investment of time and energy in empowerment activities.

### Seven Basic and Two Advanced CAPE-abilities

CAPE learning tools and activities help teach and reinforce seven basic skill areas in interactions with others, plus two advanced skills for self-advocates and leaders. These skills can be applied in activities of daily living, health care and services, learning and working, sexuality, socializing, and participation in the community. Developing these empowerment skills may require a long-range learning plan or a shorter-range plan for specific skill development, depending on the individual's needs. The skill areas below are not steps to be learned or practiced in a particular order, but rather are a collection of essential components for one's overall ability to connect, self-protect, and thrive. For most people, these skills are acquired over time through positive interactions with peers and support people. The success of learning depends on planning, attention to learning styles, access, and specific intervention.

CAPE includes three different handouts that lists these skills and provide summaries of each. These handouts, shown on the following pages, are meant to be photocopied and distributed. The first is a comprehensive two-page handout that focuses on the seven basic CAPE-abilities and two advanced skills, while linking the practical advice given in this chapter with broader skills that are important in all aspects of life, not just abuse prevention and empowerment. The second handout is a *plain language* version that summarizes the information presented in the first handout. *Plain Language*, also known as *Plain English* and *Simple English*, is meant to make writing clear and understandable. Simple vocabulary and sentence structure help make writing more accessible to a broad population of readers, including individuals with cognitive, developmental, emotional, learning, communication, and psycho-social impairments. The third handout, the *Empowerment Wheel for People with Disabilities*, uses the wheel design that is well-known in the domestic violence community to stress the integral nature of knowing and practicing all of these skills in order to understand them and become empowered to prevent abuse.

Following the handouts is a series of ideas about how to assess which of these skills you or the people you know need to work on most, and then there are practical suggestions about how to work on those skills. CAPE also provides a series of resource tips and success stories that are relevant for each skill and serve as examples of how these abilities can make a real difference in preventing abuse and increasing empowerment. This chapter concludes with a handout that is a goals chart meant to help people concretely decide which specific steps they can take to improve certain skills. An example chart is provided to help understand how practicing abuse prevention and empowerment skills can become a part of daily life.

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1 For more information about *Plain Language*, see [http://www.plainlanguage.gov/](http://www.plainlanguage.gov/)
BASIC SKILLS

Seven CAPE-abilities and the corresponding general skill areas:

1. Decide You Are Important                 Self-Respect

You are important and you deserve good help and respect. Decide that getting the best help and learning the other skills below are worth the effort.

2. Own Your Own Body                         Boundaries

Your body belongs to you. You decide who touches you and how. Your body, your sexuality, your health, your care, your medications, your physical safety, and your life all belong to you.

3. Be Assertive                             Confidence

Say no when you mean no. Be aware and respond to possible threats, fraud, swindle, or any compromises to your safety and well-being in interactions with others, including your family, personal assistants, care providers, and strangers.

4. Take Charge of Your Life, Stuff, and Relationships Responsibility

You decide what happens with your needs and help. Be in charge of adaptive equipment, phone, and other communication devices, and keys. Be responsible and use good judgment about your healthcare, medications, your use of alcohol or drugs, and financial matters and materials, to the greatest extent possible. You are the boss; be a good boss: recognize helpers as people with their own needs.

5. Be Ready and Able to Disclose Difficulties and Get Help Get Help

Identify and contact resource people who can help you plan your safety and well-being and to whom you can disclose difficulties and ask for help if something goes wrong.

6. Don’t Blame Yourself If Someone Hurts You Resilience

Be aware of disability discrimination and mistreatment. These are never your fault. Resist internalizing (blaming yourself for) mistreatment or discriminatory attitudes and behaviors. You always deserve to be treated well and with respect. If you are treated badly, you can recover and go on to resume living a good life.

7. Have Fun, Make Friends and Connect with the Community! Participation

Participate in community activities on a regular basis. Be connected to others; have a circle or network of friends and acquaintances you are in touch with. Make sure others are aware of your safety and well-being. This can include family, friends, and neighbors, or community or spiritual groups.
ADVANCED SKILLS

Two “advanced” CAP E-abilities for self-advocates and leaders

8. Be Entitled: Know Your Rights and Resources
   Self-Advocacy

Learn about disability rights and laws, and the services you are eligible for. Learn about the history of the disability rights community. Be a proud disabled person.

9. Be a Leader
   Leadership

Exercise your skills in the community for your own empowerment and to help others. Leadership is the most powerful way to reinforce all the previous skills, learn new ones, and help change the world.
Plain Language Version

1. Decide You Are Important

You are important and you deserve good help and respect. Decide that getting the best help and learning the other skills below are worth the effort.

2. Own Your Own Body

Your body belongs to you. You decide who touches you or does something to your body. This includes sex, your care, your health, your medicine, and your safety.

3. Be Assertive

Say no if you mean no. Be ready if something or someone gets in the way of your safety, and say no!

4. Be In Charge of Your Own Life

Be in charge of your things, like your phone, keys, medicine, money. Be responsible and use judgment about your health and your alcohol use.

5. Tell and Get Help If Something Goes Wrong

Have someone you can call and talk to, someone you trust if you need help with your safety, or if something goes wrong.

6. Don’t Blame Yourself If Someone Hurts You

It is not your fault if someone hurts you. You always deserve to be treated well and with respect. You can recover and live a good life.

7. Say Yes to Fun, Friends, and Connection!

Be connected to people, for example, your family, friends, neighbors, church or spiritual groups. Let your friends know how you are.

Advanced CAPE-abilities

8. Know Your Rights and Resources

Learn about your rights. Learn about services in the disability community. Be a proud disabled person.

9. Be a Leader

Use your skills. Lead other people and help change the world.
Empowerment Wheel for People with Disabilities

Take **POWER AND CONTROL** of your safety and your life

---

**You Are Important**
Getting the best help and learning these skills are worth the effort.

**Own Your Body**
You control your care, health, medicine, sexuality, and safety. You decide who touches you and how.

**Be Assertive**
Tell people how you want to be treated. Watch out for fraud. Say "no" if you feel harmed or threatened.

**Be In Charge**
You decide about your needs, possessions, personal assistance, activities, communication, and money. Be responsible about alcohol and drugs.

**Tell Somebody**
Know people you can contact about abuse or other problems. Don't be silent about abuse. If you need immediate help, call 911.

**You Are Strong**
If you get abused, don't give up. Don't blame yourself. You can recover and live a good life.

**Know Your Rights**
Learn about your rights and the services you can get. Be an informed and proud disabled person!

**Connect with People**
Communicate with family, neighbors, and community groups. Make friends and tell them how you are.

---

CAPE-abilities for Self-Protection from Abuse

www.wid.org/cape
Assessing Empowerment and Self-Protection Needs

How do we determine what the abuse-prevention needs of our populations are? Here are some suggestions:

1. Ask Questions

For many populations of people with disabilities, this is the obvious approach. You might want to ask the following questions:

- What would make you feel safer?
- What would make you feel more in charge of your life?
- What would make you feel more confident?
- What do you need to better manage or relate to people who help you with your disability needs?
- What do you need to learn to be more confident and more skilled?
- What skills would help you get your needs met?

If working with a group, consider asking potential participants to fill out a simple questionnaire, or interview people individually or in a group. Your participants may not give you clear answers but at least they will reveal some important clues.

2. Use the Quiz

For people facing difficulties with personal assistant skills management or relationships with family care providers, use the Personal Assistance Quiz on the Multimedia CD to identify specific skill areas that need attention. Administer the quiz or sections of the quiz to your group or individual. Or go through the quiz points yourself or with a partner or co-worker, considering the needs of your participants. You may want to alter the quiz questions, or develop a new quiz, which more precisely addresses specific needs and difficulties of your group.

3. Share CAPE Videos and Comic Book Scenes

Present one of the short CAPE videos or a few of the Comic Book Scenes to assess your group’s response to them. Participants’ reactions will give you information. Note or record their comments, questions, concerns, and priorities. Reflect on these with a partner to begin to develop short- and long-range goals for your group.

4. Read Stories in *Sticks and Stones*

Some people may not yet be able to disclose difficulties or ask for help, or they may respond passively to mistreatment, or generally feel powerless or victimized. Read through the stories in *Sticks and Stones* for examples of disabled people’s difficulties and successes in confronting abuse. Which ones seem to ring true for your group? Bring one or more of these stories to the group, to read...
CHAPTER 3. EMPOWERMENT SKILLS

Multicultural Tip #16: Knowing about and Asserting Rights and Needs

Latinos with disabilities, along with people of many other cultural backgrounds residing in the United States, may be passive when it comes to asserting their needs and rights. Rights may not have been respected in their countries of origin, and they may feel that as immigrants, they don’t deserve the rights of other residents of the United States. Of course, legal rights to services and entitlements, particularly for illegal immigrants, may vary.

For more tips, see Chapter 10.

 aloud or read together, and then listen to and observe participants’ reactions to plan the next steps.

5. Discuss CAPE-abilities

Some populations of disabled people may not be able to identify or articulate their needs verbally. Others, because of specific impairments, may not be able to access the print or multimedia formats in our program, or may require interpretation. Look through the CAPE-abilities with your group or individual in mind. Discuss these together with a parent, provider, or resource person who knows the group or individual. Select the skills or objectives that seem most appropriate to start with. Begin to develop a plan for the group or individual, which builds on and reinforces these skills.

6. Practice Safety Tips Exercises

For people who are unaware of safety hazards or pitfalls in their relationships with others, look through the ideas and suggestions for games and events about safety that are included in Chapter 16 and consider how they can be employed with the population you work with.
Applying the Skills

This section is primarily addressed to the disabled individual. Educators, parents, or friends can reframe the questions and comments. This section will help participants consider which of the basic skills need developing or strengthening. Below is a discussion of each skill and ideas about how to explore it.

Skill One: Decide You Are Important

Consider these questions:

- Do you feel you are important? Why or why not? How would you know if you were important to yourself or others?
- Do you feel you deserve good help and respect? Is there something in the way of this?
- Is it worth the effort to get the help and skills you need to live a stronger and more fulfilling life? Why or why not?

Empowerment is about self-esteem, feeling good about yourself, and knowing you are worthy of respect and high-quality personal assistance. Most people with disabilities have difficulties with self-esteem at various times in their lives because they are targeted with discriminatory attitudes and mistreatment. It is nearly impossible to avoid internalizing some of these wrong attitudes. An individual with low self-esteem may feel they deserve abuse or even come to expect abuse or violence. They may see abuse as an ordinary part of their life. Yet self-esteem can be improved! Below are important first steps to improve self-esteem:

1. Begin to tell your story and get listened to by a calm and friendly listener.
2. Be encouraged to notice you have things to offer others.
3. Be encouraged to notice that you, like everyone else, have needs for assistance, and that you deserve help.
4. Decide you are a good and important person, just the way you are.

CAPE resources: Find, share, discuss, and compare the stories in Sticks and Stones that resonate with life situations. Activities practiced in a support group setting are important. Structured interaction helps teach interpersonal skills and build self-esteem. The short video Talking about Abuse and Disability is a quick way to introduce the topic to a new audience. Ask yourself (or the disabled person) on a regular basis, “What is one small (or large) thing that’s going well in your life?” Set a goal to notice what is good about you (or him or herself).
CHAPTER 3. EMPOWERMENT SKILLS

Skill Two: Own Your Body

Consider these questions:

- Do you feel your body is your own?
- Do you stop someone who touches you in a way you don’t want?
- Do you ask specifically for what you want with your care?
- Does someone control or withhold your medication or food without your consent?
- Does someone make you feel scared for your safety or threaten to harm you?

CAPE resources: The Comic Book Scenes offer examples of disabled people taking charge of their care and setting boundaries about physical touch. The video Strong and Informed discusses sexual boundaries. Discuss and compare the stories in Sticks and Stones that resonate with the lives of disabled people you know. Invite people to talk about how they want to be touched and cared for. People can practice saying, “That’s not how I want to be touched. Let me tell you how.” Using dolls or stuffed animals helps to reveal deeper feelings, what happened, or what should happen.

This skill is about reclaiming your body. Disabled people may feel like their bodies are not their own. Parents and medical and care providers may forget to ask or explain before they touch or do things. People who were disabled as children didn’t get to decide what happened to them. They may have had painful surgery or treatment, been sexually abused, isolated, or abandoned. They may feel it is okay for others to hurt them.

Rob is a 56-year-old man with muscular dystrophy who lives with his wife and two children. He has struggled with attendant care over the years, feeling confused about the responsibility of hiring, training, and firing personal attendants. Once he was dropped by an attendant who hadn’t been adequately trained, and Rob’s leg was broken. He also realized he was depending on his wife too much when his attendants didn’t show up, and it was straining their marriage. He took the PAS quiz, and read the stories in Sticks and Stones, realizing he identified with several of the stories. He decided he needed to be assertive with his attendants and improve his skills as a boss. Rob made a list of goals for the next 6 months, which he discussed with his wife and a peer counselor and posted over his desk. He also signed up for PAS training at a Center for Independent Living and joined an online support group. Eventually, Rob became a peer counselor at his local Center for Independent Living.
Skill Three: Be Assertive

Consider these questions:

- Can you say “No” when you mean no?
- Can you think of a time when you did say no despite pressure to put up with something? What happened?
- Are there times when you get mistreated because you don’t know how to stop mistreatment?
- Do you ever just go along with something you don’t want because it’s too hard or scary to speak up? Or you don’t want to hurt someone else’s feelings?

Disabled people can feel afraid to speak up. Saying no isn’t easy for anyone. We are all taught to be agreeable. Disabled people who are passive in the face of mistreatment need help to realize they can decide what they are willing to put up with.

**Darleen** became paraplegic at age 28 when her husband hit her and she fell down a flight of stairs. She spent 6 months in rehab, while her twin girls were placed with her parents in another state. She vowed to regain custody of her children and return to a full life. A social worker referred her to a women’s center that used CAPE empowerment tools, including a support group for abuse survivors. The group met every week to discuss stories and movies recommended in the CAPE resource sections. Darleen especially liked the *Handling Anger* Powerpoint and the *Sticks and Stones* stories because they helped her understand how vulnerable she had been to her former husband’s rage. She knew she would never let herself be a “victim” again. With the help of the women’s center, she met with a lawyer and developed an empowerment plan to live on her own and get her children back. The judge who presided in her case was very moved by the determination revealed in her written plan, and helped her move quickly through the court system’s paperwork. Two years later, Darleen did get her girls back, and is now in a part-time teaching certificate program.
Skill Four: Take Charge of Your Life, Stuff, and Relationships

Consider these questions:

- Do you feel that you get to make important choices about your life?
- Do you direct the people who help you? Do they respect your direction? Are you a good director of the help you need and ask for?
- Is your home and are your things arranged the way you need and want them to be?

This skill is central to independent living. Being responsible for and in charge of your life, possessions, and relationships is essential for directing your own life. Being responsible means prioritizing and taking care of things that matter for your life to go well.

CAPE Resources: The PAS Quiz, Comic Book Scenes, and PAS Scenarios for Men can help identify specific areas of difficulty in attendant care relationships. Make a list of challenges and set goals. See the success stories profiled in Sticks and Stones and the sidebars in CAPE. Use the Goals Chart on page 60. The PowerPoint presentation Handling Anger can help with challenging relationships. Practice the Safety and Crime Prevention Questions and Tips list in Chapter 16.
CHAPTER 3. EMPOWERMENT SKILLS

Skill Five: Be Ready and Able to Disclose Difficulties and Get Help

Consider these questions:

- Do you have one or more individuals in your life who are empathetic listeners?

- Can you identify two or more individuals in your circle of friends you can really talk to about your life and your needs? Are the individuals you identified up-to-date on your personal care needs, health or medical status or personal assistant situation?

CAPE Resources: The Comic Book Scenes, PAS Scenarios, and the short video Strong and Informed offer role models of people disclosing abuse and asking for help. The PowerPoint presentation “Handling Anger” teaches steps to take in improving communication. Make a list of people you could talk to if things get difficult with your care. If you can’t think of anyone, make a short list of people you would like to be able to talk to about your personal care. Set a goal to ask them to be your contact person.

This skill is about building a good support network and reaching out to others for support. Everyone needs a circle of friends and resource people he or she can contact when difficulties arise. People with disabilities need to have at least one person, better are three or four, who know about their assistance needs and are familiar with the interpersonal issues related to personal care.

Edna is a 79-year-old woman with rheumatoid arthritis who has lived alone since her husband died 10 years ago. She had always been independent, but when her limitations prevented her from driving, she started to have her groceries delivered. Yet she became very isolated in the process. She occasionally asked a neighbor to stop by, but her neighbor was elderly as well. Edna also hired someone to clean and cook, but soon realized this person stole some of her jewelry and checks, so she became afraid to hire anyone else. She was also afraid of falling and of the house catching fire. Then, Edna heard about the local senior center on the radio and contacted them. The center sent a van to pick her up for weekly activities. Among the senior center’s offerings were abuse-prevention training events, where she learned to better screen and supervise her personal assistants, and Senior Safety BINGO. Edna also met with a counselor at the senior center. Together, they drew up goals which included learning safety tips, hiring nursing students from a local college, and using the local van service. A year later, Edna felt safer and was getting out regularly to visit friends and shop on her own.
CHAPTER 3. EMPOWERMENT SKILLS

Skill Six: Don’t Blame Yourself if Someone Hurts You

Consider these questions:

- Do you blame yourself when something goes wrong or someone treats you badly?
- Do you feel like it is your fault when you have unexpected difficulties?
- Do you know how to find emotional support if you are upset? What do you do? Who do you turn to?
- What would you tell another disabled person who was mistreated? Would you tell yourself the same thing?

This skill is about resilience and knowing you can recover from a difficult or abusive interaction and go on to live a strong, good life. Abuse feels terrible, but it doesn’t have to have permanent effects.

A central theme of *Sticks and Stones* is resilience. Being resilient means the ability to bounce back after you get over the hurt. Disabled people have resisted and struggled with abuse all throughout history. The success of the disability rights movement in countries around the world has helped disabled people recover from mistreatment. Disability rights activists have used their past difficulties as motivation to organize and improve living conditions for themselves and for disabled people everywhere.

CAPE Resources: Find, share, and discuss the stories in *Sticks and Stones*. Write or tell your own success story! Support group activities and counseling are important to recovery from abuse. See the Chapter 8 on Peer Counseling Assault Survivors. Look at the Movies for Empowerment list in Chapter 13 for inspiring movies that help by offering role models of people confronting difficulties and succeeding.
CHAPTER 3. EMPOWERMENT SKILLS

Skill Seven: Have Fun, Make Friends and Connect with the Community!

Consider these questions:

- During the last month(s), how many times have you participated in something you really enjoyed?
- During the last month(s), how many times have you turned down an invitation to do something fun? What were the reasons?
- Do you have friends who encourage you to do fun activities in the community?
- Do you have a way to get out and meet people?

CAPE Resources: Learning about community access and community programs that welcome people with disabilities is an important step to meeting people. The Movies for Empowerment list in Chapter 13 is a good source of movies to see with friends. Make a list of fun things you would like to do. Support groups and training events can include time to brainstorm and announce community activities and ideas for fun.

This skill is about participating in life and growing together with others. We must be able to say yes to good things, not just no to bad things. Participating with friends and family in enjoyable activities is important to living well and enjoying life.

Sally is a 37-year-old woman with spina bifida who described her childhood as “way over-protected.” She was able to enter a CIL transitional living program and found an apartment with a disabled roommate. Her peer counselor asked her what she needed to learn to feel safer living in the community. Sally spoke of an incident where she fell, was unable to get up, and sat for hours on the floor not knowing if her roommate would return. She couldn’t reach her phone. Her peer counselor offered Sally the CAPE tools. She took the PAS quiz, and her score revealed she needed help learning to direct her care routine. Sally also looked at some of CAPE’s other multimedia resources and especially liked the short videos and the comic scenes. She could relate to the pictures and stories and enjoyed discussing these in a group at the CIL with several other disabled people with similar needs. Sally, with the help of her peer counselor, developed a written plan for the next year. Her goals were to regularly be in touch with others, make some new friends, improve the access in her apartment and always carry her cell phone. She joined a recreation program at the local YWCA to make more friends and feel more connected. At the end of a year, she was proud that she had met her goals and felt safer and more active in her life. See Sally’s Goal Chart on page 59.
CHAPTER 3. EMPOWERMENT SKILLS

Advanced Skills

Skill Eight: Be Entitled – Know Your Rights and Resources

Consider these questions:

- Do you know your rights as a citizen with disabilities?
- Have you heard of the Americans with Disabilities Act (ADA) and know what it stands for? Do you know about the disability-related laws in your state?
- Do you know of groups in your community who are working for your rights?
- Are you aware of the proud history of the Disability Rights and Independent Living Movements?

This skill is about knowing your rights. Informed individuals are empowered individuals! People with disabilities have a proud history of working to create and enforce laws that protect our rights. But the challenges continue. We need everyone to participate! Can you join us? What difference might this make in your life?

CAPE Resources: The Disability Awareness Workshop offers activities which help people learn about key disability concepts, the Americans with Disabilities Act, and other laws and resources. Become familiar with the main abuse-prevention organizations and websites to expand your knowledge of community and national rights and resources.

People with disabilities have to be leaders against abuse. Too often, people who are not disabled are spokespersons about issues in which we have expertise. Let’s no longer remain silent about issues of abuse and harassment. (Lynne Koral in “Abuse from a Wide Range”)
CHAPTER 3. EMPOWERMENT SKILLS

Skill Nine: Be a Leader

Consider these questions:

- Do you know what you can contribute to empowering people with disabilities?
- Would you like to be a leader? What would that mean to you?
- Do you know what your leadership skills are?
- How are you already a leader among your circle of friends and contacts?
- What would you like to learn about leadership?

This skill is about joining the Disability Rights and Independent Living Movements. Thousands of people with disabilities have moved into leadership roles in their communities. People need role models. You can become a leader and role model through your community organizations.

CAPE Resources: Consider leading or co-leading a support group or one of the Disability Awareness Workshop activities. Become familiar with the concepts and resources in the PAS Quiz, the PowerPoint presentation Handling Anger, and the short video Strong and Informed to share information and ideas with others. Appreciate your power and your contribution to the disability community and the world!

Cheryl is a peer counselor at a busy Center for Independent Living in the Midwest. Over the years, she has heard many complaints from consumers about abuse incidents, but she wasn’t sure how to help them. She knew the stack of “Avoid Abuse” handouts on the counter at the front door wasn’t enough to make a difference in clients’ lives. So Cheryl suggested to the center’s executive director that they create a plan to develop a support group about abuse experiences. They drew up an agenda and advertised the group and were surprised by the enthusiastic response. Fourteen people joined, with 11 continuing for 6 months. The group utilized the CAPE Support Group guidelines in chapter [12] and used the Disability Awareness Workshop activities. They explored various learning tools, meeting twice a month for 6 months, with occasional movie nights to watch and discuss movies recommended by CAPE in chapter [13]. Participants reported feeling much safer and enjoyed meeting others with similar concerns.
Developing Your Own Learning Tools for Specific Populations

No curriculum can address the learning needs of all people with disabilities. There are many hundreds of types of impairments, which intersect with other categories, such as age, gender, cultural and ethnic background, educational level, etc., resulting in thousands of categories of learners. CAPE offers a range of learning tools, but these will not be adequate for all individuals and groups of people. After you assess group-specific learning needs, you will likely want to develop your own learning tools and activities.

To develop new learning tools, here are some suggestions and references:

- Create an “empowerment learning tools project” with your constituents or organization. Gather people with disabilities, family members, providers, staff, board members, etc. for a brainstorming session to generate ideas on learning tools that would address specific needs. You might generate some ideas and apply for a grant to develop your specific learning tools.

- Use the ideas in the Teaching Guide in *Sticks and Stones* to produce stories of disabled people confronting and resisting abuse. Share these stories in the ways described in the Teaching Guide, such as informal newsletters or sharing time at events.

- Existing games like BINGO and cards are simple and familiar to most individuals, and they offer models of unlimited variations for learning games. (See the Disability Awareness Workshop and Chapter 16, “Safety and Abuse-Prevention Tips for Games and Events,” for examples of how to adapt a game like BINGO and make it educational and empowering.)

- Drawings or photos work very well to elicit conversation and fun interaction. They don’t need to be professional looking. Stick figures are very fashionable in popular art and cartoons on the web and in popular print media. Take advantage of this current style and try your hand at using figures to teach and learn. The easy availability of cameras on cell phones and disposable cameras enables all sorts of opportunities for creative and productive play and learning.

High-Tech Options

- Our short CAPE videos were created with Adobe Premier Pro. This versatile software is used by the Center for Digital Storytelling ([http://www.storycenter.org/](http://www.storycenter.org/)), an organization that offers workshops to individuals and groups all around the United States to create wonderful autobiographical and educational movies.
You Tube (http://www.youtube.com) is an amazing website for the public to share their creative home-made movies. (There is also a lot of junk there.) Browsing through YouTube can inspire ideas about education and learning.

The Internet is full of sites on learning games. For example, the Kid’s Page (http://www.thekidzpage.com), offers a wide variety of games. You can also browse game stores and libraries for ideas.

Make an Empowerment Learning/ Skills Plan

An “empowerment learning plan” can be developed for individuals or groups that sets reasonable goals, develops ideas for a range of activities, includes built-in checkpoints for assessment of skills, and offers ongoing reinforcement. Setting goals, building in a strong support system, and regularly checking in with individuals on how things are going are all important to this process. The success stories included alongside the descriptions of the CAPE-abilities and Sally’s example goal chart on page 59 illustrate the goal-setting process.
Goals Chart for CAPE – Sally’s Example (see her story on page 54)

<table>
<thead>
<tr>
<th>Goals – What you want to change:</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Feel safer at home, especially in emergencies.</em> Make new friends; be more active. Improve access in my apartment.</td>
<td><em>Can I do this!?</em></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Rewards – How this will make your life better:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Enjoy my life more, get out and have fun!</em> Not have to worry about falling.</td>
<td><em>This sounds great!</em></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Steps – Reasonable steps that can help you get there:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Keep cell phone charged and always in reach.</em> Program phone with friends’ numbers.</td>
<td><em>This is a good first step toward feeling safer.</em></td>
</tr>
<tr>
<td><em>Take a class at the Recreation Center.</em></td>
<td></td>
</tr>
<tr>
<td><em>Get grab bars in bathroom and hallways.</em> Find and schedule carpenter to install grab bars.*</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CAPE Tools and other resources to help you learn and set goals:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Sticks and Stones stories, CAPE movies and comic scenes,</em> PAS Quiz, PAS websites. <em>Meet and talk to peers at a Center for Independent Living.</em></td>
<td><em>I like the idea of doing this with peers.</em></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Timeline – How long will you need?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Six months, with check-ins in 2 and 4 months</em></td>
<td><em>Is this enough? Let’s see!</em></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Support System – Who or what can help or support you?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Peer counselor check in with me in 2 months and 4 months.</em> <em>Tell my roommate and sister about this plan.</em> Make a note on the calendar in 1 and 2 months to assess goals. Post a note to remind myself about charging and keeping my phone.*</td>
<td><em>I don’t have to do it alone!</em></td>
</tr>
</tbody>
</table>

**Table 3.1:** This is an example of a goals chart to achieve greater empowerment and prevent abuse. Use the empty chart on the following page to list your own goals.
### Goals Chart for CAPE

<table>
<thead>
<tr>
<th>Goals</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goals – What you want to change:</td>
<td></td>
</tr>
</tbody>
</table>

| Rewards – How this will make your life better: |  |

| Steps – Reasonable steps that can help you get there: |  |

| CAPE Tools and other resources to help you learn and set goals: |  |

| Timeline – How long will you need? |  |

| Support System – Who or what can help or support you? Who can check in with you? |  |

**Table 3.2:** Fill in this chart with your goals and the ways you will achieve them.
Part II

Key Issues
The People Who Help: Family and Paid Providers and Personal Assistants

To enable people with disabilities to live without abuse or the threat of abuse, the needs of the people who help—family members, friends, paid personal assistants—must be considered. Currently, a largely female workforce of family members provides voluntary assistance. Those paid for this work are mostly people at entry level, young workers, people of color, or immigrants. These workers occupy the lowest rung on the ladder of healthcare providers. They are generally unpaid or underpaid, overworked, and under-recognized in the labor force. Yet their value is essential to the working of society. Fortunately, family members and paid providers are beginning to organize and advocate for community support programs, increased wages, benefits, and better working conditions.

In this chapter, we explore the conditions and needs of those who help disabled people live in the community. The perspectives offered here can also help people with disabilities better understand what it is like to be a care provider. See the CAPE video *A Good Job* (about the needs of care providers) on our Multimedia CD.

Women’s Work

The workforce providing care to individuals with disabilities is primarily composed of women, and women’s work is often not recognized as “real work.” Caregiving is undervalued in American society, whether it is caring for young ones or people with disabilities or elders. Providing care is associated with dependence and vulnerability, qualities our society would like to ignore. Estimates of the proportion of female providers in the field are as high as 95%.1

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Traditionally, female care providers are seen as selfless givers, without needs of their own. Many feminist writers have explored the politics and practices of caregiving. Susan Wendell suggests that “an adequate ethic of care must address the needs of providers and the possibilities for reciprocal care,” creating a new model of interdependence. Reframing the fundamental nature of the caregiving job, and the relationship between disabled individuals and their helpers, means seeing it as one of mutual care and mutual respect. The idea that providers don’t need care themselves must be challenged, along with the notion that people with disabilities don’t have caring or resources to offer.

As more and more women continue to move into the workforce, families and disabled family members are required to seek paid providers from outside the home. But due to the “housekeeper” model, providers are often treated like maids and regarded as domestics rather than skilled workers whose work enhances the independence and self-determination of disabled people.

Family Providers

Suddenly I found myself one of those sandwich moms. I was a single mother with teenagers. When my father had a stroke, there was no way I was putting him away. Now I work fulltime at work and then fulltime at home. The kids help out some, but they’ve got their lives. Do I have a life?

The vast majority of disabled people needing personal care, about 79% in the United States, are assisted by family members. Most families do this work out of love and devotion to family members with disabilities. However, this caretaker work can be difficult and confusing.

In families, everyone needs help sometimes. We expect to care for babies and children and people who are temporarily ill. But denial of long-term disability in our society prevents us from planning and learning to offer assistance to family members who become permanently disabled. Before it happens, the likelihood of disability occurring to someone we love seems impossibly remote. But to those of us to whom it happens, statistics are meaningless. Disability happens. Families must respond, and do. Whenever disability creates a significant need for help, whether at the time of an individual’s birth or at a later time in his or her life, family members must

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handle the grief and shock of the gradual or profound changes in the life of the disabled person as well as how they may impact others in the family.

In many cultures, wives, daughters, and daughters-in-law have traditionally provided care for elderly and disabled family members. Occasionally, husbands, sons, and brothers become the providers of significant help. Our society expects providers to be sensitive and thoughtful to those receiving help. But many family providers may need help with the logistics of care, handling the stressful situation, and understanding their own feelings. Under the duress of providing care, it can be difficult for family members to remember their own needs for rest, sleep, nutrition, and exercise, not to mention opportunities for learning and enjoyable activities. Family providers need support to take good care of themselves, both for the sake of disabled loved ones, and for themselves.

It can be confusing to find that assisting a beloved family member feels difficult, even overwhelming. Interacting closely and for long hours with very ill or demented people can overwhelm anyone. Feeling angry or frustrated is a natural and understandable response to this challenging situation. Caregivers need to remember that it is essential to take breaks from the work. It is equally important not to let guilt, obligation, or grief about a loved one’s situation stop family members from taking the best care of themselves. Providing care can be isolating, and no one should be the sole provider of care for a significantly disabled family member. If possible, other family members and paid helpers should be involved on the team of support for disabled people.

A growing body of literature for family providers is becoming available and an increasing number of community programs exist. Support groups for family providers enable them to realize they are not alone in their feelings and in the challenges of the work. There are many useful sources of information and training on how to handle the full range of issues related to providing care and assistance for a disabled family member. See the resources listed at the end of this chapter. For readers interested in starting their own groups, CAPE’s Chapter 12 addresses support group planning, implementation, and facilitation issues.
CHAPTER 4. THE PEOPLE WHO HELP

The Paid Provider’s Job

Paid providers may also be called para-professionals, homecare workers, attendants, personal assistants, aides, or nurse’s aides. Some paid providers have been professionally trained or have received certification; others get their training on the job in people’s homes.

While there are books and programs for family providers, very little has been written for the thousands of providers who work in others’ homes. This reflects how little attention our society gives to paid providers, even though our country greatly depends on them.\(^5\)

Attractions and Difficulties of the Job

Many paid providers started out by caring for disabled family members, which then sets a lifelong pattern of caring for others.

I have a 98-year-old grandmother, [who] needed care years ago after my grandfather died. I’ve been caring ever since I was young, taking care of children, elderly, family, friends, volunteer work ...every year somebody else was needing care ... I wasn’t really drawn to this as


a profession necessarily, it’s just something I’ve always done well\[^a\].

Working as a paid caregiver has many attractions, such as flexible hours and the potential for working part-time near the provider’s home. For some jobs, housing and board may be included. Bringing a child along to work may be possible as well. Providing care at the disabled person’s home allows for a more humane and higher quality relationship with the individual needing assistance than is possible in healthcare facilities. Many providers experience great personal satisfaction from enabling severely disabled people to live good lives because they are getting the help they need and deserve.

Yet working as a paid caretaker has its share of difficulties, such as low pay; few job benefits (like vacation or sick pay); inadequate hours to serve client needs; and less than full appreciation or respect for the labor provided. Additionally, the job can involve physical work, such as lifting, which may put providers at risk for injury. Sometimes there are stressful interpersonal dynamics, such as personal boundary and control struggles with clients and clients’ families. Some of these are described below in more detail.

Pay for Care

In most states in the United States, hired providers are paid low wages, with benefits being the lowest in the field of healthcare. Although paid providers and disabled people both depend on the existence of this job, they are forced to submit to a dysfunctional system. Most homecare and personal assistance services (PAS) providers are without health insurance, sick leave, vacation, or transportation benefits. Payment comes from a variety of sources, such as federal (including Medicare and Medicaid), state, county, and private money. However, as yet no standards have been established for wages and benefits for homecare providers or personal assistants. The generally low wages of homecare workers are ironic given the cost benefit of homecare to taxpayers, as compared to institutionalized care. As one worker observed:

We are saving the government a lot of money, you know. How much would they have to pay out if that person was in a convalescent hospital?  

Unionization

In many states, homecare/PAS providers have been considered independent contractors, and are therefore not allowed to organize and may even be exempt from minimum wage requirements as “private contractors.” Other states have begun to organize homecare workers. California, New York, Illinois, Oregon, Washington State, and Arkansas, as well as parts of Canada, have homecare union locals of the Services Employee International Union (SEIU), United Domestic Workers (UDW), and other unions. Negotiating for higher pay and benefits is a primary value, but unions can also offer training in lifting techniques, protection against back injury, prevention of infection, and other skills.

While unionization of homecare workers has definite benefits, it also raises many complex issues. For instance, how do you evaluate working conditions and enforce appropriate medical standards in people’s homes? Unionization has been, and still is, controversial in the disability rights community. Disabled people may fear that union requirements will undermine consumer-directed independent living standards, which hold that consumers hire, train, direct, and fire their own providers as they choose.

Inadequate Hours to Serve Client Needs

When an agency determines how many hours clients are entitled to receive homecare, it

\[^{7}\text{Ibid.}\]


CHAPTER 4. THE PEOPLE WHO HELP

also affects providers. Typically, an agency social worker periodically interviews clients, using a standardized questionnaire form assessing the person’s needs. Then she or he determines the allocation of funds to pay for providers. Often, agency social workers are under pressure from their agencies to adhere to tight budgets. As a result, providers may have to rush clients through their care routine or are forced to work overtime.

Providers may also find themselves in a difficult position if their clients require emergency hospitalization. In most states, by regulation, once clients are hospitalized, the provider is no longer entitled to wages. However, providers recognize that they may be an essential advocate and helper for the client in the hospital, especially if there are no family members involved. Sometimes they work for free because client needs continue or even increase in emergency situations.

On my day off my [elderly] client fell. The paramedics took her to hospital. I went with her. I didn’t get paid for that day, but I knew she needed me. What could I do? I’ve been using attendants for about fifteen years. They help me with getting out of bed, bathed, dressed and ready for meals. Another attendant comes at 11 pm to help me go back to bed. I pay my attendants pretty well, supplementing the money they get from Federal and State programs. I have roommates who are not officially attendants but who help me out in a pinch. There are more pinches than you might think... I needed a substitute attendant. My regular attendant, Tensin, was traveling to Tibet for three months. I don’t enjoy the process of hiring new attendants; many who apply are far from what I am looking for... (Mike Larkin in “Falling Down on the Job”)

What If the Caregiver Gets Sick?

Providers face another dilemma if they get sick. They don’t want to leave the client without care, but rarely do counties have any reliable substitute, backup system, or plan for (or really have any feasible way of facilitating) adequate backup support in the event of provider illness. Since there is no provision of sick leave for most providers, they risk becoming a contagion to clients by working when they have a cold, for example. Ironically, but not surprisingly, a large proportion of providers themselves have chronic health conditions. Certainly, they deserve adequate health coverage, given that they are working in the healthcare system, providing care for others.

Race, Gender, and Job Status

The majority of people receiving formal long-term care services are white, and a
majority of paid providers are people of color. Ethnic and racial differences between client and provider may contribute to tension and confusion between workers, families, and disabled individuals receiving care. Immigrant or undocumented providers who do not have legal status experience even greater difficulties in their work when their clients and families are unaware of their complex situation. Or they may even be taken unfair advantage of because of their situation.

**Interpersonal and Boundary Issues**

The complexities of the job and of the relationship between client and provider can go unrecognized even by family members or agency personnel close to the situation. The intimate nature of the work creates challenging interpersonal dynamics. Work duties are altered and complicated when performed in someone’s home. Intimate types of work may blur the usual boundaries between employee and employer.

Sometimes these boundary confusions are between provider and the client, and sometimes between the provider and the client’s family. Family members can mistakenly treat the provider like a maid, rather than someone hired to specifically assist with the disabled client’s needs. The provider may be happy to help other family members when appropriate, but these gray areas are hazardous.

Providers may find themselves “caught in the middle” between lines of authority, including the disabled or elderly person, the family, the referring agency, and medical providers, all of whom may conflict subtly or significantly in their assessment of needs and service plan. The provider may have to decide on the spot how to handle charged situations with little support or guidance from others. If providers feel they are not respected for their work, they may become deeply unsatisfied. As this worker observed:

They may not acknowledge you when you come into a room...And then not talk to you—like a person... "Go over there and do this," instead of, “could you please bring that?”

**Attachment and Loss**

Providers may be told by their agency to keep a professional distance from clients. This creates a dilemma for providers. Many providers feel a deep professional and personal connection and commitment to their clients and complicated situations may arise. Clients may die. This can be stressful to providers for a variety of reasons: it is the loss of someone they cared about, the loss of

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a job and income, and for live-in providers, the loss of their living situation.

The family of the client will have their own complex reactions to the death of their relative, which may additionally impact the provider. Sometimes family members project their feelings about the client onto the provider, even in relation to the death of the client. The provider is in a position of daily caring and has inevitably grown close to that person, and he or she may feel resentment on behalf of the client when the family isn’t able to visit more often. The death of a client can be doubly difficult if the provider is not treated well by the family. One provider told of the day her client, with whom she had lived with for 10 years, died.

The son came in there and asked me what happened. He didn’t say, "I’m sorry you had to find her like this," or anything like that. After the police left, I’m standing there thinking maybe this man would want to talk to me. He just ignored me and walked past me right out the door.\(^\text{13}\)

We must recognize that these interpersonal issues of negotiating boundaries, receiving respect, and handling loss go much deeper than people struggling to have comfortable and appropriate interactions. They reveal the unique and complex interplay of disability, race, gender, age, and class in the relationship between disabled services consumer and provider. Our culture maintains a denial of the realities of disability and aging, disclaiming meaningful responsibility for disabled and elderly people. Essentially, our society marginalizes both disabled people and their care providers. The solution lies

\(^{13}\)Ibid.
Multicultural Tip #17: Being Aware of Cultural Preferences

Be aware that Latin American and Asian cultures, among many others, may be very polite. Services providers should not assume that a disabled person prefers informality, such as use of his or her first name. Allow the disabled person to establish the formality of the relationship. For more tips, see Chapter 10.

not only in improved wages and benefits, but also in reworking the services system to address society’s marginalization of people with disabilities, elders, and discriminatory practices on the basis of gender, race, and class.
Prevention of sexual abuse is an urgent concern for individuals with disabilities and their allies. Because of persistent myths and confusions, many people still assume that disabled individuals are unable to participate in sexual activity, should not want to, or should be prevented from doing so. Parents, family members, teachers, services providers, and the general public have sometimes been led to believe that people with disabilities should not be included in discussions or education about sex. Yet this automatic exclusion creates many potential difficulties for disabled young people in preventing sexual abuse, sexually transmitted diseases, and unwanted pregnancies. Additionally, these myths greatly limit closeness, relationships, and sexual enjoyment in the lives of disabled people of all ages. Ironically, the stereotype of asexuality makes disabled people more likely to be sexually abused.

**Disabled People Are Sexual People**

People with disabilities have the same sexual thoughts, feelings, and need for love, affection, intimacy, and companionship as anyone else and deserve the right to enjoy sexual relationships. The Sexuality Information and Education Council of the United States (SIECUS) maintains that “sexuality is a fundamental part of being human...[an aspect of ourselves that is] worthy of dignity and respect.” SIECUS advocates for the right of all, including people with disabilities, to have access to accurate information about sexuality and sexual health services. Parents and other family members, friends, teachers, and services providers can help disabled

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I used to be “double disadvantaged.”
First as a woman, second as one with mobility limitations.
Men viewed me as a safe target.
All roads led towards me for free sex.

Then AIDS’ scourge emerged.
Their ignorant thoughts of me:
“She does not move much.
Slim chance of getting AIDS.”

Now I am triple disadvantaged.
Now I have AIDS.
Now I am the endangered species.
And now we are both in danger.

(Peter Bodo Ong’aro in “Danger: Disabled Woman with AIDS”)

adults, adolescents, and children learn about these topics by including them in age-appropriate discussions and education about sexuality.

**Why Sexual Abuse Occurs**

Adolescents and adults with disabilities are much more likely to be sexually abused than their non-disabled peers. Current statistics show that disabled children are four to ten times more likely to be abused than non-disabled children.\(^3\) The history of discriminatory attitudes and practices, which continue to result in the mistreatment, segregation, and social exclusion of disabled people, discussed in depth in Chapter 2, helps explain the increased incidence of sexual abuse of disabled people. Sexuality and disabled individuals are taboo subjects and the resulting silence on these topics may actually make disabled people more attractive to sexual perpetrators. Disabled people may be perceived as easy targets because they may have difficulty recognizing, resisting, or disclosing abuse. Indeed, disabled people may have more difficulty reporting what has happened to them or be less likely to be believed. Sexism in tandem with disability oppression results in the higher frequency of rape of women with disabilities – more than three times the rate for non-disabled women.\(^4\)

In general, most incidents of sexual abuse are perpetrated by persons known to their victims, a circumstance that also applies to disabled victims of sexual abuse. Sexual abuse can include any attempts at forcing, threatening, coercing, or manipulating the disabled individual into unwanted sexual contact, such as rape or other undesired acts. Any sexual activity with an individual who lacks the ability to give clear consent is abusive and illegal.\(^5\) Sexual


abuse may also involve controlling another individual with unwanted language or talk, or forced viewing of sexual activities or pictures.

The complex factors surrounding personal care provision in the lives of disabled people can contribute to the potential for sexual abuse. In the personal assistance relationship, the social and personal boundaries typically associated with work duties are altered when performed in the home by employed or informal providers. The physical proximity and intimate nature of the work can confound typical social and emotional boundaries. Disabled people wanting to maintain a business-like personal

For Youth. [http://www.advocatesforyouth.org/PUBLICATIONS/frtp/challengedyouth.htm](http://www.advocatesforyouth.org/PUBLICATIONS/frtp/challengedyouth.htm)
When I was in ninth grade, I experienced abuse outside the home. I thought I had befriended a group of high school girls, but it turned out that they had other motives. They brought me to their houses when no adults were home and made me take off my pants and touched my private parts. They threatened that I would “get it” at school if I told anyone. I was used by them for an entire year; I was too scared to tell anyone. (James Meadours in “James’s Story”)

assistance relationship sometimes find that the nature of the job leads to a sense of familiarity, which is difficult to counteract. As one woman put it, “They [personal assistants] feel like they’re your best friend because they’ve helped you get your pants on in the morning.” This familiarity has the potential to set the stage for possible abuse, particularly around matters of physical contact.

The line between appropriate touching, as an essential part of the job, and inappropriate touching, which could lead to unwanted sexual contact, is not always clearly definable: bathing and dressing are such intimate activities that it is not surprising that these altered boundaries can create confusion. A disabled woman spoke of this boundary confusion:

“You have somebody doing intimate work for you...so they give you a little massage - is that okay or not okay? They’re always undressing you. That’s how things get gray. Things get strange.”

The need for establishing clear boundaries in personal care is rarely even addressed in independent living training or books about personal assistance. The taboo of discussing issues of sexuality, especially in the context of disability, obscures the need for open attention to these veiled but significant issues.

The Dangers of Overprotection

Sometimes well-intentioned parents, family members, or guardians discourage disabled young people, and even adults, from entering social situations where they might meet peers with whom they could learn about sexual relationships. This protective tendency is understandable because family or care providers hope to prevent emotional rejection and abuse. Yet overprotecting disabled young people actually increases the likelihood of abuse because it precludes developmental learning from peer friendships and romantic relationships. Furthermore, these learning experiences underlie the deeper understanding of self-protection from abuse. Unfortunately, some young people with disabilities are introduced to sex when someone, usually an older or more dominating figure, abuses them or lures them


7 Ibid.
When we did finally have sex, she called me names afterward, trying to shame me for my sexual responsiveness. Hurt and angry, I told her such treatment was unacceptable. “I took your dog to the vet!” she shot back. That woke me up. Katie felt entitled to abuse me because she “helped” me. (Sharon Wachsler in “A Partner Who Values Me”)

into nonconsensual sexual activities. As a result, they may come to believe that they have no other choice but to accept abuse and that they should be glad if anyone shows any kind of interest in them.

Likewise, circumstances concerning impairments and necessary care provision can affect sexual development. For example, sexual self-exploration through masturbation is a natural part of sexual learning. However, some individuals may have physical impairments that limit their ability to learn about their own bodies and sexual sensations. Others may feel under such scrutiny by caregivers that they cannot find a way to self-explore. Additionally, some impairments require caregivers to handle the individual’s body in ways that make physical touch feel clinical or even painful, instead of pleasurable. These disabled individuals may be left with a sense of lack of control or ownership over their own bodies and sexuality, which could potentially increase the likelihood for confusion about sexual boundaries and self-protection.

The Need for Information about Sexuality

When people with disabilities have adequate information about sex, they are much more likely to avoid, interrupt, or disclose sexual abuse or violence. They will also be more likely to get the help they need. Sexuality education should include not only facts about sex and biology, but also information and guidance about how to manage and enjoy relationships, make responsible choices, understand the community’s social and ethical standards, and develop one’s own sense of right and wrong. While not all individuals will choose to be sexually active, everyone needs information about sexuality, in addition to learning about socializing, friendships, healthy boundaries in relationships, and awareness of one’s own body and the bodies of others. Important to sexual development are assertiveness, positive self-image, thoughtful self-care, good decision-making skills, and a personal code of ethics.

Appropriate sexuality education helps individuals with disabilities recognize when someone is trying to take advantage of them. Sex education offers the skills to recognize and say no to unwanted physical contact and the ability to report incidents of sexual abuse. Sexuality education can increase a person’s awareness of the consequences of

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In the 1980s, I participated in a series of sexuality awareness trainings for the Boston area disability community called Sexual Attitude Reassessment. I facilitated a panel of disabled people willing to be role models in sharing stories of reclaiming their sexuality. Some panel members were quite explicit in describing how they engaged in sexual activity with assistance or with adaptive equipment and so forth. After the panel spoke, I asked for questions from the audience. A young man in the front row shyly raised his hand. His question: “How do you make friends?” I was a young adult myself, embarking on my work as an activist, trainer and researcher. I began to grasp then at a deeper level the challenge for many people with disabilities in connecting with others to the extent of achieving romantic and sexual relationships. (Marsha Saxton)

sexual activity, such as the emotional impact of sexual encounters, as well as the risk of pregnancy or sexually transmitted diseases. Additionally, both males and females with disabilities can be targeted with sexual harassment on the job or in educational settings and thus must be included in training about sexual harassment.

When family, teachers, and peers include young disabled persons in age-appropriate discussions about sexuality and sexual abuse prevention, they learn to feel respected and expect others to do the same. Because individuals have different value systems, their understandings of what is age-appropriate will vary. The references included at the end of this chapter are meant to help parents and educators find ways to best address these issues. Disability-related learning tools and accommodations in sexuality education can enable disabled people to acquire information despite impairments that may affect learning. For example, blind children have limitations in their visual channels for information about human anatomy. Anatomically correct dolls and appropriate verbal explanation can help these children acquire necessary information.

For young people with impairments that preclude typical sexual developmental learning, like the inability to self-explore through masturbation, there are no ready answers. Similarly, for children with impairments that require intimate care, such as urinary catheterization, parents may feel at a loss as to how to support the child’s positive sexual development. Rather than evading the issues, it helps these young people if their parents verbally acknowledge this dilemma, explaining that this limitation can be transcended later, in adulthood, when the disabled individual becomes independent from family caregivers and is thus in a better

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My sixteen year-old daughter, Lily, has autism. We’ve talked with her quite a bit about bullying from other kids at her school, encouraging her frequently to tell us if something bad happened at school. We’ve also talked to her about how people might try to touch her in ways that are not okay, and that she should never go along with this. I haven’t known how much to bring up the issue of sex with her. She doesn’t express interest in the topic, as with most other topics.

A couple of years ago, she came home from school obviously upset and shaking. I asked her to tell me what happened. At first she said, “Nothing.” But I knew something hurtful had happened because she looked away even more than usual. Later in the evening, she said, “A boy at school told me to take off my jeans.” My heart sank and I sat down next to her, trying to stay calm. “What happened?” I asked. She told me a boy she knew had gotten her into an empty room. “He said he wanted to see my belly button,” she said.

I asked, “What did you do?”

She said she knew he was just bothering her. “I told him leave me alone, like you said. Then I ran to the bus stop and waited for Sandy (her bus driver). There were some other kids at the stop.”

I secretly breathed a huge sigh of relief. I said, “Lily, you did exactly the right thing. Do you know this boy?” She said, “Well, he looks nice, but he says mean things.” It took a few days for her to come home with his name. We called the school. We eventually found out this boy had tried this before with non-disabled girls. We don’t know if he was ever successful with his intentions, but we did pursue the matter and got him expelled from the school.

A year later, I read a newspaper story about a young woman the article said was retarded, who had been raped and beaten by a man who enticed her with candy. I thought, “That could have happened to Lily!” Then I thought, “But it didn’t.” Thank god we’d talked about it before that happened, and she knew what to do.

(Janelle Westerly in “A Tragedy That Didn’t Happen”)

The issues of sexual surrogacy, as well as provision of personal assistance services for sexual activities, are both controversial in the disability community. Use of sexual surrogates by disabled people has been recommended by many, including Masters and Johnson in the 1970s. However, complex issues for sex workers, particularly women, remain a problematic concern.

Self-Reflection Is a Key for Allies

How can people with disabilities find the information they need about sex and protection from sexual abuse? How can allies, including parents of disabled children as...
CHAPTER 5. SEXUAL ABUSE PREVENTION

Resources You Can Use

- YAI/National Institute for People with Disabilities Network offers sexuality workshops and social activities for developmentally disabled people. [http://www.yai.org](http://www.yai.org)

- SafePlace offers a 24-hour hotline and crisis services for women, men, and children who experience sexual and domestic violence. It also offers specialized counseling, personal safety, and sexuality education services for adolescents and adults with disabilities. [http://www.austin-safeplace.org](http://www.austin-safeplace.org)

- The Center for Research on Women with Disabilities at the Baylor College of Medicine in Houston, Texas, also offers good information and statistics related to violence against and abuse of women with disabilities. [http://www bcm.edu/crowd/?PMID=1325](http://www.bcm.edu/crowd/?PMID=1325)

- Sexuality and Disability provides original scholarly articles addressing the psychological and medical aspects of sexuality in relation to rehabilitation and disability. [http://www.springerlink.com/content/?k=Sexuality+and+Disability](http://www.springerlink.com/content/?k=Sexuality+and+Disability)

- DeafHope offers a 24-hour hotline, and empowerment and education services, to Deaf women and children who are survivors of domestic and sexual violence. [http://www.deaf-hope.org](http://www.deaf-hope.org)

well as friends and teachers of disabled adults, initiate these important educational discussions? What can allies do to increase their own comfort with these topics to help make conversations about them useful? Most people, including parents, educators, and service professionals, feel somewhat or very awkward talking about sex, especially with someone else who also feels awkward. Whether you are a disabled adult seeking information for yourself, or a family member, teacher, or services provider, start the process by reading some of the resources listed at the end of this chapter and exploring your own feelings and values about sex and disability. The more opportunities allies of disabled adults and children have to reflect on their own values and feelings about sexuality, the more relaxed and confidence-inspiring they will be in conversation with the people they hope to educate. Disabled adults can request a session with a peer counselor at an Independent Living Center or with a social worker. Try addressing
the following questions alone or in discussion with a peer, parent, ally, or educator:

- How did I first learn about sex?
- What information am I lacking about sex in general, or sexuality and disability?
- What would be a useful next step in learning?
- What have I been told about sex and disability?
- What fears or concerns do I have, either for myself or about the disabled people I know?
- What are potential areas of confusion in relation to sex and sexual abuse?
- (For parents and teachers) What do I think is age-appropriate information for my child or student, and why?
- What do I need to know to empower myself or the individuals I’m concerned about to self-protect against sexual abuse?
- What are my personal barriers to openly raising and discussing issues of sexuality?

Starting the Conversation

Ideally, parents, teachers, and allies will become confident and relaxed enough to raise these topics in conversation, offering opportunities for disabled people to ask their own questions. It is fine to admit, “I don’t know,” if a disabled young person or adult asks a difficult question. You can seek the answers together. Sometimes parents who feel uncomfortable initiating discussions about sexuality offer appropriate books to their children, either by giving the material directly to them or by leaving it in plain view. This approach to sexuality education, while indirect, is much better than doing nothing, because it sends the message that sexuality is a subject worth addressing. Also, it may open up the topic for later conversation. If you feel awkward, be willing to say so, but also add, “Let’s talk anyway because the subject is important.” Make sure to invite individuals to ask any questions they might have about sexuality and brainstorm on what they need to learn more about. Parents should not worry that they have to address the topic perfectly or correctly. They only need to give it their best efforts. Laughing and giggling are completely appropriate to diffuse any embarrassment. It may even help the learning process. Also, talking about sexuality does not have to be serious. While self-protection from sexual abuse is certainly a serious issue, the topic is best raised with levity and in a relaxed manner.

Many excellent resource materials on a range of sexuality-related issues are available to people with disabilities, parents, teachers, and services providers. A list of some of these is included below. CAPE materials related to sexuality include a short video, Strong and Informed, that offers young women with disabilities an introduction to dating safety guidelines and basic information about
Multicultural Tip #20: Communicating with Patience and Respect

It may take a little extra time to establish a relationship of trust because of cultural and language differences. Patience, respect, and genuine friendliness communicate well in any language. For more tips, see Chapter 10.

sexual abuse prevention. CAPE’s Chapter 2, Personal Assistance, Interdependence and “Vulnerability,” offers additional resources, as does chapter 9 which addresses specific populations, including youth with physical and/or developmental disabilities; and chapter 8 which focuses on peer counseling abuse survivors. The CAPE Movie Guide, on page 167 lists films that address relationships, sexuality, and abuse issues and can be used as a basis for discussion about these issues.
Books and Videos about Sexuality and Disability

  This video production is by a group of young women with disabilities. They use humor, music, interviews, and frank discussion to talk about their relationship with their own sexuality.

  In clear, explicit language, this book teaches appropriate sexual behavior to people with developmental disabilities. Based on California law, it is easily applicable to other states.

  An assessment instrument to use with adults with developmental or other cognitive disabilities when they have become victims of sexual assault that does not clearly fall within the physical coercion category.

  This is an anthology of essays by lesbian authors with disabilities.

  This guide is meant for parents, educators, and professionals and is intended to help educate children with Down Syndrome about their sexuality.

  This curriculum for educators provides information about how to design sexuality education classes that are accessible for students with developmental disabilities.

  This handbook is an excellent example of literature making the link between sexuality and resistance to sexual violence. Two of the book’s chapters, “Sexuality” and “Abuse, violence, and self-defense,” touch upon this critical link.
CHAPTER 5. SEXUAL ABUSE PREVENTION

  This video is meant for young people with developmental disabilities, as well as for their parents and care providers. It provides detailed sex education as well as discussing friendship, dating, and romance.

  This curriculum is designed to help educators, social workers, psychologists, and others teach young people with developmental disabilities how to prevent sexual abuse.

  This book is an examination of the relationship between sexuality and disability from both an academic perspective and through many firsthand accounts.

  This article analyzes teen pregnancy, sexuality education, and family planning for young people with disabilities and gives suggestions for public policy.

  This book includes 15 interviews with couples with disabilities discussing their relationships and their experiences raising children.

  This book is for parents of children with intellectual disabilities and gives information about how to talk to and educate children about sexuality and sexual development.
CHAPTER 6

Handling Anger with Attendants and Caregivers

Upset Feelings

Disabled people who live independently with the help of personal assistance may experience upset feelings in their relationships with attendants or caregivers. Upsets can happen in any relationship. In the personal assistance relationship, ongoing tension may increase the risk for poor quality care or even abuse or neglect. An angry conflict can become an excuse for an attendant or caregiver to release his or her frustration by hitting, slapping, punishing, or abandoning a disabled individual. Without thinking through the consequences, a disabled individual can inadvertently make a tense situation worse by blaming the attendant or by being demanding.

Yet this cycle can be stopped. Awareness and good communication skills can help to ease anger and improve the quality of assistance. The suggestions below are not easy to remember when we are angry. However, with practice they can become more automatic when a tense situation arises. It is well worth the time it takes to learn and practice these steps. It will save hours of upset, avoid fights, and improve the quality of your personal assistance.

About Anger

Anger is a natural human emotion, an ordinary part of life. It is the emotion that comes up when we feel that our power or control is threatened or taken away, or our needs are ignored. Feelings of anger, irritation, resentment, or annoyance come up in every relationship, especially in close relationships. In our families and in our society at large, we don’t get much support for dealing with our feelings of anger or help with constructive ways of dealing with conflict.

1In addition to the resources in this chapter, see the Handling Anger Powerpoint and the short video A Good Job on the CAPE Multimedia CD.
Boys and men are given models of toughness, denial, and violence on TV and movies as appropriate ways to handle anger. Girls and women are expected to cry sometimes, but not to get angry. Women's anger is often disrespected or made fun of. Both men and women need new approaches for dealing with anger.

Often we blame someone else when we feel upset, not only making it the other person's fault that we feel bad, but also putting us at the mercy of the other because we allow him or her to be in charge of how we feel. We need another point of view about how to handle angry feelings that enables us to address our needs.

Reasons to Be Angry

There are many reasons for anger to arise in a relationship with an attendant or provider. Let's consider some of them.

It is natural to experience feelings of anger about having a disability. It is understandable to feel frustration at not being able to do what others are able to do or what you used to be able to do by yourself. The additional frustration that comes from discriminatory attitudes or exclusion from ordinary activities adds “insult to injury.” Anger is a natural, predictable response to this mistreatment.

Caregivers and assistants may understand a disabled person's needs. Then again, they may not. They may seem unresponsive or behave incompetently. They may be controlling or neglectful. A disabled individual may feel upset and angry at the caregiver, which may trigger angry feelings in the caregiver, who then directs his or her anger back at the disabled person. This situation can quickly spin out of control.

Because the relationship between the disabled individual and the person in the helping role is so complicated, additional feelings of confusion can arise when either one feels angry. The person feeling anger may wonder:

- Am I a bad person for feeling upset at a disabled person?
- Am I selfish for feeling angry or resentful towards someone trying to help me?
- Shouldn’t I just feel grateful for getting help (especially if the help is unpaid)?
- Do I have to just put up with this tension?

Attendants and family providers can sometimes feel overworked, underpaid, unappreciated, or even manipulated. Family caregivers may also feel angry at other family members because they are not offering to help. And paid caregivers may feel angry at a disabled individual's family members for the same reasons.

Sometimes attendants are asked to do things they don’t feel comfortable doing for personal reasons. These reasons may not be apparent to the disabled person. For example, an attendant was asked to sleep just for one night on a mat on the floor in the room of someone who was ill. At first, the attendant refused, but without explaining...
why. Then, he finally admitted that he had been homeless a while before, and that sleeping on the floor felt degrading to him.²

The key to solving problems in the relationship between disabled individuals and their personal assistants and caregivers is good communication. If you are having trouble dealing with angry feelings, the suggestions and exercises below will help. First, there are general suggestions for handling anger. Then, we offer specific steps to improve communication with your attendant or caregiver if a conflict arises.

The following suggestions are addressed directly to individuals with disabilities. Suggestions for facilitators are included later in this chapter on page 92. See the accompanying PowerPoint slides on the Multimedia CD for use with training events or support groups. Individuals can also print out the PowerPoint slides for concise, helpful reminders.

General Suggestions for Handling Anger

The goal of good communication with your attendant or caregiver is not to simply express or even upset feelings. The goal is to communicate well so your needs get met. If you angrily or loudly tell your attendants or caregivers that they did something wrong, they will be much less likely to remember your request. Angry words and tones scare people. They will become defensive and worried about their own needs and feelings, rather than learning or paying attention to your needs. Worse, they may retaliate or respond in ways that threaten or frighten you. The desire to direct anger at someone else is a red flag, a warning signal that you are not going to get your needs met well, if at all. If you find yourself thinking, “Let me tell you,” stop! Rethink your approach with these suggestions.³

a. Accept Your Feelings

Remind yourself that your anger is understandable, no matter what triggered it, and then try to accept your feelings. It doesn’t help to tell yourself your feelings are wrong. Your feelings are real and you are entitled to


feel what you feel. However, the action you take based on these feelings is the important part in dealing effectively with your anger. You may want to ask yourself the following questions:

- How do I usually deal with anger?
- How well does it work? What can I do differently?

b. Talk about Your Anger

Talk to a neutral friend you trust about what made you upset. It’s best to talk to a confidant before the anger builds up. Admitting anger is difficult for most of us. However, if we admit our anger, we are more likely to think of options to handle the situation better. Ask yourself if you have someone you can talk to about your relationship with your attendant(s) or caregiver(s). Every disabled person needs at least one individual, preferably two or more, to confide in. Once you have identified the individual(s), contact him or her whenever you recognize that you are dwelling on an upset. Ask him or her to listen to you without giving advice or expressing opinions. About 10 or 15 minutes of being listened to can make a big difference. Possible ways to phrase your request might be:

- Could you do me a favor and please listen to me for a few minutes? Just listen and not give me any advice? Thanks. We can trade listening if you want.
- I just need to talk about something for a few minutes. All you have to do is listen. You don’t have to say anything. I’ll return the favor sometime when you need this.

You might feel uncomfortable asking at first. When you’re alone, practice asking people you’d like to confide in. Most people are glad to be asked and would love the opportunity to help, and get listened to in return. If you can’t think of anyone to talk to, think through these steps on paper, or practice in front of a mirror, a pet, or a teddy bear. Spiritual people can ask God or a higher power to listen.

c. Role-Play the Upset

Perhaps your friend or a peer counselor can offer to help you role-play by being a stand-in for the attendant or caregiver. Role-playing the upset allows you to safely vent your anger. It may even bring laughter, which is helpful in giving you a different perspective and new ideas for handling these difficult situations. (Let yourself laugh about it whenever possible!)

d. Connect Present and Past Upsets

Ask yourself (or think out loud with your trusted friend) if the current situation reminds you of other upsets in your life. Maybe some anger from long ago is being triggered by the current upset. Talking about it or writing it down can help you stop confusing the present difficulties with those from the past.
CHAPTER 6. HANDLING ANGER

e. Focus on Your Body
Notice how anger feels in your body. Try to focus on where in your body you hold anger, and how it feels physically. Does something feel tight? Is your breathing restricted? Try to relax your body and become aware of your breathing. Say to yourself, “Let go,” and continue to breathe evenly. This can help diffuse the anger. Many people use relaxation exercises or meditation to help them deal with anger.

f. Identify and Name Your Feelings
Identify and name your emotions. For example, are you dwelling on something like, “It’s all his fault, what a bad person!”? Are you repeating scenes and upsetting words in your mind? Instead, try to separate your emotions from “who is to blame.” Look underneath the anger at your other feelings: Are you feeling scared? Anxious? Disappointed? Sad? Are you upset with yourself, too? Identify and try to put a name to each of these emotions.

g. Practice Role Reversal
Your own and the other person’s point of view can be very different. Reversing roles can be helpful to achieve a more generous perspective. Try to imagine what your attendant or family member is feeling. Imagine yourself in her position. Take into account her life situation. You may not know much about their view, but even guessing can be useful in reaching for empathy. This will give you much more power in the relationship because you will focus on the bigger picture, not just your own complaints.

h. Offer Positive Feedback
When someone in a helping role or any other kind of relationship feels appreciated, he or she will have more patience for conflict if it arises. Offering positive feedback on a regular basis is like putting kindness into a savings account to be used in need. If confusion or an upset occurs, the person will be more likely to be understanding if they feel recognized as valuable. Give specific comments, for example, “I appreciate the way you did such and such,” or “I notice you are thoughtful about knocking before you enter.”

i. Lighten Up
Negative thinking blocks new ideas. Positive thinking helps you come up with new ideas. Sometimes it helps to think about difficult things with creativity or humor. Here are some approaches: Imagine that the person or people you are upset with are animals, circus clowns, or aliens from another world. It might make you laugh out loud, reminding you not to take yourself too seriously. Or imagine you are Wonder Woman or Spider Man or your favorite superhero and you are facing the same upsetting situation. Writing creatively about upsets can also be helpful in dealing with these challenges. Keep the story confidential and use fictitious names to protect the identities of the people you are
writing about. Write a short story or keep a “dream journal.”

Imagination can help you take the upset less seriously, so you can think more creatively about what you can do to either change the situation or accept it for the time being. Again, find opportunities to laugh about it. Laughter is truly good medicine for anger and for helping clarify thinking.

j. Don’t Put Up with Abuse!

Positive thinking doesn’t mean putting up with mistreatment! If you are being mistreated or abused, get support to change your situation. Get help! Contact a social worker, minister or rabbi, nurse or other resource person if you do not feel safe talking about your difficulties with friends or family. If you are in immediate danger, call 911.

Handling a Conflict with Your Attendant or Caregiver

The steps below will help you handle common difficulties in the attendant/caregiver relationship. Keep reminding yourself that your main goal is to get your needs met. The desire to vent your anger at the person who made you feel upset is understandable. But this won’t help you get what you need. It may have the opposite effect. Getting in a fight with the other person almost never results in your needs being met.

Go through the steps in the same order in which they are listed below, and without skipping any steps. It is well worth the time it takes to help you to think and act with clarity. With practice, preferably with a trusted listener, you will get better at this. Steps One and Two will help you get clear in your mind about what you want to do. Steps Three through Seven will help you communicate effectively with your attendant or caregiver.

Step One: Let Go of Blame and Take Responsibility

Decide to take responsibility to improve the situation, despite wanting to blame the other person. You need to view yourself as the boss of your own care. It is your job to initiate change. This might feel scary but it is worth it. We often have more control in relationships than we feel we do.

Ask yourself:

- Can I take responsibility to make it work better?
CHAPTER 6. HANDLING ANGER

- Am I scared or embarrassed?
- Does taking responsibility seem worth the challenge?

**Step Two: Identify Your Triggers**

Describe in your own mind, as objectively as you can, the behavior or factors that are triggering your anger. Ideally, describe this to a neutral person first, who can listen, relaxedly. Write the issues down if you wish. Your description should be framed like a journalist’s, that is, give “just the facts.” It is important for you to think clearly about what you want to change.

Ask yourself:

- Is my caregiver doing something that annoys me and I don’t understand why he or she does it that way?
- What exactly is bothering me?
- Can I describe it clearly to myself?
- Why do I think he or she might be doing that? Can I ask that person?

**Step Three: Get Clear on Your Needs**

Get clear on the needs you want met in your relationship with your attendant.

Ask yourself about these common needs related to attendant care:

- Do I consider my attendant to be reliable and on time?
- Do I feel safe with my personal assistant?
- Does my caregiver pay good attention to my needs?
- Is he or she a good listener?
- Does my attendant have a positive attitude?
- Does he or she show concern for my comfort?
- Do I feel my caregiver is honest and trustworthy?
- Does my attendant respect my privacy?
- Is he or she good at following my instructions?
- Does my caregiver show respect for my independence?
- Does he or she respect my choices?

It can be helpful to make a list of things you want to change. Many people have trouble describing their own needs. You might ask a friend to help you brainstorm. Or you can start a list and add to it over time as you think of things.

**Step Four: Make Positive Requests**

Be ready to frame your needs as positive requests. *(Do rather than Don’t.)* Upset people typically focus on what they don’t want. They might say: “Don’t come late!” or, “Don’t boss me around!”

Instead, make requests specific about what you *do* want. You might say:
CHAPTER 6. HANDLING ANGER

- I want you to arrive for work at 8 a.m. Please call if you will be more than 10 minutes late.

- I need you to respect my ways of doing things. If you have a suggestion, please wait until after my morning routine when I am up in my wheelchair.

Ask yourself:

- Do I state my requests as positive actions? (Do rather than Don't)

- What are my requests? Can I write or state them out loud as positive requests?

Step Five: Be Ready to Request Agreement for Behavior Change

Is your attendant or caregiver repeatedly doing something that you don't like? When you ask someone to change their current behavior, be specific and request agreement that the person will do what you ask for.

If you say, “I wish you would leave me alone,” you are being vague and unclear about exactly what you want. If you say, “You were bothering me yesterday,” you are blaming without giving information about what was wrong.

Instead, ask yourself what specific action your attendant or caregiver can take to improve your care. Phrase it as a request for agreement, so your attendant is definitely agreeing to change his or her behavior.

Instead of saying, “Stop hanging around when I am on the phone,” say, “Would you agree to give me privacy when I am on the phone? I will call you when I need you. Thanks.”

Instead of saying, “I hate it when you smoke around me,” say, “Will you agree to smoke outside, at least 20 feet from the door?”

By asking, the attendant or caregiver’s response will be an agreement to your request. He or she will be more likely to remember an agreement than a complaint. If your caretaker forgets, you can say, “Remember that you agreed to smoke outside, at least 20 feet from the door? Thanks.”

Ask yourself:

- Am I clear and specific with my requests?

- Do I request agreement?

Practice asking for specific agreement about a specific request. Say, “Will you agree to __________________?”

Step Six: Decide If You Are Ready to Talk

When you have tried the steps above, decide if you are ready to talk to your attendant in a way that will likely improve the communication and increase the quality of your care.

Ask yourself:

- Do I understand specifically what I am upset about?

- Have I considered my attendant’s point of view?
• Am I able to describe my needs? And can I state specifically what I want as a request and ask for agreement?

• Am I ready to talk? And am I ready to listen to the other person’s point of view?

• Here is a crucial question: Am I ready to keep calm if the other person gets defensive? Remember, your caretaker won’t have had time to prepare and think it through like you have.

Step Seven: Have the Meeting

Set up a time to talk in a relaxed setting. Go ahead and talk. Then, listen to your attendant for a few minutes. Be patient and listen. Your attendant or caregiver won’t have had time to plan his or her reaction as you are planning now. You may have to listen to the other person’s confusion (and possibly his or her blame!) It is usually worthwhile to be willing to listen for a few minutes for the sake of a better relationship.

But don’t put up with verbal abuse. If the meeting isn’t going well, don’t let it turn into a fight. Say, “I’m sorry, this isn’t going well. Let’s talk another time.” Sometimes, waiting a day or two, or even an hour or two, will ease the upset and allow a useful conversation.

Make sure your caregiver understands you, and listen to his or her point of view. Then thank your attendant or caregiver for speaking honestly with you.

After the meeting, ask yourself:

• How did it go?

• Do I feel my needs will be better met in the future?

• Did I remember to appreciate my attendant or caregiver?

• Did I appreciate myself for being clear and direct?

Suggestions for Facilitators

Teaching the concepts and skills in this chapter can be one of the most important resources to help disabled people avoid abuse
and improve the quality of their personal assistance. Anger is one of the primary triggers for violent abuse and mistreatment.

For most audiences, this material will seem logical, yet challenging to recall in tense situations where it is most needed. Some facilitators modify and print out the PowerPoint slides to distribute as a poster for the wall to help remind people of the skills they might need in a tense situation. One participant taped this to the inside of her closet door. She reviewed the ideas and steps when things got tense with her caregivers.

Below are suggestions for building the steps into training workshops or an ongoing support group:

1. Read and become familiar with the material in this chapter and the accompanying PowerPoint slides. Feel free to modify the PowerPoint slides for your particular participants’ learning needs.

2. Assess and reflect on your population’s learning needs. How much information can your audience take in, in a single session or series of training sessions? How long will each session take, for example, 30 minutes, or an hour, or longer? Some participants can address several points in a single session. Others will need one session on each point, with plenty of review. For most audiences of disabled people living independently, estimate between 3 and 10 sessions for participants to grasp, practice, and implement this set of ideas and behaviors.

3. Begin the discussion with the About Anger section on page 84. You can read this aloud or summarize the points. Ask participants to share stories of ways they’ve handled their own emotions in the past. Then move on to the next sections. With the General Suggestions for Handling Anger section on page 86 and the Handling a Conflict with Your Attendant or Caregiver section on page 89 introduce each point one at a time, with plenty of time for discussion and personal sharing.

4. Use of role-play is the most helpful source of practice for individuals to incorporate these steps into everyday life. Role-playing allows practical rehearsing of new behaviors. Role-play can also bring laughter, which makes learning more fun. Encourage participants to come up with their own scenarios. Some groups have created skits contrasting negative and positive models of interaction. Exaggerated, or “bad,” examples of anger management help dramatize crucial points and are laughable, funny, and therefore very effective.

5. Appreciate participants for their creativity and commitment to getting their needs met, transforming their lives, and making the world a more peaceful and communicative place.
CHAPTER 7

Confronting Violence

If we are to effectively help ourselves and others resist or recover from violence, we must be willing to confront the reality of violence and our emotions about it. The idea of aggression for most people triggers feelings of fear and a desire to turn away. But many people also notice in themselves a kind of fascination with violence. We may have fleeting violent images and experience a preoccupation with these images, despite the desire to stop them. This fascination is understandable. Of course, violence is inherently frightening. But in our society, violence, because it is forbidden and considered a sin, offers a kind of allure that is greatly exploited by the media. We find ourselves regularly compelled to witness aggression, damage of property, and explosions on television and on the news, and in movies, cartoons, and video games. The majority of people who regularly watch TV see some violence every day. While many Hollywood and TV films educate us about social issues, they also use shocking images of violence to sell entertainment. These images play on our own personal histories of exposure to violence, whatever that may be.

Throughout the history of humanity, the use of force has been part of the human experience, and in the animal kingdom, violence remains necessary for survival. In the United States, we may forget that in many countries around the world, particularly war-torn countries, adults and children witness acts of aggression and killing on a regular basis. While some believe aggression is inherent in human behavior, others believe it is no longer a necessary part of our human experience and can be ended.

In so-called civilized societies, we may hold the belief that we are immune from violence. At the same time, we remain afraid of violence in our cities, and we try to protect our children from exposure to it, even though we really don’t know
CHAPTER 7. CONFRONTING VIOLENCE

how to help reduce or stop violence. Yet hundreds of violence prevention books and training programs are available. Some social programs, such as youth programs, have been successful in reducing violence in cities. Documentaries, such as Michael Moore’s Bowling for Columbine, expose the confusing paradox of guns. We want the freedom to bear arms for protection, yet the prevalence of guns, often easily available even to emotionally disturbed youth and adults, increases the violence. There are internationally known leaders who address violence in their leadership, among them the Dalai Lama. We revere historic leaders, such as Mahatma Gandhi and Martin Luther King Jr. who both strongly advocated nonviolence. Ironically, both were assassinated because of their radical work for peace through pacifism. Many people bravely continue to work on violence and war prevention, nationally and internationally.

Most residents of the United States say they deplore the violence of war, but they have little knowledge of or can hardly picture the daily violence in the lives of soldiers who participate(d) in war. Soldiers returning from war, including those who have become disabled by war, have very little opportunity to talk about what happened to them or what they witnessed. They learn to become silent. They internalize the taboo of talking about the horrors of war, even though they witnessed it or participated in it. Yet some important small-scale programs, the workshops Maxine Hong Kingston started to facilitate, for example, are trying new approaches in working with veterans’ war experiences.

Violence against People with Disabilities

Violent mistreatment is as devastating to people with disabilities as it is to anyone else. Violence kills and injures. Violence, to investigate disabled veteran organizations, meet peers, and learn more about benefits and resources.

1Veterans disabled from war injuries greatly need support to talk about what happened to them. Don’t assume that the military offers adequate counseling or promotes appropriate disability veteran benefits. Ask disabled veterans if they have had a chance to talk about how they became disabled, and if they would like to talk about it. Encourage vets


There is nothing more isolating than the pain of violation. It forces victims to question themselves and their world because it destroys two essential beliefs: (1) their sense of trust and (2) their sense of control over their lives. After the crime is over, victims begin to struggle with their reactions...they are often overcome with fear, anger, guilt and shame. They may feel contaminated and unworthy of help. Their relationships with family and friends can be seriously disrupted, and if they become involved with the police and the courts, they may come to believe that no one understands or cares about what has happened to them.

including the violence of war, can disable people or further injure people already disabled. But threats of violence, whether or not the assault actually occurs, also keep disabled people living in fear and isolation. They destroy confidence and prevent disabled individuals from working, learning, and emotionally growing.

Physical abuse can be directed against people with disabilities of all ages, with all kinds of physical, sensory, cognitive or emotional impairment or chronic health conditions. Physical abuse is defined as any physical mistreatment, such as rough handling, pushing, hitting, slapping or other force, with or without weapons, or throwing things, or the threat of these. It can include forced or pressured sexual activity, such as rape, or the threat of forced sex. Physical mistreatment can occur within the family, directed at disabled individuals who require personal assistance. It can be perpetrated by anyone, including family members, spouses, informal or paid assistants or services providers. An example is offered by a man with muscular dystrophy:

He [the attendant] and I got into a verbal altercation… so he thought he would put me in my place by throwing me up on the back of the chair, then letting me hang there. I’m on a ventilator. I had already been off for an hour and a half, and I was getting winded. He just kept screaming at me, [forced me] to apologize to him… I was hardly able to breathe, and I’m supposed to apologize to this guy. He really scared the hell out of me.

Violence against disabled individuals may be hidden or not easily apparent. Bruises or scars, additional weakness, or other results of violence may be dismissed as an outcome of the person’s impairment. Many studies document physical assault of elders and disabled people in institutions, which can include physical restraints, such as tying people to beds or chairs, forced medication, forced sterilization, shock treatment, forced drugging, and inadequate informed consent for medical treatment.

What is unique about violence against disabled people is that it may still be


considered acceptable in certain circumstances. “Mercy killing,” or euthanasia, while technically illegal in most countries, is still considered by some to be justified under certain circumstances. Dr. Jack Kevorkian, nick-named “Dr. Death” and notorious for assisting in the death of disabled people, still has many supporters. A judge or jury may be lenient when a defendant has killed a family member with a disability, particularly when that person was a severely disabled infant, an older person, or someone with a communication or cognitive disability. Yet such judicial leniency conveys the message that killing disabled people may be for the best. With respect to domestic violence, police and the legal system have little experience and few guidelines in addressing violence between disabled persons and caregivers in the home. Police may be called to a domestic violence situation involving a disabled person, but assume these instances should be handled within the realm of social work or nursing.

Sometimes the legal and moral status of “personhood” for people with disabilities actually comes into question. In some instances, disabled individuals may not be regarded by abusers (as well as intervening authorities) as fully human or “whole persons” and may therefore not receive adequate recognition of their moral, legal, or human rights. Abusive family members may be regarded as saintly because they care for the disabled family member. The abusive behavior may thus be ignored or overlooked by authorities or even be considered a logical outcome of the burden of taking care of a disabled family member. Violent crime, hate crime, and theft perpetrated against people with disabilities should be investigated and prosecuted to the same extent as crime against anybody. Hate crime legislation in all states should include hate crimes directed against disabled people. The criminal justice system must end discriminatory notions that mistreatment of disabled persons is justifiable in certain contexts, including abuse or criminal acts perpetrated by family members.

Self-Defense for Disabled People

Self-defense courses usually ignore or fail to include people with disabilities. This exclusion is based on the following assumptions: (a) violent acts are most often caused by strangers on the street, and (b) physical agility is essential for self-protection. However, both assumptions are inaccurate. While a person with a disability may seem to be a somewhat easier target for crime, violence from strangers is in fact rare. More commonly, violence directed at both disabled and non-disabled people occurs within family relationships or neighborhood acquaintances. Secondly, for the rare encounter with a criminal on the street, the use of one’s own voice, an empowered attitude, and common-sense street smarts are often the best first-line defenses. The concept and practice of self-defense and martial arts for people with disabilities is being explored by a wide range of programs and resources.

many quite creative and innovative. These programs teach the use of one’s voice and a positive (“Don’t mess with me!”) attitude as deterrence. Some programs teach techniques that employ self-protective use of assistive devices, including one’s wheelchair. CAPE does not endorse any of these specific programs because their general safety and practicality have yet to be clearly researched. However, we encourage those interested in abuse and violence prevention to explore and investigate self-defense programs, and conduct research on their efficacy. Several such programs are listed at the end of this chapter.

People Who Are Violent Abusers

Understandably, we tend to regard violent abusers as “bad people.” What confuses us is that abusers of disabled people are often also family members or other people we may care about, and who, despite their abusive behavior, may care about us. Violent abusers inflict pain and punishment in order to control others. People who abuse others are likely themselves people in pain. They were probably physically or emotionally abused earlier in their lives. They may have been hit, locked up, humiliated, verbally or sexually assaulted, or abused in other ways. What happened to them may be too painful for them to remember. Later in life, these abused individuals may turn into abusers themselves by repeating the abuse they had to endure and directing it at someone else, usually someone smaller or weaker. They want to feel on the powerful side of their terrible (conscious or unconscious) memories. Abusers need help to stop hurting others and there are ways to get this help.

While we may understand why formerly abused individuals become abusers themselves, we cannot condone violence under any circumstances. We also cannot wait for abusers to finally stop hurting others or let people off the hook for their violent actions. We must, at all times, hold abusers accountable for the violence they commit. If abusive spouses, family members, or caregivers cannot stop their own violence, the disabled individual or a friend, guardian, or advocate must take steps to change the situation in order to stop the violence immediately.

Counseling is one way to begin to break the cycle of violent abuse. However, counseling or any kind of therapeutic program usually takes a long time to work. And abusers have to stick with it. They may need years to understand how their personal history contributed to their violent behavior, not to mention the unflagging effort needed to learn and then consistently practice how to stop themselves from continuing their violent ways. While abusers who seek help are to be applauded, disabled individuals should not be patient while abusers struggle through the long-term process of dealing with their violent behavior. The result could be injury or death. The pattern of violence directed at disabled individuals must be broken by changing the interaction. Abusive providers may be removed from their caregiving duties, or must no longer be permitted to be alone with the disabled individual. Many disabled people are in living situations where they are dependent on
My friend noticed I held my head as if I were flinching, waiting to be hit. In my M.S. support group I finally worked up the courage to talk about being smacked around as a teenager by my father. I cried and cried and Sarah, the leader, held my hand and everyone just listened. I was embarrassed but they said, “Keep going.” I told the stories many times. I began to laugh about my weird family, and notice that they were all wounded in some way. A couple of years later, my friend said, “You’re holding your head up straighter.” That’s not the only difference, I feel stronger. I’m holding my head high in my life. (L.C. [deceased], personal communiqué, 2006)

abusive caregivers. They may feel they have no other options, financially, logistically, or emotionally, to the situation they are in. The learning tools and resources in CAPE can help disabled people realize that they can find a way to get help. They can disclose the abuse and turn to others they can trust for help. They can find another way to live, where violence and abuse are not something to endure in order to survive.

If We Could Talk to a Violent Abuser

Wouldn’t it be good if we could sit abusers down and talk to them about their violence? Wouldn’t it be great if we could convince them to stop? Very few violent abusers are willing to admit their actions. Few abusers would pick up a pamphlet on how to stop their own violence. They are in denial or they are ashamed to admit their behavior even to themselves. Yet if we could sit them down and talk to them, we would want to say something like this:

You may feel humiliated to admit that you feel like hurting someone. It takes courage to reach out and get help. But reaching out for help will change your life and the lives of your loved ones for the better. You can get free of this terrible burden. You can change your life and stop the abuse. You don’t have to be alone in this struggle. You are not an evil person. You have been hurt, and you are repeating the hurt. You can stop this behavior. But to do so, you must get help.

At this point, you may notice abusers indicating, verbally and nonverbally, that they are open to or appreciate suggestions that can help them with their violent behavior right now. If that is the case, you could say the following:

Here are some things that will help you right now. When you feel angry, scared or overwhelmed, you may feel like hitting, harming, or punishing someone. When this happens, you must leave the situation as soon as you can, even if it’s just for a few minutes. This is not
the time to “talk it through” with the person you feel like hurting. You must leave the room. But before you do so, you will have to decide if a child, disabled person, or elder will be in greater danger if left alone. If the individual is in danger of falling or needing medicine or water, you will have to think about whether it is better to leave for even a short time or to stay and hurt them. You can tell a child or adult that you must leave for a few minutes. Say, “I must leave the room now. But I will come back right away.”

Even if the person is crying or begging you stay, it is better for you to leave the room than to stay and hit or abuse. It is okay for an adult or child to cry by themselves for a few minutes, while you leave to clear your head. You do not need to abandon a child or disabled adult or an elderly person. But you do need to take a break and you should try to do so without delay. Go to another room or go outside for a few minutes.

Move around to release energy. Do something active: walk or jump in place, run, lie down on the floor, kick your feet, or do sit-ups. If you feel like punching, wrap your hand in a towel and hit a pillow or soft chair. Don’t hurt yourself. Hurting yourself is repeating the violence. That will never help you or your loved one. If you feel like crying, let yourself cry. If you feel like shouting, put a folded towel over your mouth and shout. If you have spiritual beliefs, pray for help. Do not drive a car if you are angry. Getting in an accident will not help. Do not drink alcohol, use drugs, or take someone else’s prescription medication. If you take prescribed medication, don’t take extra pills. Using drugs or alcohol will keep you stuck in the pattern of abuse and delay or prevent your stopping this pattern for good.

If no one else in your home can help you, make contact with someone outside your home. If you have a friend, counselor, or spiritual advisor, call them. If you can’t think of anyone else, there are some phone numbers you can call. You may need additional counseling resources.

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6 Call 800-273-8258, a general crisis and suicide hotline. You don’t have to feel suicidal to get help from a hotline. Or call 411 and tell the operator you need a crisis hotline or a spiritual hotline. An example is a Christian group, Women of Substance, 866-86ABUSE. Tell the counselor you are upset and afraid you might hurt someone. They will listen to you and help you think about how to get help.

7 To find counseling or mental health services, search the Center for Mental Health Services (CMHS) website. CMHS is part of the Substance Abuse and Mental Health Services Administration, which directs efforts to improve mental health treatment services for Americans. Search by state to locate a community mental health agency. [http://mentalhealth.samhsa.gov/cmhs](http://mentalhealth.samhsa.gov/cmhs)
CHAPTER 7. CONFRONTING VIOLENCE

Violence-Prevention Resources, Organizations, and Websites

- **The National Criminal Justice Reference Service (NCJRS)**, which is administered by the Office of Justice Programs (OJP), United States Department of Justice, offers information on crime, law, victims, and crime prevention. [http://www.ncjrs.org](http://www.ncjrs.org)

- **The Center on Juvenile and Criminal Justice (CJCJ)** provides direct service, technical assistance, and policy research on juvenile and criminal justice. [http://www.cjcj.org](http://www.cjcj.org)

- **The Center for the Study and Prevention of Violence (CSPV)**, at the University of Colorado at Boulder, provides evaluation and dissemination of best practices on violence prevention and drugs. Its focus is on youth, children, schools, and families. [http://www.colorado.edu/cspv](http://www.colorado.edu/cspv)

- **The Centers for Disease Control and Prevention (CDC)**, a part of the United States Department Health and Human Services, offers health and safety topics and general information on birth defects, diseases, genetics, environmental health, injury, and violence, including a section on women with disabilities and links to domestic violence organizations. [http://www.cdc.gov](http://www.cdc.gov)

- **The Directory of Crime Victim Services**, an online resource maintained by the Office for Victims of Crime (OVC) Resource Center, which is part of the OJP, helps services providers and individuals locate non-emergency crime victim service agencies in the United States and abroad. [http://ovc.ncjrs.org/findvictimservices](http://ovc.ncjrs.org/findvictimservices)

- **Working with Victims of Crime with Disabilities**, a bulletin based on the findings of one of the first projects centered only on disabled people within the criminal justice system, reports on factors and resources in assisting disabled victims of crime. [http://ojp.usdoj.gov/ovc/publications/factsheets/disable.htm](http://ojp.usdoj.gov/ovc/publications/factsheets/disable.htm)

- **Disabled Crime Victims Assistance, Inc. (DCVA)** helps adults, children, and seniors who became disabled as a result of a violent crime or those already disabled before they became a crime victim. [http://www.dcvainc.org](http://www.dcvainc.org)
CHAPTER 7. CONFRONTING VIOLENCE

Self-Defense and Martial Arts Programs for People with Disabilities

Depending on physical skills and limitations, some people with disabilities can learn selfdefense techniques and/or practice martial arts. Many local programs include people with various kinds of disabilities in their activities. Inquire at recreation programs, college campus programs, and other community groups.

Please note: CAPE does not endorse these programs, due to insufficient research on their efficacy and safety. However, we do encourage thoughtful exploration and evaluation. Here are a few web references, which our researchers considered to be reputable:


- Model Mugging offers training for women that is centered on personal empowerment, safety, and self-defense. It advocates the perspective that "the more prepared you are to defend yourself, the less likely you will ever have to" do so. Training is offered in 6 U.S. states, and 7 countries outside the United States. [http://www.modelmugging.org](http://www.modelmugging.org)


- Victims of Crime with Disabilities Resource Guide provides the most comprehensive collection of information and resources focused on ending crimes against people with disabilities. The website includes an extensive resources database, current news and updates, a searchable calendar of events, information on funding opportunities, and online discussions. [http://wind.uwyo.edu/resourcemodule](http://wind.uwyo.edu/resourcemodule)
Violent abuse is devastating to disabled individuals. Years later, these experiences can continue to have an impact on the assaulted individual’s sense of well-being and ability to live independently. Even without being targeted with overt abuse, people with disabilities are already made to feel relatively powerless in our society. Consequently, when a disabled person is assaulted, his or her feelings of powerlessness and victimization may be greatly reinforced. The individual may retreat, feel hopeless, or come to believe that no one can be trusted.

This chapter offers suggestions for disability self-help group leaders, independent living peer counselors, and domestic violence and rape crisis counselors to help people with disabilities deal with experiences of violent abuse. Counseling and peer support can be enormously helpful in assisting individuals to recover from an assault, regain trust in others, reclaim their sense of well-being, and ultimately, proceed to live the lives they want.

Benefits of Peer Counseling

Peer counseling should not be viewed as a low-cost, lesser-value alternative to professional counseling. Often support from peers is an equally effective path to recovery. Ideally, support is offered by well-trained, experienced counselors who can offer relaxed, attentive, and skilled listening to the disturbing stories that an abused individual needs to disclose. However, the idea that only trained professionals should handle the emotional needs of disabled assault survivors is not workable. For one, a serious shortage of professionally trained counselors who are knowledgeable about disability issues still exists across the United States and around the world. Thus, while Community Mental Health Centers can offer appropriate services and referrals, these resources are not
available in all areas of the United States.\footnote{For locations of Community Mental Health Centers in your area, please visit \url{http://mentalhealth.samhsa.gov/databases/}} Secondly, disabled individuals covered by Medicaid, as well as those who are under- or uninsured, may have no financial resources to pay for professional counseling. Also, many health insurance programs have very limited coverage for mental health counseling.

Fortunately, one-on-one counseling and support groups led by peer counselors in disability organizations and domestic violence programs, as well as informal sharing within peer friendships, can offer effective resources for disabled assault survivors. These settings allow affected individuals to share their stories with peers and receive support and caring attention, which greatly assist their emotional healing and empowerment. The concept of peer counseling usually implies a shared set of personal characteristics or life experiences. Peer counselors in Independent Living Centers and domestic violence programs do not need to have the same, or even similar, disabilities in order to provide a safe environment for a disabled assault survivor to open up. They do need to be familiar with disability experience and be able to be relaxed around the charged issues of assault. A thorough familiarity with the materials in CAPE is an excellent starting point to begin this process.

Addressing Potential Concerns

Peer counselors or individuals in peer friendships face the risk that the distressing stories of disabled assault survivors could frighten or emotionally trigger certain reactions in them. Another concern of sharing assault experiences is that individuals might become uncontrollably upset if they confront and reveal what happened to them. But this possibility is no more likely to happen with disabled people than with any other constituency of individuals telling their painful stories of hardship and mistreatment. We must not assume disabled people, especially disabled women, are incapable of recovering from assault. We must not abandon people out of fear of not being able to deliver so-called expert counseling. We must offer the best we can, while actively expanding the
highest quality support and resources to empower our disabled constituencies. Human beings are amazingly resilient. Together we can and do change lives.

The main resource that peer counseling can offer is good listening, accompanied by a generous and genuine attitude of acceptance (or “positive regard,” as discussed in CAPE’s Chapter 12, Facilitating Support Groups) and validation. Peer counselors should be ready to refer individuals to additional community resources, such as disability financial benefits, housing resources, personal assistance services, substance abuse resources, as well as professional counseling, where appropriate.

Starting the Peer Counseling Process

To begin the one-on-one peer counseling process, invite the person to be counseled to introduce him- or herself and describe his or her current life. If an assault has been disclosed, gradually and patiently invite the individual to talk about what happened and the effects of these experiences on his or her life. Open-ended questions best enable individuals to explore the impact of the abuse. For example, the following questions may elicit reflective responses:

- What do you need to talk about?
- What’s on your mind?
- How are things going in your life?

It is helpful to offer reassurance that individuals can talk about anything they want. Let them know there is no specific agenda for the counseling. If the individual mentions the assault, peer counselors can ask what the individual believes he or she needs to help him- or herself to recover from the experience. Of course, initially, the disabled person may have little idea of what might be helpful. The counselor’s encouragement will help him or her begin to gain confidence in focusing on and expressing his or her own ideas about self-empowerment.

Key Aspects of Peer Counseling

It is important for the peer counselor to reach for a clear understanding of the daily specifics taking place in the disabled individual’s life because they can make moving beyond an assault experience complex. For example, the disabled individual may require personal assistance for bathing and dressing. Having someone else touch her body or be in her living space may remind her, consciously or not, of the assault.

Many people with disabilities have limited knowledge of their own body parts, and they may have little or no information about sexuality. Additionally, they may have been told never to talk about these topics. Thus, discussing these issues may feel difficult. The counselor’s patience is essential.

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2 Civjan, S. (1997). Tips for working with sexual abuse survivors who have disabilities. Personal Safety Awareness Center, Safe Place, Austin TX. For more information about Safe Place and the educational materials it offers, see the resource list at the end of this chapter.
Likewise, the peer counselor’s positive regard for the disabled assault survivor is extremely important. Peer counselors need to hold a consistent attitude that, under the circumstances, the disabled individual did the best he or she could to resist and, later, to handle the assault. It is generally not helpful for the counselor to delve for or offer his or her own insights about the abuser or the relationship between the abused and the abuser. It is never useful to suggest in any way that the disabled person may have enabled or failed to resist the mistreatment. The peer counselor needs to trust that the assault survivor knows what he or she needs to feel and reveal.

Ultimately, given the time and the arena to explore his or her own emotions, the disabled individual will begin to gain perspective and reframe the difficulties the mistreatment may have created. For insights to be meaningful, they must come from the affected individual. The more the individual is able to disclose of the assault and talk about the experience, the more likely he or she will be to start the recovery process and continue to live the life envisioned before the assault.

Yet some disabled assault survivors may not be able, at least not yet, to verbalize what happened to them, and peer counselors need to be mindful not to push these individuals to recount the exact details of the abusive event. These specifics may be too painful to describe or recall. Also, the individual’s current life circumstances may not be conducive to enabling exploration of this disturbing incident. However, these individuals can still benefit from listening to other disabled assault survivors tell their stories or viewing movies or reading stories that address abuse issues, such as the ones listed in CAPE’s resources sections. They may also benefit from using other modalities of expression, such as art, music, movement, or metaphor to explore their emotions. Any of these activities can be built into counseling programs. Of course, people with communication disabilities may need accommodations to express or reveal their stories and feelings.

**Expressions of Emotional Release and Healing**

Emotional release in the form of crying, laughing, and shaking is a natural part of
Men in particular will likely need encouragement to talk and express emotion. Attention to non-verbal communication, such as body language and facial expression, can help the counselor grasp what the individual is feeling and expressing. Peer counselors need to accept and encourage these various forms of expression, while remaining relaxed and attentive. Tears may need to flow for a long time, and counselors can have tissues available and assist if requested. However, they need to avoid pushing tissues at a crying individual because it may imply that wiping up is the priority; it may also distract the crying individual from expressing the emotion. Sometimes laughter comes up in ways that may seem illogical or inappropriate, and peer counselors need to be alert enough to avoid responding in discouraging ways. Questions such as “Why are you laughing” or “What’s so funny?” are likely to stifle further emotional expression.

Laughter doesn’t have to mean something is humorous. It accompanies exploring feelings of fear, shame, and embarrassment and counselors should accept it with a relaxed smile. If an individual begins to shake while telling of an abusive incident, peer counselors should not try to stop the person or calm him or her down. Shaking is one means of releasing pent-up fear from the assault. There is no need to focus a lot of attention on the shaking itself.

Just like yawning, stretching, or sweating, the body best knows what it needs to do. Peer counselors just need to stay relaxed and attentive and allow the individual to continue. If the individual expresses concern about shaking, counselors can reassure him or her that shaking is a natural part of emotional release and healing.

When an assault survivor continues to feel or act victimized, even with intervention, it is because the impact of the traumatic experience is still with him or her. Peer counselors should never suggest that the individual needs to “get over it.” The best way to overcome getting stuck in a feeling of being a victim is interacting with peers and mentors who demonstrate taking power in their own lives. Being told that one’s feelings are wrong keeps people stuck in those feelings. Counselors need to appreciate the individual for all that he or she is doing to recover from the assault and its effects. As described in CAPE’s chapter 12, Facilitating Support Groups, at the end of the counseling sessions, peer counselors can also assist the individual in refocusing his or her attention away from the upsetting memories and onto his or her present life. Likewise, they can encourage individuals who have experienced assault to learn about self-protection to increase the likelihood that the abuse will not happen again. Learning and applying the CAPE-abilities, the basic skills presented in CAPE’s Chapter 3, are particularly important for disabled abuse survivors. These skills will enable disabled individuals to learn to protect themselves.
CHAPTER 8. PEER COUNSELING FOR ASSAULT SURVIVORS

Resources You Can Use

- Rape, Abuse and Incest National Network (RAINN) is a national anti-sexual assault agency providing free and confidential help 24/7 at 1-800-656-HOPE (4673). To find a rape crisis center locally, go to http://centers.rainn.org/.

- National Domestic Violence Hotline (NDVH) also provides help 24/7 at 1-800-799-SAFE (7223) or 1-800-787-3224 (TTY). http://www.ndvh.org

- Austin Safe Place offers resources and training in disability related violence prevention for professionals, families, and students in domestic violence, sexual assault, and rape crisis. Call Austin Safe Place’s 24-hour hotline at 512-267-SAFE (7233) or 512-927-9616 (TTY) for immediate help. http://www.safeplace.org/

- National Organization for Victim Assistance (NOVA) advocates for the rights of crime victims, offers direct services to them, and trains and aids other agencies serving victims of crime. NOVA offers information and referrals to victims of crime and disaster 24/7 at 1-800-TRY-NOVA or (703) 535-6682. NOVA has recommendations for criminal justice agencies and local disability rights specialists at http://www.trynova.org/victiminfo/ovc-disabilities/recagencies.html

- Independent Living USA (ILUSA) has a website to find an Independent Living Center in your state or community. http://www.ilusa.com/links/ilcenters.htm

- National Mental Health Information Center (NMHIC) provides information on the quality and range of services and resources available to individuals with mental illnesses. http://mentalhealth.samhsa.gov/databases/

from future mistreatment and develop new levels of self-confidence.

Preparing to Offer Counseling

Ideally, prior to providing counseling services, peer counselors will:

1. explore and understand crucial issues related to violence and disability;  
2. take time to consider the impact of physical and verbal abuse on the lives of people with disabilities;  
3. explore a wide range of approaches to counseling about recovery from and self-
CHAPTER 8. PEER COUNSELING FOR ASSAULT SURVIVORS

protection against violence, including use of story-telling, humor, and writing.

How can counselors and services providers prepare themselves to help individuals with disabilities effectively resist and/or recover from violence? Below are some discussion/stimulus questions that will help disability services providers and domestic-violence providers plan for and develop their own peer counseling approaches for disabled participants:

1. When and how does mistreatment shift from abuse to violence? 
   Brainstorm and discuss distinctions in the ways people define violence. Counselors need to explore their own personal histories of exposure to aggression, and their own values about violence. This will effect their emotional reactions to hearing from others about violent mistreatment.

2. What are the effects of violence on different populations of disabled people? What might be unique for these various populations: women with disabilities, men with disabilities, children and teenagers with disabilities, elders with disabilities or elders who become disabled later in life, and disabled individuals with specific impairments or other specific characteristics?

3. Try to imagine a world where there is no more violence. 
   What would need to change for this to happen? What would change for people with disabilities if they could be assured they would never be mistreated again? What would need to change for communities, families, and governments?

4. Explore the stories of violence in Sticks and Stones and peruse the teaching-guide suggestions about employing creative writing.

5. Consider using role-playing to practice saying no to potentially abusive situations. Possible scenarios for saying no could be:
   - A stranger on the street saying, “Hey baby, how about a little kiss?”
CHAPTER 8. PEER COUNSELING FOR ASSAULT SURVIVORS

Who Are Mandated Reporters? What Are They Required to Do?

Mandated Reporters are individuals who provide services for children, disabled adults, or elders who are considered dependent upon care. Such providers are required by law in each state (usually under the Social Services Welfare and Institutions code) to report in writing, immediately or as soon as possible, any incident or suspicion of abuse or neglect to their state’s Department of Social Services. Mandated reporters include personal assistants, healthcare providers, teachers, all kinds of services providers, including clergy and police, and family providers, whether they are paid or unpaid. A report of abuse may trigger an investigation into the affected person’s living situation, which sometimes can result in the removal of the affected individual from his or her current living situation. Typically, additional services are sought to address abuse or neglect. The requirement for mandated reporters to report any incident or suspicion of abuse or neglect has been designed to protect individuals who could be in danger. Services providers should contact their Department of Social Services to find out about regulations and requirements in their state.

- A medical provider saying, “You must take this; it is for your own good.”
- A services provider saying, “I’m sorry, dear, you need more protection and must go into a nursing home.”

6. Practice approaches to laughter, humor, and play. Assault, of course, is very serious business, but occasional levity enables learning and retention of self-protection skills, as well as avoiding the pitfall of too much heaviness. Laughter and play help shift the focus from victimization to empowerment and reinforce the crucial skill of changing one’s point of view, for example, from tragedy to opportunity for growth.

Get Support for Yourself

It is not easy to offer to listen to stories of assault or rape or other kinds of violent abuse. Disability peer counselors and rape crisis counselors must make sure to get support for themselves. Within appropriate bounds of confidentiality (changing names and identifying details), counselors need to find a place to talk to someone they trust, a supervisor or a friend, for example, and, if needed, allow their own tears to flow. This work is so important! Let us remember to appreciate our skill and spirit and celebrate the difference we make in the world.
Populations: Women, Men, Elders, Youth, High Risk Disabilities

CAPE resources can be used with a wide range of populations of people with disabilities. We offer some perspectives and specific ideas about five key populations of people with disabilities: women with disabilities; men with disabilities; elders, including elders with recently acquired, age-related disabilities and disabled people who have reached older age; youth with disabilities; and high-risk-for-abuse populations, including people with developmental, cognitive, emotional, and communication impairments.

Women with Disabilities

Several national surveys show that women with disabilities consider violence and abuse issues to be a high priority concern.\(^1\) Meeting the needs of women with the majority of research, writing, and training about abuse and violence prevention for people with disabilities have focused on the experiences of disabled women. Compared to women in the general population,\(^2\) disabled women face twice the risk of being abused than women without disabilities.\(^3\) In North America, about 15,000 to 19,000 women with developmental disabilities are raped each year.

\(^1\)Berkeley Planning Associates conducted a survey of 100 disabled women which found that abuse and violence protection was ranked as their first priority. Retrieved December 10, 2007, from http://www.ncjrs.gov/pdfiles/172837.pdf


The patterns of sexism that can lead to abuse potentially operate more intensely in relationships between disabled women and their male partners. Similar to women without disabilities, disabled women are usually abused by men whom they know and most of the assaults occur at the victim’s residence.\footnote{Ibid.} However, disabled women also experience abuse from services providers, including family and personal assistance providers, whose assistance may be essential to the disabled women’s ability to live independently in the community. All these factors can create serious logistical conflicts for a disabled woman. If her abusive spouse or other family member is removed from her residence, she may find herself in jeopardy of being placed in an institution, which in turn would mean an end to her living independently.

There are many complex issues for disabled women in maintaining independence while relying on personal assistance services. The independent living model of self-directed personal assistance considers disabled individuals to be in charge of their own needs and to direct the activities of their services providers. However, disabled women may not be regarded or supported to be self-directing. Few families and communities typically train disabled women to be employers or directors of their personal assistance providers, a circumstance clearly reflected in the insight made by one disabled woman from our studies about her socialization as a woman and how it affected her supervision of her personal assistant:

I think directing one’s services is compounded by being a woman and being socialized to be agreeable and to look out for other people’s needs, sometimes more than one’s own.\footnote{Saxton, M., Curry, M. A., Powers, L. E., Maley, S., Eckels, K. & Gross, J. (2001). Bring my scooter so I can leave you: A study of disabled women handling abuse by personal assistance providers. Violence Against Women, 7(4) 393-417.}

Another woman’s ironic comment illuminates a stark difficulty in her intention to assert her independence:

You finally say, "Okay this is it, I’m going to do whatever I can to change this marriage. And by the way, can you bring my scooter to me so I can leave you?"\footnote{Ibid.}

A woman’s dependence upon her spouse may not only be limited to financial and/or emotional needs but can also include basic needs for sustenance or mobility. Difficulties with self-direction can also be influenced by childhood disability experiences, as revealed by one disabled woman’s comment about her upbringing:

\footnote{Ibid.}
Nobody ever really taught me how to be on my own. I didn’t really have a separate sense of self. An able bodied child crawls away from mommy at the age of two....I always had to be dependent on somebody else to get basic needs met.\(^8\)

The Domestic Violence Prevention movement is beginning to address the needs of women with disabilities by providing training for staff and improving disability access to their community resources and services.\(^9\) Still, a lot of work remains to be done to bring domestic violence services for disabled women up to the standards of services for non-disabled women.\(^10\) Meanwhile, the disability community is beginning to place more emphasis on preventing abuse and violence from happening by empowering disabled women and girls to learn to assert direction over their own lives and personal care, and to get help if abuse is threatened.\(^11\) For example, the Deaf community has developed domestic violence and abuse prevention resources for the specific needs of women who are Deaf or Deaf-Blind and who use sign language as their primary means of communication.

CAPE offers disabled women of all ages a range of activities and resources to increase their confidence and autonomy in personal assistance relationships and in their lives in general. The Personal Assistance Quiz encourages women to assess their own personal assistance skills and learn more about self-direction. The Comic Book Scenes illustrate and encourage discussion of common difficulties in personal assistance direction. The Movie Guide selections help stimulate thinking and learning about abuse prevention. CAPE’s short videos, especially Strong and Informed, help young disabled women consider safety issues in dating relationships and raise key issues about sexuality.

Men with Disabilities

In contrast to the strong movement of and literature by women with disabilities, the lives and unique challenges of men with disabilities have only begun to be explored by social researchers in the last ten years.\(^12\) At WID, we partnered with Portland State University to explore personal assistance abuse issues for men with disabilities by conducting

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\(^8\)Ibid.


\(^12\)Shakespeare, T. (1999). The sexual politics of disabled masculinity. Sexuality and Disability, 17(1), 53-64.
CHAPTER 9. POPULATIONS

Violence-Prevention Resources for Women with Disabilities

- **Center for Research on Women with Disabilities** (CROWD) at Baylor College of Medicine disseminates information on health and life choices of women with disabilities, including violence facts, interventions, access to domestic violence programs, and guidelines for professionals. [http://www.bcm.edu/crowd](http://www.bcm.edu/crowd)

- **DeafHope** (Hayward, CA) offers support for deaf survivors of violence, training and support for professionals, 24-hour TTY hotline, Deaf power wheelchair online, newsletter, prevention and safety tips. [http://www.deaf-hope.org](http://www.deaf-hope.org)

- **SafePlace** focuses on ending rape, sexual abuse, and domestic violence; provides a 24-hour hotline in English and Spanish, and offers videos, training materials, programs, services, and links. [http://www.austin-safeplace.org](http://www.austin-safeplace.org)

- **Illinois Coalition Against Sexual Assault** (ICASA) offers information about crisis centers, a library, and an online newsletter in English and Spanish with downloadable brochures, posters, and short videos. [http://www.icasa.org](http://www.icasa.org)

- **National Online Resource Center on Violence Against Women** provides extensive online resources for education, prevention, research, and public campaigns. [http://www.vawnet.org](http://www.vawnet.org)

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surveys of men living independently. Of those surveyed, 9% reported physical violence at the hands of care providers; 12% disclosed having experienced serious neglect; 23% told of having been handled roughly by those in helping roles; and 43% mentioned experiencing verbal abuse from providers upon whom they depended for assistance. 

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Disabled men have particular difficulties in disclosing abuse. The male ethic of refusing to “squeal” (revealing a perpetrator’s name and act; a term used by several participants) was mentioned as a source of resistance to disclosure. Another difficulty arose from the men’s hesitancy to verbalize feelings about vulnerability, which some attributed to gender socialization that discourages men from showing emotions. As one of the participants observed,
Violence-Prevention Resources for Men with Disabilities

- MaleSurvivor: Overcoming Sexual Victimization of Boys & Men offers information and resources for male survivors of sexual abuse, their families, friends, and clinicians. The website features an online directory of professionals who work with male survivors. [http://www.malesurvivor.org/](http://www.malesurvivor.org/)

- Christopher and Dana Reeve Paralysis Resource Center offers information and resources for individuals with mobility impairments. [http://www.christopherreeve.org/site/c.mtKZKgMWKwG/b.4453431/k.A0C5/Sexuality_for_Men.htm](http://www.christopherreeve.org/site/c.mtKZKgMWKwG/b.4453431/k.A0C5/Sexuality_for_Men.htm)


- The Men’s Bibliography is an extensive online bibliography that focuses on writings on men, masculinities, gender, and sexualities. It includes some references for men with disabilities. [http://mensbiblio.xyonline.net/](http://mensbiblio.xyonline.net/)

- Paul Kivel has written several books that offer information and advice for young men about preventing violence. Young Men’s Work and The Men’s Work Series are both available for purchase from his website. [http://www.paulkivel.com/books.php](http://www.paulkivel.com/books.php)

Society has always imposed on men that we are supposed to be able to defend ourselves and if physically tackled, we are supposed to be able to punch them back. I can’t punch them back. It’s veryemasculating...to tell somebody, "I was abused by this person."...Disabled men have a tendency to just swallow it and stay silent.\(^{14}\)

Many of the men who were surveyed talked of feeling shame and blaming themselves.\(^{14}\)

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CHAPTER 9. POPULATIONS

**Figure 9.1:** Men with and without disabilities, like sprinter Oscar Pistorius, are expected by society to be strong—expectations that may prevent them from reporting abuse.

Some of the few resources specifically developed to address the needs of disabled men are listed below. Men, like women, can benefit from support groups and events with a special focus on gender experience. Men with disabilities need opportunities to share and discuss their concerns about abuse, violence, and personal assistance; individually, in mixed groups of men and women, and in men-only groups. One noteworthy aspect we discovered was that many of the men in the focus groups were eager to meet again to discuss their lives as disabled men. Many indicated that no one had ever asked them before what is was like to be a man with a disability.

CAPE’s PAS Scenarios for Men with Disabilities (Chapter 14) focus on particular abuse issues for men. Other CAPE materials, including the Movie Guide (Chapter 13), the PAS Online Quiz (on the Multimedia CD), Handling Anger with Attendants (Chapter 6, with a PowerPoint presentation on the CD), and the Safety and Abuse-Prevention Tips in Chapter 16 are also appropriate for men with disabilities.

**Elders**

The image of an elder relegated to a rocking chair on the porch has been replaced by a range of contradictory new stereotypes. These range from the ideal, grandpa or grandma poised for a backhand on the tennis court, to worst-case scenarios, older being, desolate and slumped in a wheelchair, 

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116

Ibid.
parked in a nursing-home corridor. Yet these extremes are not representative of the ordinary experience of aging in the United States.

The stereotypes of old age are in many ways as debilitating as the physical limitations themselves, the so-called age-related conditions, such as arthritis, low vision and/or hearing, heart conditions, and so forth. Of course, our bodies do wear out eventually. But ageism — discriminatory or prejudicial treatment of individuals based on their age — and negative stereotypes of older people can lead us to believe that any older person should be treated with a patronizing tone, presumed to be senile, and devalued as a burden to the family and society.

Our youth-oriented media overwhelms us with messages that gray hair and wrinkles are failures or diseases, and that they must be eradicated with products and treatments which deny and disguise the truth that growing older is a natural part of being human. Moreover, subscribing to those youth-focused media images may lead us to miss the opportunity to fully enjoy and celebrate the success of our continued survival.

Although current media images of disability are beginning to challenge stereotypes of younger people with disabilities, they have yet to enter the realm of aging with a disability. We have almost no images in the media of people with disabilities aging along with their non-disabled peers. The population of elders with disabilities includes individuals who acquire impairments later in life and those disabled earlier in life who then reach old age. Both populations may be subject to abuse and both can benefit from empowerment activities to help them resist mistreatment and get help. CAPE includes resources designed to help educate elders who live independently, so they can recognize and resist abuse and remain independent.

It is worth reiterating that old age, along with disability and increased dependence on others for help, do not cause abuse. Abuse is caused by the actions of abusers and by social attitudes that devalue or target certain people or kinds of people. Elder abuse is defined as intentional or unintentional hurting of someone 65 years or older, at home or in an institution, occurring in a relationship where there is an assumption of trust and care.\(^\text{[16]}\) Elder abuse may consist of any of the following:

- physical abuse, including assault or violent mistreatment of any kind;

CHAPTER 9. POPULATIONS

- financial abuse, such as theft, unauthorized use of the elder’s funds, forgery, scamming, or fraud;
- emotional abuse, including humiliating, ridiculing, withholding contact with others, threatening, yelling, or punishing;
- neglect, including ignoring, isolating, withholding care, medications or other needs, and not monitoring potential self-neglect of personal hygiene, food, water, shelter, medications, or medical care;
- sexual abuse, such as coercion of any unwanted sexual activity, sexual assault, rape, or unwanted sexual verbal interaction.

British researchers first referred to elder abuse in the early 1970s, and in 1975, Robert Butler’s book Why Survive? Being Old in America, which described the "battered old person syndrome" (now called elder abuse), won the Pulitzer Prize.\(^\text{17}\) Since then, mistreatment of older individuals has been recognized as a substantial problem in the United States, leading to the passage of elder abuse laws in all 50 states. Although prevalence is difficult to determine, estimates suggest that about 4% to 6% of older persons are victimized by abuse each year.\(^\text{18}\)

Yet only about one out of eight cases of abuse is reported and few elder abusers are prosecuted. One reason is that abusers are primarily adult offspring of the abused elder, making intervention difficult.\(^\text{19}\)

The presence of disability is a crucial element in the abuse of elder persons. As a result of adult abuse registries, a profile has emerged regarding disability and elder abuse: 50% of abused elders have severe limitations in physical and/or mental functioning and require some degree of dependence upon others for personal assistance.\(^\text{20}\)

Many studies document that stereotypes of elderly persons as passive, helpless victims are unfounded and that educational activities to help seniors avert abuse can be effective.\(^\text{21}\) Increasingly, senior centers, faith-based organizations, and healthcare and community groups are addressing elder abuse prevention and are seeking educational resources to deal with this need. Unfortunately, the majority of educational materials on elder abuse are still written for services providers and trainers, rather than for older individuals themselves.

CAPE provides abuse-prevention principles, assessment, and educational tools that all apply to elderly persons who live independently in the community. Generational differences sometimes make it harder


\(^{19}\)Ibid.

\(^{20}\)Ibid.

Violence-Prevention Resources for Elders

- **National Center on Elder Abuse**, Administration on Aging, offers extensive resources in several languages, a library, referrals and information about chapters. [http://www.ncea.aoa.gov](http://www.ncea.aoa.gov)

- **Minnesota Center Against Violence and Abuse (MINCAVA)** offers articles, training modules, and video lists on elder abuse. [http://www.mincava.umn.edu/categories/885](http://www.mincava.umn.edu/categories/885)

- **National Committee for the Prevention of Elder Abuse** provides resources on elder abuse and prevention strategies. [http://www.preventelderabuse.org](http://www.preventelderabuse.org)

- **Texas Department of Family and Protective Services** offers a resource kit for protecting elders and adults with disabilities. The kit is available in English and Spanish and can be downloaded from [http://www.dfps.state.tx.us/everyonesbusiness/PDFs/English-APSinserts.pdf](http://www.dfps.state.tx.us/everyonesbusiness/PDFs/English-APSinserts.pdf)

- **Rehabilitation Research and Training Center on Aging with Developmental Disabilities (RRTCADD)**, University of Illinois at Chicago, offers resources on healthy aging and using an empowerment and self-determination model. [http://www.rrtcadd.org](http://www.rrtcadd.org)

- **Terra Nova Films, Inc.** produces and distributes video training resources on aging. [http://www.terranova.org](http://www.terranova.org)

- **Advocacy Centre for the Eldery, Toronto**, offers a training manual with basic definitions and what-to-do tips for different groups of people involved with abused elders. [http://www.cleo.on.ca/english/pub/onpub/PDF/seniors/elderab.pdf](http://www.cleo.on.ca/english/pub/onpub/PDF/seniors/elderab.pdf)

- **Gray Panthers, Age and Youth in Action**, is an inter-generational activist organization with a focus on social change. They do not directly address elder abuse, but offer an empowered model of elders as leaders and essential partners in social transformation. [http://www.graypanthers.org/](http://www.graypanthers.org/)

- **San Francisco Network of Support for Community Living Planning**, includes audio training segments on elder abuse, forms and resources for mandated report of abuse. [http://sanfrancisco.networkofcare.org/aging/elder_abuse.cfm](http://sanfrancisco.networkofcare.org/aging/elder_abuse.cfm)
for elders to embrace a proud disability identity, yet they are increasingly becoming self-advocates in combating both ageism and disability discrimination.

CAPE’s Multimedia CD includes the short video *A Good Job*, which is designed for elders and their family members. *A Good Job* discusses how to effectively supervise personal assistants and maintain good communication to assure quality, self-determined personal care. CAPE’s Chapter 16, *Safety and Abuse-Prevention Tips for Games and Events* engages seniors in an ongoing conversation about these crucial issues.

**Youth with Disabilities**

We wish for the coming generations of young people with disabilities to have much better lives than previous generations. With the *Americans with Disability Act* now in place for two decades, public access, integrated education, job accommodations, and gradually shifting attitudes have helped make the community more accessible and inclusive. This shift in policy and attitudes has enabled many young people with disabilities to become more knowledgeable and assertive about their own needs and rights. Many disabled teens now plan to find jobs in their chosen fields, enjoy dating, and expect to marry and have families. They may have only heard or read about a time in history when disabled people could not get into a movie theater or onto a city bus.

But these same teens know mistreatment on the basis of disability. Our society is still far from eliminating discriminatory social practices directed at people with disabilities of all ages. For young people with disabilities these can range from snide comments to social exclusion, from bullying to brutal mistreatment. Many parents of these teens still struggle with the ordeal of “mainstream” education. Unlike parents of non-disabled youth, most parents of disabled youth must continually advocate for their disabled children, expending enormous effort in meetings and communications with teachers and administrators to insist that schools grasp and respond with appropriate accommodations to disabled students’ access and learning needs. These children are, as they should be, legally entitled to an appropriate education with their non-disabled peers, and schools’ reluctance to fulfill their responsibilities is illegal discrimination.²²

CHAPTER 9. POPULATIONS

Studies of children with and without disabilities clearly document a much higher abuse rate for disabled children than for their non-disabled peers.\(^{23}\) To date, no studies have addressed the prevalence of abuse specifically among adolescents with disabilities. Violence among youth in any population has always been a difficult problem. For adolescents, school and peer groups can become an arena for abuse in the form of bullying, taunting, and hazing. Young people with disabilities are likely targets for such mistreatment from peers. The additional complexities disabled young people experience in their daily lives, dependence upon personal assistance services, interaction with a range of providers, and bus rides, for example, increase the possibility for mistreatment. We mean not to scare young people and their parents, but to raise these issues and encourage them to take steps to avoid the potentially damaging impact of abuse before it happens.

In our studies, participants recalled childhood disability experiences. Some participants described being trained in a passive, dependent role. They spoke of power imbalances influenced by their disabilities. Describing her family experience, one woman said,

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 hard it comes out. To be left on a toilet for an hour\(^{23}\)

Many adults with disabilities recommend that abuse awareness education be available to younger people with disabilities and that such awareness could have prevented numerous instances of later abuse. Reflecting on her childhood, a female participant with post-polio observed,

I wish somebody had told me as a kid that I didn’t have to take that treatment. That I could speak up, that there were people I could talk to. That’s something we can do for disabled kids now. Start them when they’re young, knowing they shouldn’t have to take that.\(^{25}\)

Those concerned with empowering disabled people to resist abuse will find that the population of youth with disabilities who utilize personal assistance from parents or others is a largely overlooked, yet significant population for study.\(^{26}\) Research on this

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\(^{25}\) Ibid.

Violence-Prevention Resources for Disabled Youth

- The Empowered Fe Fe is a group of disabled young women from Chicago who have made a video about their interests, called Beyond Disability: The Fe Fe Stories, focusing on dating, sexuality, independence, disability rights, and other topics. DUDES, Disabilities United in Determination, Education and Strength, is a group of disabled young men with many of the same interests. Both are supported by Access Living in Chicago, a Center for Independent Living. [http://www.alyouthinfo.org]

- GimpGirl Community offers support meetings online to discuss themes relevant to young women and girls with disabilities. [http://www.gimpgirl.com/]

- About-Face focuses on the media’s impact on the physical, mental, and emotional well-being of women. Using practical and activist methods, About-Face challenges our culture’s overemphasis on physical appearance. [http://www.about-face.org]

- Kids Included Together (KIT) provides training for youth organizations committed to including children with disabilities in their existing recreational, social and child care programs. KIT offers live training, e-Learning and a library of books, videos, DVDs, and other materials. [http://www.kitonline.org/aboutkit/aboutkit.html]

- Child Abuse and Neglect/Disability Outreach Project (CAN/DO), funded by the California Governor’s Office for Criminal Justice Planning and created by veteran abuse prevention advocate, Nora Baladarian, provides resources for children with disabilities and their families. [http://disability-abuse.com/cando/]

- Partners for Youth with Disabilities (PYD), is a mentoring and educational program that matches youth and adults with disabilities, among many other activities design to foster positive self-images and independent living skills. PYD offers a free, downloadable mentorship training guide. [http://www.pyd.org/]

- The Alliance for Inclusive Education offers innovative models and resources for parents to help disabled children learn, make friends, have a voice in school and throughout life. The alliance also provides resources so families can create mutual support networks. [http://www.allie.org.uk/]

- National Information Center for Children and Youth with Disabilities (NICCHY) offers information, bibliographies and other resources for parents of youth and teens with disabilities, as well as services providers, and educators. [http://www.nichcy.org]

- Red Flag Green Flag Prevention and Treatment offers materials about sexual abuse and domestic violence for children and families, such as coloring and comic books and training guides. [http://www.redflaggreenflag.com/]

122
population’s learning and independent living needs must become a higher priority. The vast majority of disabled youth depend on volunteer family care and receive no formal training in independent living skills until their twenties or later.\textsuperscript{27} Formal training can potentially begin in adolescence, enabling skill development for self-direction of personal care to be a more appropriate developmental process for youth as they mature. One of the women interviewed in our survey spoke of finally overcoming her early mistreatment. As an adult, she was eventually able to take charge and actively direct her own care:

\begin{quote}
It took me about five years of hiring people, when I realized that I didn’t have to accept those things. Because of the experience growing up, I feel more vulnerable to allowing it to happen now. Now I feel the power to say, "No, this isn’t going to be okay."\textsuperscript{28}
\end{quote}

If she and others like her could have had earlier abuse awareness training and support, it wouldn’t have taken her so long to speak up against mistreatment.

Preventing abuse of disabled youth in all arenas, including personal assistance, interpersonal relationships, school, home, neighborhoods, and communities is clearly a crucial concern and high priority for action. Abuse awareness and prevention issues must be raised among parents and teachers, and when appropriate, directly discussed with disabled children and adolescents themselves. Many youth with disabilities are capable of learning about abuse awareness at earlier ages than parents and teachers realize. Teachers and parents must decide at what age young people are ready to grasp the crucial issues of self-protection. CAPE recommends that parents and teachers work together to make abuse awareness and empowerment activities a regular part of educational programs for adolescents with disabilities in school, after-school, scouts, recreation, and summer-camp activities. Mentor programs that partner disabled youth with disabled adults are highly effective in enabling youth to transcend typical social and personal barriers. These programs also allow disabled adults to share and model assertiveness in resisting mistreatment.

Most CAPE tools are appropriate for adolescents or can be adapted to meet their particular needs. The CAPE-abilities and the Empowerment Wheel, in Chapter \textsuperscript{3} are useful resources for training disabled young people in safety and self-protection, as well as in independent living skills in general. The Comic Book Scenes on the Multimedia Tools CD are good stimuli for discussion among youth learning to direct their personal assistance needs. Many of the movies listed in the Movie Guide (Chapter \textsuperscript{13}) are appropriate for adolescents. CAPE's
Multimedia CD also includes *Strong and Informed*, a short video specifically designed for young women with disabilities.

**High Risk Populations: People with Developmental, Cognitive, Emotional, and Communication Impairments**

Among people with disabilities, those with developmental, cognitive, communication, learning, and psycho-social impairments are at the highest risk of abuse. This population includes people with head injuries; those who are labeled “retarded,” “multiply handicapped,” or “emotionally disturbed”; individuals with hearing and/or vision loss; people who have learning disabilities; and those with autism spectrum disorders. Many factors operate to increase the risk of mistreatment for people with these impairments. They may have communication disabilities which make it harder for them to resist or disclose abuse. Additionally, their limitations in discerning interpersonal nuances, exercising judgment, or establishing social boundaries may attract abusers. Furthermore, individuals with these impairments may not be viewed as credible, even about their own experience, which makes it harder for them to trust others to whom they could disclose abuse.

Living circumstances is another factor that may increase risk of mistreatment. Many disabled people now living independently have been institutionalized at some point in their lives. During that time, they may have become accustomed to a lack of privacy, few physical boundaries, or a reduced sense of ownership over their own bodies. Likewise, they may have had multiple care providers handling bathing and dressing with limited compassion or sensitivity. They may have been trained to comply with authority and had little choice about personal habits, clothing, bedtime, and other decisions. They may have been institutionalized as infants or small children, resulting in deep feelings of abandonment and difficulties in asserting their choices in later relationships. Moreover, feelings of loneliness or rejection can make individuals desperate for any attention.

Historically, it was assumed that people with developmental disabilities were “hypersexual” and that acting out sexual behavior was caused by or in some way within the nature of their impairment. It was not understood that an individual displaying inappropriate sexual behavior had likely been sexually abused by someone else, often

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31 CAPE’s primary intended population is people living independently in the community with personal assistance. While institutionalized people typically have very limited autonomy and potential for self-protection, we encourage allies to institutionalized people to adapt CAPE materials for people in institutions in their planning for independent living.
an adult in the family or community. Few adolescents and adults with developmental disabilities have been given adequate education about sexuality. The assumption that they will not engage in sexual or romantic relationships, and therefore don’t need information about sexuality, greatly contributes to the likelihood that they will be sexually abused. (See CAPE’s Chapter 5 on Sexuality.)

Some people with disabilities may be unable or unwilling to disclose abuse experiences due to communication impairments, fear of retribution, or other reasons. Yet services providers and family members need to be alert to signs of abuse, such as increased difficulties in school, at work, or with social interactions. Sometimes abused individuals will revert to childlike habits or withdraw from engaging with others. Those who have been sexually abused may exhibit a heightened interest in sexual expression or conversely refuse to be touched by others, including care providers. They may also have an increased difficulty with sleep. Various abuse screening tools have been developed to enable services providers to quickly identify key signs of abuse. Clinical training is available for medical services providers to learn effective and sensitive interviewing techniques.

Self-advocates with developmental disabilities, their families, and services providers have collaborated to create an impressive collection of informational materials and training resources about self-protection from abuse. Using interactive exercises, photos, drawings, puppets, songs, art, theater, music, games, and stories, these training programs help disabled adolescents, adults, and children understand appropriate touching and physical boundaries, learn to say no to mistreatment, disclose difficulties, and get help. Suggestions of programs are listed below.

People with cognitive disabilities will not benefit much from a website or a pamphlet, because they may have less access to learning through reading. Moreover, looking at a website or reading a pamphlet is not likely to give these individuals a sense of connection to others and a sense of support from the community. Yet both are crucial to empower cognitively disabled people to learn.

People with autism or other neurologic impairments that limit interactive skills also need social connections for safety. Indeed, many people with these kinds of impairments may need significant protection from abusive situations because their social perceptual skills may be limited. In school settings, they may be targeted with bullying or harassment. They may not enjoy group activities if they have difficulty with interpreting social cues. But, as is true for anyone else with victims of sexual assault. 

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33 For example, a Sexual Assault Nurse Examiner (SANE) is a registered nurse (RN) who has received clinical training in forensic examination of victims of sexual assault. [http://www.ncdsv.org/publications_sanesart.html](http://www.ncdsv.org/publications_sanesart.html)
Kenny still remembers an abusive event that was inflicted upon him by a paid caretaker in 1991. At that time, the direct support staff working with Kenny hit or pushed him on his chest. Kenny continues to remind me of what happened on a weekly basis. Our dialogue goes something like this:

“Dale, do you remember when [name withheld] hit my heart?”
“Yes, I do, Kenny.”
“What happened to him?”
“You remember, Kenny ... what happened?”
“You fired him!”
“Yes, I did. We can’t have people acting like that.”

“NO! He can’t do that. He gets fired.”

It is important to recognize the impact that abuse has on people. Although this incident has long since passed, Kenny knows two things: a caregiver hired to work in his own home betrayed his trust; and the agency through which he receives services—my place of employment—did exactly what he had hoped and expected by removing a staff member he perceived as a threat. Kenny knows that he can report allegations of abuse to any agency personnel, and that such allegations will be handled swiftly and seriously. The faith Kenny now has in his service provider should be guaranteed to everyone. He believes in a safe future, but has had difficulty letting go of this disturbing memory.

(Dale Blonigen in “He Gets Fired”)

impairments, social connections with people who love and care about them are their lifeline to safety and abuse prevention.

A difficult challenge for services providers and families of cognitively disabled people is making empowerment and abuse-prevention activities a high priority on the overwhelming list of other needs and concerns they must address. Thus, while juggling educational needs, independent living training, personal care, disability benefits, medical issues, housing, employment and other tasks, they often place abuse prevention at the bottom of the list. Yet, we must give it priority. When abuse occurs, we recognize in retrospect that abuse-prevention training might well have prevented heartache and the enormous expense levied on the abused individual’s self-esteem, physical well-being, and independence.

We recommend that abuse-prevention activities be given the same importance as other kinds of training and resources. For example, every issue of an organization’s newsletter, every website about disabled people’s lives, and every training event can include some focus on empowerment and resistance to abuse, discrimination, and mistreatment. Addressing self-protection from abuse will make everything else on the long list of needs more meaningful and effective.

See the Sticks and Stones story included in Chapter 5, “A Tragedy That Didn’t Happen,” by Janelle Westerly, for an example of an adolescent autistic girl with autism who was empowered to resist abuse.
Violence-Prevention Resources for Higher Risk Populations


- *Sprout* is an organization dedicated to helping individuals with developmental disabilities and mental retardation grow through challenging and safe travel experiences. Based in New York City, its programs are available to people with MR/DD and the agencies that serve them throughout the United States. [http://www.gosprout.org/](http://www.gosprout.org/)

- *The Autism Awareness Centre Inc.* assists individuals who have autism, Pervasive Developmental Disorder (PDD), Asperger Syndrome and other disorders such as Tourette Syndrome, Attention Deficit Hyperactivity Disorder (ADHD) and Attention Deficit Disorder (ADD) through communication, behavioral intervention methods and biomedical interventions. [http://www.autismawarenesscentre.org/](http://www.autismawarenesscentre.org/)


- *Autism Society of America* offers resources in English and Spanish for people with autism, family members, and services providers. [http://www.autism-society.org/autismo](http://www.autism-society.org/autismo)
A “circle of friends” is a growing concept within the developmental disabilities community. The circle is a group formed and typically convened by family, but may also include and be initiated by friends, teachers, or services providers. Such a circle can help disabled individuals learn about abuse and abuse prevention as well as a host of other life challenges. The circle of friends works together as a team, meeting and brainstorming, generating new strategies and learning together about new ways to empower and ensure the independence of the disabled individual. The process can empower the team members as well as the disabled individuals at the center of the circle. Many models exist for creating circles of friends and connecting with resource people who care about and actively support disabled individuals. Some of them are listed in the references below. The recent award-winning film “The Collector of Bedford Street,” created by Alice Elliot, documents the process for a group of New York neighbors who develop a trust fund and enlist community resources to enable their disabled friend and neighbor, Larry Selman, to remain independent.

CAPE materials, including the Comic Book Scenes, Chapter 6, Handling Anger with Attendants, and its corresponding PowerPoint presentation, the safety games, short videos, and stories featured in *Sticks and Stones* can be used with these populations of higher risk individuals. Teachers, trainers, group facilitators, or parents can adapt materials if necessary, and plan for the pace of learning. Short videos and PowerPoint slides can be stopped at any time to clarify, discuss, and reinforce the presented information. Besides verbal interaction, training events can involve many modalities, such as music, movement, artwork, and laughter. We hope resource people will be inspired to create their own educational materials and share them with others.

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CHAPTER 10

Tips for Multicultural Inclusion

All parts of CAPE have been translated into Spanish. Ideally, abuse and violence prevention materials should be available in all languages, all around the world. The World Institute on Disability (WID) has decided to start with Spanish because it is the most widely spoken minority language in the United States. WID created Proyecto Vision, which is the first program of its kind to address the needs of Latinos with disabilities in the United States.1 Below, we offer suggestions for inclusion of disabled people from diverse backgrounds, their families, and disability services personnel, and consider issues like translation and service provision.

We primarily focus on people of Latin American descent, but most of these concepts are applicable to people with any language or cultural background. These 20 suggestions are also distributed in sidebars throughout the CAPE text to alert readers of these issues, which may still be unfamiliar to some and/or considered a low priority. If implemented gradually, these suggestions will help make cultural diversity, along with disability inclusion, seem meaningful and exciting, rather than a chore or an obligation.

Suggestions for Facilitating or Enhancing Cultural Awareness and Diversity Training

1. Becoming Aware of Multicultural Issues and Disability

Offer diversity training and awareness events for staff and membership about ethnic, cultural, and racial issues, addressing where they intersect with disability issues. Regularly ask staff, clients, and members which issues concerning diversity and cultural sharing they would like to learn more about.

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1 More information about Proyecto Vision can be found at: [http://www.proyectovision.net/](http://www.proyectovision.net/)
2. Encouraging All to Reflect on Cultural Backgrounds

Invite individuals from all cultural backgrounds to share information with others about their culture’s food, celebrations, music, and histories. The common lack of focus for people of European heritage on their own cultural heritage results in a “vanilla identity,” reinforcing the assumption that they are “the same,” whereas people of color or people from non-mainstream backgrounds are “different.” Encourage everyone to reflect on his or her heritage. This helps make cultural diversity a fact of life for everyone.

3. Respecting Holidays and Celebrations

Don’t assume everyone recognizes mainstream American holidays or celebrations. And don’t assume holidays are equivalent because they coincide approximately in the same season. For example, Hanukkah is sometimes called “the Jewish Christmas.” This is inaccurate. Hanukkah is the eight-day Jewish festival of light, which falls about the same time of year, and commemorates the purification of the Temple of Jerusalem in 165 B.C. Christmas is the annual feast that commemorates the birth of Jesus Christ on December 25.

4. Exploring the Range of Identities and Communities

People have cultural and personal identities in many realms besides race or ethnicity. For example, individuals who identify with the Deaf community typically use a capital D in the word Deaf when referring to the community, its culture, and the distinct perspectives of people who use American Sign Language (ASL) as their primary language. Other areas defining cultural and personal identities include sexual orientation, such as the Lesbian, Gay, Bisexual, or Transgender communities. For many, the connections among people with disabilities have emerged strongly enough for disabled people to identify as the “disability community.” Invite people, if they feel comfortable doing so, to share and educate each other about these various communities and identities.

Suggestions for Practicing Language and Cultural Translation

5. Using Examples to Clarify Unfamiliar Concepts

Use many examples as a way of clarifying concepts when confusing or complex tech-
nical terms are introduced. Even people who speak English well and native English speakers may not be familiar with the terms used within the disability community.

6. Paying Attention to Translating Terms

When translating educational materials, don’t make assumptions that terms will readily translate. An example is independent living in cultures where interdependence and reliance on family for personal care is more highly valued than in mainstream American society.

7. Translating Materials with the Target Audience in Mind

Make sure to explain terms in meaningful ways in translated materials, by involving disabled people and family members from specific language communities. For example, encourage Latinos with disabilities to define these concepts for themselves in ways that they find comfortable.

8. Budgeting for Language and Cultural Translation

Consider the language translation needs of your group for events and publications. Then be sure to include in your budget the costs for language translation of educational materials, workshops, and seminars, as well as for real-time captioning and/or sign language interpretation for people with hearing loss.

9. Utilizing a Wide Range of Media for Promoting Materials

Promote translated educational materials in the appropriate media of the community. Consider radio shows, community-access TV shows, magazines, websites, public service announcements, etc.

10. Incorporating Already Translated Material

Disability organizations at the local, state, and federal level have begun translating educational materials into many languages. A good model is the California Protection and Advocacy Inc. (PAI), which offers many of their educational materials in up to a dozen languages besides English.² Hold high expectations and standards for translations provided by agencies in your state.

Suggestions for Service Provision

11. Recruiting for Diversity

Actively recruit staff and volunteers who reflect clients’ or members’ diversity of racial, ethnic, cultural, and personal identities.

12. Including Culture in Disability Education

Individualize independent living and abuse-prevention planning for consumers to include cultural as well as health and disability accommodation needs.

²http://www.pai-ca.org/issues/services_pubs.html
Resources You Can Use

- Proyecto Vision, the World Institute on Disability’s program about employment resources for Latinos with disabilities. [http://www.proyectovision.net/](http://www.proyectovision.net/)


13. Taking Into Account Social Barriers

Remember, low-income disabled people can be limited in their access to transportation, technology, and information. Don’t assume equal access for everyone is always available.

14. Considering Educational Differences

Immigrants may have little formal education levels even in their native languages. Whenever possible, provide educational material in audiovisual media in addition to written information.

15. Learning about Cultural Barriers

Explore cultural barriers to access and accommodation for disabled people within the specific populations and communities you work with. This may require some research for services providers from outside the community. Ask your participants to educate you about their communities’ attitudes and practices.

16. Knowing about and Asserting Rights and Needs

Latinos with disabilities, along with people of many other cultural backgrounds residing in the United States, may be passive when
CHAPTER 10. TIPS FOR MULTICULTURAL INCLUSION

17. Being Aware of Cultural Preferences

Be aware that Latin American and Asian cultures, among many others, may be very polite. Services providers should not assume that a disabled person prefers informality, such as use of his or her first name. Allow the disabled person to establish the formality of the relationship.

18. Utilizing Services from Diverse Organizations

Create partnerships with diverse multicultural organizations and services providers and share information about disability, abuse prevention, and cultural resources.

19. Replicating Studies with Your Target Population

Replicate studies done on mainstream disability community issues with representative populations of people with disabilities from diverse cultural backgrounds.

20. Communicating with Patience and Respect

It may take a little extra time to establish a relationship of trust because of cultural and language differences. Patience, respect, and genuine friendliness communicate well in any language.

it comes to asserting their needs and rights. Rights may not have been respected in their countries of origin, and they may feel that as immigrants, they don’t deserve the rights of other residents of the United States. Of course, legal rights to services and entitlements, particularly for illegal immigrants, may vary.
Part III

Training Tools
Empowerment Training Sessions and Events

The suggestions in this chapter offer ideas and explanations for developing and structuring empowerment training sessions and events. Keep in mind that training needs of populations of disabled people or families will vary, so feel free to make adaptations. We also encourage studying CAPE’s Chapter 12 on Support Group Facilitation because training events and support groups can be similar with respect to group dynamics.

The following issues are addressed in this chapter:

1. Assessing Qualifications for Trainers
2. Establishing Group Ground Rules
3. Planning in Advance and Getting Feedback
4. Setting Up Clear and Attainable Goals for the Session or Event
5. Choosing Empowerment Activities
6. Knowing How Much Information Is Needed
7. Giving the Event a Positive Title
8. Creating an Effective Outreach Plan
9. Specifying the Meeting Logistics
10. Handling Training Group Dynamics
11. Devising a Welcome and Opening
12. Determining the Central Activity
13. Incorporating a Secondary Activity and Breaks
14. Using Socializing as the Main Focus
15. Indicating Any Plans for Follow-up Activities
16. Preparing and Collecting Evaluation Forms
17. Using a Focused Closing
Assessing Qualifications for Trainers

Anyone who is interested in helping disabled people with empowerment, self-protection, and safety skills can be a trainer. However, interested individuals must have good organizing and follow-through skills; be able to set clear and attainable goals; be good listeners, be welcoming and confident; and hold high expectations for others. They also should be respectful, genuine, reasonably relaxed when facing interpersonal conflict, and willing to ask for help when necessary. Trainers should be able to evaluate the group and be prepared to make referrals to community resources when appropriate.

Although it is helpful to have experience in facilitating training sessions on a range of issues, beginners can nevertheless be effective. However, one essential prerequisite for leading training events is experience as a participant. Observing and participating in the dynamics of a group will help potential trainers become comfortable and familiar with the range of possible situations that can occur during training sessions. Sometimes surprises, including conflict, arise, and witnessing other leaders handle these challenges helps immeasurably. If you are not experienced with facilitating training events, make sure to have a co-leader who is.

Establishing Group Ground Rules

Some group activities will include sharing very personal stories, thoughts, feelings, and opinions. To ensure confidentiality, mutual respect, and good listening skills, group facilitators need to have ground rules in place and know how to enforce them. See CAPE’s chapter 12 on Support Group Facilitation for establishing ground rules. If possible, ask for input on appropriate training-related ground rules from the individuals you will be training or from people who know your population.

Planning in Advance and Getting Feedback

Before facilitating an actual training event, take sufficient time to plan and rehearse your training-session activities with a partner or co-facilitator or think them through by
yourself, imagining your group’s potential responses. Make a written agenda for yourself with the specific components of the session’s plan.

**Setting Up Clear and Attainable Goals for the Session or Event**

Decide what goals you have in mind for your participants as well as for yourself as the trainer. What do you hope to achieve? What specific skills do you hope to impart? Formulating clear and attainable goals beforehand will enable you to assess the effectiveness of the training.

**Choosing Empowerment Activities**

Select empowerment tools from CAPE that best fit your group, based on your assessment of the participants’ needs. Feel free to change or adapt the tools or make up new ones and experiment. You know the individuals you are working with – trust your practical and intuitive knowledge and your thinking. Also, encourage your participants to give you feedback about which aspects of the empowerment tools they find useful and effective and in which sequence they need to be presented and practiced.

**Knowing How Much Information Is Needed**

The amount of information to be addressed in a single training session will vary greatly and depend on the particular makeup of the participating group members. Like any other group of people, different populations of disabled people have different needs and different learning styles. However, it is usually best to start slowly, aiming for a modest amount of new information, combined with some fun activities that emphasize building connections with others within the group. Experiment as you proceed to work with your group and learn what participants enjoy and can handle. Regularly ask for group members’ feedback to find out if the new information is adequate in quantity, quality, and usefulness, and if there is anything else participants would like to learn about.

**Giving the Event a Positive Title**

Give the training event a positive title by using active, appealing words, such as “Empowerment Training Session,” “Independence and Personal Assistance,” “Assertiveness Training,” “Safety Skills,” “Life Management Skills,” or “Getting Good Help.” Be creative – it is important to be positive to attract people. Don’t call your training session “abuse prevention” or “violence prevention,” unless your group has specifically asked for these words in the title. The word “abuse” is charged, as is the word “violence.” Both words evoke frightening images, and most people don’t like to go to events on scary or stigmatized topics. (Though many people like scary movies, they know watching them will be fun and entertaining.)

Thus, many disabled people who feel abused or mistreated and want help may still resist participating or signing up for an event that incorporates words such as “abuse prevention” into its title. They may
feel embarrassed or afraid to reveal how vulnerable they feel. Similarly, some people who have experienced abuse are reluctant to revisit their feelings about it. Others may shy away from participating because they dread the possibility of being labeled negatively. Men or teens, for example, might fear that others will see them attending an abuse-related event and subsequently label or regard them as weak or “uncool.”

Additionally, other individuals, such as some seniors or those new to using personal assistance, may not know that they need to learn about abuse prevention and therefore choose not to attend sessions that address the topic. Consequently, using a neutral or upbeat title will make it more likely that these individuals decide to attend the event. If appropriate, perhaps you can add “abuse prevention” at the end of the title, for example, “Empowerment Skills and Abuse Prevention,” if that will attract more of the people you want to reach. If you are not sure about which terms and words to use, do a little informal research. Ask a few of your potential group members what words or titles would best attract them.

Creating an Effective Outreach Plan

Devising an effective outreach plan to promote the planned training session or event is just as important as giving it a positive title. Outreach or recruitment for groups can be done with flyers, bulletin boards, email or postal mailings, newsletters, and ads in newsletters and websites. Also, you can promote empowerment training sessions with announcements and presentations at community centers and events and by word-of-mouth via already interested members.

Specifying the Meeting Logistics

Planning session logistics include selecting the meeting place, determining scheduling issues, arranging for appropriate accommodations, and providing the necessary materials. You will need to decide whether the training session will be a one-time event or an ongoing series of several events, such as a weekly class or monthly meetings. It is also important that you consider the length of each session, with a focus on participants’ attention spans and their needs for taking breaks. The facilitator or a volunteer may need to be responsible for reminder calls or emails, rides or transportation, and parking. A key logistical component is disability access. Consider the range of necessary disability accommodations for learning needs.
and personal assistance services for bathroom and other personal needs. Consider financial aspects, whether or not there will be refreshments, and who will set up, clean up, and lock up.

Handling Training Group Dynamics

As in support groups, interpersonal difficulties can sometimes arise in training sessions. See Chapter [12] Facilitating Support Groups, for discussions on Dominating Members, Handling Conflict between Members, and other topics that are relevant for training sessions. Plan or brainstorm with a partner for possible pitfalls with your target audience in mind.

Devising a Welcome and Opening

On the day of the first scheduled session, gather your attendees and welcome them with a warm introduction, such as, “Thanks for coming! I’m really glad you could make it.” Offer some brief introductory comments, referring to the logistics of the meeting and the goals of the event.

If appropriate for this population of disabled people, and the size and time allocated for the group, open the session by getting all present involved. It is usually good to start with something positive. For example, facilitate the opening by asking participants: “What’s something good in your life?” Or, “What’s something positive (or fun, or interesting, etc.) you’ve done or seen recently?” If participants don’t know each other, ask for their names. You might ask people to say something about what attracted them to this event. Keep these opening questions light and pleasant and try to avoid intense or personal topics. The facilitator might start in order to model answering the questions posed.

If you want your group members to share personal information, it is often useful to wait until they are more comfortable with each other. Opening the session with requests for personal introductions can be intimidating or make people feel “put on the spot.” Also, participants will be able to pay better attention to each other if they are more relaxed.

Determining the Central Activity

The central or primary activity addresses your learning objectives for each session. This activity may involve presenting new information through stories or multimedia tools, such as a video or PowerPoint presentation, or other activities you devise. If you are inexperienced with facilitating training events, you might want to rehearse your central learning activity with a partner or, if you have one, a co-facilitator in advance, so you can anticipate possible responses of your group and brainstorm about potential confusions, distractions, or other challenges.

Incorporating a Secondary Learning Activity and Breaks

An optional secondary learning activity can help participants integrate the objectives of the primary learning activity. It might be
something you can alternate or switch to for variety of focus. A secondary empowerment activity could be socializing; playing a game; exercising or moving around; using guided meditation; engaging participants in creative activities, such as crafts, singing or joking; laughing; serving refreshments; or allocating more time for personal or general sharing. The secondary learning activity can be helpful to reinforce the session’s objective. It can connect group members to each other, allowing them to apply the new information they are learning in the context of relationships with others. The secondary learning activity can be fun and entertaining as well and thus help break the stereotype that learning is a stiff and boring activity.

CAPE’s Chapter 12 on Facilitating Support Groups has two sections on page 154, one titled Creativity, the other, Humor, which offer ideas for secondary activities. Adequate breaks are not optional! With or without refreshments, they also offer opportunities for participants to interact with each other. When scheduling breaks, make sure to not only include adequate time for bathroom breaks and rest, but also informal time for participants to get to know each other.

Using Socializing as the Main Focus
Consider having a party for empowerment purposes. For some disabled group members, the central empowerment activity will be socializing and conversational communication. Both will be useful for individuals who are relatively isolated or inexperienced with social events, have difficulties meeting others, or who just need additional time to get to know their fellow group members before feeling comfortable engaging in other activities. For some groups, this kind of socializing will be enhanced by involving a few more experienced people, volunteers from the peer group, for instance, who can circulate and help connect participants with each other in conversation.

Indicating Plans for Follow-up Activities
Before the end of the training session or event, make time to mention or discuss plans for any follow-up activities. Let participants know whether or not there will be another meeting, homework of any kind, or an evaluation.
Preparing and Collecting Evaluation Forms

Evaluation by group members not only helps you improve the training activities but it also empowers the trainees. Suggest and create opportunities for participants to offer constructive criticism or suggestions and allow adequate time for them to be considered and explored.

If trainers want or need specific feedback, distribute a brief and easy to complete evaluation form, and give participants enough time to fill it out with any assistance they might need. Evaluation forms are often distributed haphazardly at the end of an event, left in handout packets on tables near the exit doors for participants to grab, for example. Some participants may need to leave early and/or forget to fill them out before they leave. To avoid either scenario, you could mention the evaluation forms several times during the training event, so participants become and remain aware of them.

Your first mention of the evaluation forms, as well as when you plan to distribute and explain them, could be at the beginning of the session, right after you have made the introductory comments and addressed the logistics and the goals of the event. Your second mention of the forms will likely happen towards the end of the session, when you will actually hand them out and address any questions or concerns participants might have about completing them. Giving out a token prize, such as a plastic whistle or pen, for completing and returning the form is surprisingly effective. You can also distribute a certificate of training or participation in exchange for the evaluation form. Whether or not you decide to use incentives, you need to make sure to collect the completed evaluation forms.

Using a Focused Closing

Training sessions benefit from a positive focused closing, such as having each group member briefly share a comment, a positive reflection, for example, on the event. A focused closing helps participants reflect on the experience and gives them the opportunity to hear how others think or feel about the training session. A structured closing can also work as a brief review of the session, because participants will usually share different points.

Here are some suggestions for closing questions:

- Share one aspect of the session you found useful.
Multicultural Tip #2: Encouraging All to Reflect on Cultural Backgrounds

Invite individuals from all cultural backgrounds to share information with others about their culture’s food, celebrations, music, and histories. The common lack of focus for people of European heritage on their own cultural heritage results in a “vanilla identity,” reinforcing the assumption that they are “the same,” whereas people of color or people from non-mainstream backgrounds are “different.” Encourage everyone to reflect on his or her heritage. This helps make cultural diversity a fact of life for everyone. For more tips, see Chapter 10.

- Describe one way you plan to apply something you’ve learned today.
- What is the next step in your learning about empowerment training?

Avoid closing questions that invite evaluative or critical comments at the very end of a session, when there is no time left for facilitators to respond. Negative feedback given under these circumstances can easily degenerate into complaints or unfounded criticisms, and with insufficient time to address them, they can cause the whole session to end on a sour note. Of course, participants may have constructive criticism. If that is the case, they do deserve more than cursory time to articulate their comments and suggestions. However, if a participant launches into a lengthy critical comment, interrupt him or her with, “Thanks, we’d love to hear your ideas, but we are closing now. I (or the co-facilitator) would be happy to meet with you for a few minutes after we close to discuss your ideas.”

Thank participants for having come, for their involvement in these important issues, and, if appropriate, for the group relationships they have developed. You may also express your hope of seeing them again in the future. Also, take the time to express your gratitude to all. For example, as your concluding remarks to all present, you could say, “Thanks to all participants for your commitment to this important work. You are making an enormous difference!”
CHAPTER 12

Facilitating Support Groups

Contents

The Power of Support Groups

Planning in Advance

• Goals of the Group

• Group Members Contact outside the Group

• Qualifications for Support-Group Leaders

• Prerequisites for Leading Support Groups

• Shared Leading

• Regular Planning

• Finite or Open Duration, Closed or Open Membership

• Logistics

• Outreach
CHAPTER 12. FACILITATING SUPPORT GROUPS

Leading Skills and Activities

- Ground Rules
  - Confidentiality
  - Positive Regard
  - Good Listening

- Styles or Modes of Leading
  - Conversational Discussion Style
  - Taking Turns
  - Following a Script or Prescribed Agenda
  - Listening Pairs or Threes

- Openings and Closings

- Shared Responsibility

- Group Members Leaving

- Keeping an Eye on the Time

- Creativity

- Humor and Fun

- Bringing Objects and Photos

Including Participants with Communication Impairments

- Defining the Population

- Focusing on Inclusiveness

- Resources
CHAPTER 12. FACILITATING SUPPORT GROUPS

Group Challenges

- Deeper Sharing
- Disclosure of Painful or Unexpected Information
- Dominating Members
- Conflict between Members
- Why Conflict Arises
- Tips on Handling Conflict
- Dealing with Troublemakers
- Apology is Powerful
- Brief Listening to Upset Members
- If the Meeting Must End Early
- If the Leader Gets Hooked
- Check-in After an Upset
- Asking Someone to Leave
- Difficulties Can Be Useful

Evaluation

Rewards of Leading Support Groups
The Power of Support Groups

Support groups are among the best and most popular approaches to empowering and connecting people. Leading a support group can be a rewarding and growth-enhancing activity. However, it can also be very challenging. This chapter discusses ideas and approaches to facilitating an effective support group.

Planning in Advance

Goals of the Group

Start your planning session by thinking about the goals of the group. Goals may change with input from members. However, facilitators should decide in advance what they want the group’s objectives to be so they can better orient members. Goals of a support group can include the following:

- Sharing stories, thoughts, ideas, and emotions
- Listening and learning about commonalities and differences
- Breaking debilitating isolation and realizing that no one is alone with particular feelings and experiences
- Deepening understanding of personal or social issues
- Grappling with difficult life experiences
- Exploring new ways of learning or acquiring new skills

Group Members Having Contact outside the Group

Depending on the goals of the group, some facilitators encourage practicing support skills or socializing outside of the scheduled meetings, while others may explicitly discourage this. Thus, whether or not group members can share contact details or consider going out after or between regular group meetings for social or specific types of interaction should be clarified early by discussion and/or clear guidelines.

Qualifications for Support-Group Leaders

Support-group leaders must have good organizing and follow-through skills, be able to set relevant goals, be good listeners, be welcoming, confident, and empathetic, and hold high expectations for others. They should be respectful, warm, genuine, relatively calm when facing interpersonal conflict, and willing to ask for help when necessary. Support-group leaders should be prepared to make referrals to community resources, if appropriate, and be able and willing to evaluate the group.

Prerequisites for Leading Support Groups

An essential prerequisite for successful support-group leadership is experience as a group member. Leaders need to become familiar and relaxed with the dynamics of group interaction. Challenges can arise,
CHAPTER 12. FACILITATING SUPPORT GROUPS

including conflict between group participants, and observing veteran leaders address these challenges is helpful to the leaders-in-training.

Experience with meetings or trainings taking place in work settings, for example, is different from experience with support-group dynamics, which encourage emotional sharing. Potential leaders can find opportunities for group experiences in faith-based, personal-growth, and recreational activities, 12-step programs, adult-education classes, and other venues. Individuals who are not experienced with group interaction need to make sure they have a co-leader who is.

Shared Leading

Having two co-leaders facilitate a support-group meeting helps the group because two individuals are observing and responding to the group’s dynamics. Co-facilitating provides the group’s leaders with the benefit of jointly planning the meeting’s logistics and gives them the opportunity of constructive debriefing after meetings. Sharing leadership of support-group meetings also means there is a backup if one leader is absent.

If the co-leaders have comparable experiences and similar skills, the group leadership can be shared. If one individual has more experience as a leader, the other person can function as an assistant or apprentice leader and hone his or her leadership skills. To avoid unnecessary competition or confusion between co-leaders, they must decide in advance who will function as the main leader for the group series or for a specific group meeting. The designated main leader then has to exercise his or her best judgment in consultation with the co-leader.

Some groups rotate leadership duties and responsibilities. This approach has definite advantages. For one, it allows everyone the opportunity to think broadly about the group’s goals, plan meeting logistics, facilitate meetings, and be exposed to a variety of leading styles. Changing the group’s leadership after several months can also revitalize the group. Although rotating leadership may be enlivening and educational, it can have disadvantages as well. Possible drawbacks include leadership styles or goals that confuse the group and compromise long-range outcomes and group safety.

Solo leadership can be difficult, especially if conflict arises (see the section on Group Challenges on page 157). Sole responsibility for leading a support group can be a lonely job and result in early burnout, but can work if no qualified person is available to co-lead. Solo leaders, though, need to make sure to get help with the
logistics of the meetings and ensure they have someone to talk to occasionally about how the group is going, especially if leading the group gets difficult.

**Regular Planning**

Support-group leaders should initially discuss their expectations of the group, finances, logistics, and how they will share the authority and responsibility of the leadership role. Leaders may need to keep some records, such as contact information, attendance, participant roster, finances, issues raised, difficulties and solutions, ideas for future meetings, participants’ ideas, input, and evaluation. Leaders should plan whether group sessions will include only predictable activities or can have spontaneous and/or creative activities.

Leaders also need to think about topics in advance and plan approaches to the meetings. They can pose topics for discussion, and eventually, group members might even become a good source of inspiration for topics to discuss and share. Group leaders have to allow for time spent in meetings brainstorming topics for future discussion. Depending on the kind of group, facilitators may want to invite speakers, watch movies, or share reading materials as stimuli for sharing and learning. Arriving at meetings without clear ideas about the topic or focus should be avoided. In many groups, “What shall we talk about tonight?” doesn’t inspire confidence, and may make participants feel uneasy. It may be effective, however, to change the group-session focus spontaneously, depending on what participants are excited or concerned about. Leaders need to communicate regularly in person or by phone or email to plan meetings that reflect what is currently happening in the group.

**Finite or Open Duration, Closed or Open Membership**

Facilitators should determine in advance if the group meetings will be open-ended or have an ending to be determined. Also, leaders must decide whether group members can drop in or are requested to make a commitment to attend every meeting.

**Logistics**

Leaders must plan in advance for the group’s logistics. These include finding a space to meet; deciding how often and when to meet; coordinating with organizational calendars as necessary; organizing reminder calls or emails; arranging rides or transportation and parking; considering disability access and accommodations; planning finances, including whether to charge participants a fee and who will collect it, whether leaders will be paid, and whether to provide refreshments; and deciding who will set up, clean up, and lock up. Eventually, after the group is underway, participants will likely help with logistics.

**Outreach**

Outreach or recruitment for the group can be done through flyers, bulletin boards, email
Shortly after my accident, a fellow quadriplegic from the Quadriplegic Association of South Africa visited me in the hospital and encouraged me to join his group. It was his example that helped me endure what, at the time, I believed was unendurable. I hope that all disabled people and their loved ones have a chance to join organizations or support groups so that they can seek help and advice in times of need. (Ivan Montiere in “Gratitude”)

or postal mailings, newsletters, ads in newspapers, announcements and presentations at community centers and events, and word-of-mouth via already interested members.

Leading Skills and Activities

Ground Rules

Ground rules are part of the structure of successful meetings. They need to be in place prior to the first meeting. Leaders may open the first meeting by stating the ground rules and making sure that every participant understands and agrees to them. Leaders may even decide to restate the rules at the beginning of every meeting to refresh participants’ memories. Restating them is certainly a must if the meetings are open-ended and have an open enrollment.

Depending on each support group’s logistics and goals, ground rules will vary from group to group. However, the following areas are applicable to the majority of group meetings:

- Confidentiality
  A request for confidentiality allows group members to feel more comfortable sharing or discussing sensitive issues. Confidentiality is highly important for most support groups. Inform and ask that group members agree that information shared at the meetings is not to be repeated outside the group. It is not possible to guarantee that all members will respect this and regular reminders will be helpful, especially if the group is open to new members.

- Positive Regard
  Positive regard is the assumption that everyone is doing the best he or she can. Leaders can remind the group’s participants that everyone’s viewpoint is formed by his or her own personal history and values, and that these should be respected.

- Good Listening
  Group members may feel the urge to offer each other suggestions and advice. Facilitators can counteract this urge by encouraging participants to listen to each other without giving advice or interpreting what they hear. Equally helpful is teaching them to assume that everyone knows best what he or she needs, and deserves the space and support to figure it out on his or her own. Sympathetic comments, such as “I know how you feel,” may be appropriate
or not, depending on the goals of the group. Group leaders need to remind members that overenthusiastic sympathy may be felt to be patronizing or distracting, and that good listening is the best way to promote open sharing and an empowering group experience.

**Styles and Modes of Leading**

Conducting or structuring the interactions between group members can be done in various ways and these often can be combined. Yet each style has its advantages and disadvantages. Leaders can develop a repertoire of styles to use with different kinds of groups or participants.

- **Conversational Discussion Style**
  Most people are already familiar with conversational discussions in small groups, such as at parties or in classrooms. This style of interaction encourages people to speak up when they feel comfortable contributing. The disadvantage is that those with more confidence may dominate the discussion, and those with less confidence, for reasons such as language facility, race, class dynamics, age, disability, gender, etc., may end up being silent. Often, silent members want to participate, but feel hesitant. The facilitator can direct non-confrontational questions at individuals, calling on people by name to draw quieter members into the discussion. Passing around a “talking stick” (or any object) makes it more obvious in the group who is doing most of the talking and helps encourage more equal sharing.

- **Taking Turns**
  Establishing a practice of taking turns, such as going around the circle or making sure each member gets a random turn, ensures that everyone has a chance to actively participate. Turns can be timed precisely with a clock or timer, or be estimated. With the latter, leaders are responsible for paying attention so that informal, untimed turns are approximately equal. For many, taking turns is a welcome contrast to ordinary conversation because it easily enables fairer distribution of sharing. The disadvantage of having participants take turns is that members may, at first, feel restricted or stilted in responding or connecting with each other. Similarly, the restriction on crosstalk during turns may make some people feel overly controlled. Turns can be alternated with open discussion to allow the advantages of both.

- **Following a Script or Prescribed Agenda**
  Some group programs offer preset agendas with scripts or designs that prescribe a step-by-step plan for learning or sharing activities, with varying degrees of optional or individualized activities. These can help less-experienced leaders successfully facilitate groups. The downside is the lack of spontaneity
or creativity in responding to group members’ needs or preferences.

- **Listening Pairs**
  Including short timed “listening pairs,” or dyads, within a group of six or more participants can greatly enhance the effectiveness of a support group. Having group members meet in listening pairs for a few minutes, within a one- or two-hour meeting, has many advantages:

  - It encourages members to connect with each other individually, creating stronger relationships between participants, which in turn greatly enhance the group’s closeness and rapport.
  - It allows focused listening, which encourages people to share more deeply than they might feel comfortable doing in the larger group.
  - It takes good advantage of meeting time, enabling more individual focus than is typically possible in the larger group.
  - It offers a variation in the activities of the group.
  - It teaches and reinforces good listening skills in one-to-one interaction.
  - It gives the leaders time to observe and rethink the group dynamic.

Sometimes group leaders or members object to breaking off in pairs because they assume that everyone in the group would want to hear everything that’s being said. But the advantages of occasionally using listening pairs are well worth the trade-off of sometimes missing other participants’ comments.

Some participants may find dyads logistically difficult, due to mobility issues, limited space, or distraction from the noise of several pairs talking at once. Planning for specific needs in advance can help accommodate people who may otherwise not get to enjoy this opportunity.

Listening pairs may easily regress to conversation and mutual interruptions. Inviting members to stick to the role of “listener” and “speaker” helps remind them of the rare and helpful resource of receiving the full attention of a respectful listener.

### Openings and Closings

Opening group meetings with a go-around has several functions. Since support groups often focus on painful issues, sharing positive experiences in the beginning can contribute
more of a balanced view. For example, leaders could ask group members to share something that went well for them that week. Beginning the meeting with a go-around gives each person a voice and visibility in the group and helps “break the ice” for less confident people; each person will have spoken and thus speaking up spontaneously later in the discussion might be easier. Go-arounds give an opportunity to share personal information that might not emerge in discussion, so members can get to know each other better.

However, some people feel “put on the spot” in a go-around. People with differing language backgrounds, shy personalities, speech impairments, such as stuttering, or people with autism or other kinds of hidden disabilities may feel uncomfortable with the whole group focusing on them during the opening. Leaders should allow anyone to pass on their turn. Reassure everyone that it is alright to just listen. Leaders can approach people individually before or after the group meeting and ask if there is a way to make participation more comfortable.

Group meetings also benefit from a focused closing, such as a brief go-around where each member shares a comment, such as a positive reflection on the meeting. Group facilitators should avoid asking for evaluative comments or feedback at the end of the meeting because responses can degenerate into complaints or criticisms, without time to address them, because the meeting is over. (Feedback is important, just not at the very end of the meeting. Leaders can suggest that people offer constructive suggestions at a time when they can be considered.) Here are some suggestions for a focused closing:

- Share one thing that was moving or useful from this evening’s meeting.
- Say one thing you appreciate about someone else in the group.
- What’s something you’re looking forward to this week?

Shared Responsibility

Group leaders need to allow a few minutes at the beginning of the meeting for brief announcements and questions, such as where drinking water or the bathrooms are located, inquiries about refreshments, finances, logistics, reminder calls, or emails, rides, and plans for clean-up, etc. Encouraging members to share in the logistics of the meetings often enhances participants’ commitment and gives them a sense of belonging. It also lets them share some of the responsibilities and work of organizing the meetings.

Group Members Leaving

Leaders should decide in advance on how to handle people leaving the group mid-series or mid-meeting (and whether to ask them to say goodbye); how to solicit feedback from all participants, using a questionnaire or evaluation session, for example; how to determine criteria to evaluate the effectiveness of the group; and whether to have some kind of certificate or final party or event at the end, if a finite series of meetings is planned.
CHAPTER 12. FACILITATING SUPPORT GROUPS

Keeping an Eye on the Time

Leaders must keep an eye on the clock, so they will have enough time to address important group business and end the meeting with a focused closing. Leaders who find themselves often running out of time can ask a participant to help remind them unobtrusively about the time. For example, facilitators could arrange for a participant to signal how many minutes remain before the end of the meeting.

Creativity

Groups benefit from a variety of activities to keep participants’ interest. Dependence on the same kind of verbal sharing can eventually become tiresome. Use of readings, games, poetry, music, singing, arts and crafts, videos, or occasional group excursions can keep people committed and engaged, and invite creative contributions from members. Group leaders can ask participants to help generate ideas for creativity, to bring songs or arts-and-crafts materials, etc.

Humor and Fun

People need to laugh! Opportunities to laugh about difficulties and serious topics are precious and necessary. Facilitators need to think about ways to lighten up the group discussion with jokes, silliness, skits, play, or games. It is usually worth the risk of making adults feel a bit embarrassed or childish in order to have them try creative approaches to fun. Leaders can also invite participants to take turns generating ideas and opportunities for humor and fun.

Bringing Objects or Photos

Group leaders can invite members to occasionally bring personal items for a show-and-tell session. Members can bring a few family photos or treasured objects to share with the group. Making show-and-tell activities part of the group meeting helps personalize as well as make more vivid the sharing of life stories.

Including Participants with Communication Impairments

All human beings need contact with others to learn, grow, and flourish, and to become more confident about relationships. Group leaders should never assume that individuals who cannot talk or who do not communicate in the usual ways do not want to interact with others or participate in groups. People with communication impairments may in fact long for contact with others, because they are often isolated or limited from ordinary conversational communication with friends, family, and the general public. Like everyone else, they can benefit from group interaction and socializing.

Defining the Population

People with communication impairments include those who have hearing or speech or cognitive impairments, developmental disabilities, are deaf-blind, or stutter. This
population is particularly vulnerable to abusive interactions with caregivers. Abusive individuals may take advantage of someone who is less likely to disclose abuse, and this unequal power dynamic is exacerbated with people with communication impairments, making them more likely targets. Thus, they must be included in abuse-prevention learning activities.

**Focusing on Inclusiveness**

The typical focus of support groups is on talking and listening. Of course, people with
communication impairments face barriers to free-flowing verbal interaction. However, support groups can include many different kinds of interaction in addition to verbally sharing information. Interactions can include listening to and making music and rhythm, watching movies, doing artwork, engaging in movement, dance, and physical play. Opportunities for laughter are especially important.

Yet not every person with a communication impairment will or can benefit from a support group. For example, some people with autism (though not all) may not enjoy group interactions. Still, the majority of people with communication impairments are unnecessarily excluded from group activities. With some advance planning and allowing for necessary accommodations, support group leaders can include people with many kinds of communication impairments. A host of websites and printed materials pertaining to specific impairments and offering accommodation information are available. For example, topics addressed are sign language interpretation, assisted listening devices, computerized communication boards, facilitated communication, and other technologies.

Although it is crucial to include people with communication impairments in group interactions and socializing, it is equally important not to assume that they (or individuals with any kind of impairment) should only be grouped with their own kind. Disabled children and adolescents are often grouped with like peers in school, resulting in limited interaction with their non-disabled peers. Adults who stutter or have difficulties formulating their thoughts, for instance, may participate in therapeutic groups for purposes of practicing communication. While consistent group interactions may help these people improve their speech patterns, it is not the same as socializing, sharing, or learning broader social skills. Furthermore, grouping people with certain impairments may actually make interaction more challenging since accommodations are needed for both expressive and receptive communication.

Keeping disabled people together also reinforces damaging stereotypes, which become internalized by those targeted. People with communication impairments can be objectified as “them,” and not viewed as fully human. Even services providers may sometimes forget that their clients are people first, with the full range of interests, needs, and characteristics that brings any group of people together. Individuals who happen to have communication impairments also have many interests and preferences, and they, just like individuals without impairments, want to meet people who share these interests. To help boost self-esteem and empower disabled people to live good, strong lives, it is important for people with disabilities, their teachers, and parents to find opportunities for interesting and fun interaction with the broadest range of people possible.
CHAPTER 12. FACILITATING SUPPORT GROUPS

Resources

- Speechville. [http://www.speechville.com/communication-impairments.html]
- Strategies for Teaching Students with Communication Disorders. [http://www.as.wvu.edu/~scidis/comm.html]

Group Challenges

Deeper Sharing

Sometimes group members reveal a deeper level of sharing than expected. This can be considered a compliment to the group and to its leaders for creating a safe atmosphere for participants to open up and reveal personal struggles in order to move beyond them. While this level of sharing can contribute to a deepening of the group dynamic, it also can lead to some challenges for the leaders.

Disclosure of Painful or Unexpected Information

Group members sometimes surprise other participants (and often themselves) by revealing painful stories or disclosing sometimes shocking personal information. For example, members might share suicidal or homicidal thoughts or talk about recent divorces, deaths, prison terms, abortions, or suicides of loved ones. Other loaded issues that could arise include infidelity, psychiatric or disability history; gay, lesbian, or transgender identity; past or current alcoholism or illegal drug use; stories of abuse or criminal history; or terminal medical diagnoses given to group members or their loved ones. This level of sharing may or may not be welcomed by participants and, depending on the focus or goals of the group or prevailing community values, such disclosures can create confusion, embarrassment, or dismay. Others in the group may not know how to respond, causing an awkward silence or shock to ensue. Sometimes members will
make (directly or indirectly) a request for help that isn’t expected or may exceed the group’s abilities to respond adequately.

Here are some suggestions for how group leaders can respond to unexpected disclosures:

- Thank you for taking the risk of sharing your story/such personal information with us/the group.

- Thank you for sharing that with us. I know some of us, including myself, may feel a little uncomfortable (or upset, distressed, sad, etc.) hearing that and do not know how to respond, but we really appreciate your honesty and the trust you have in us by sharing this information.

- Thank you for being open with your information/story. I know others in the group would like to be of support to you. (Depending on the goals of the group, ask if he or she would be willing to speak individually after the meeting.)

If the response is yes, leaders might ask:

▷ (Name of individual) has shared some very personal/difficult information (or asked for help). Would anyone in the group like to connect with him or her about this after the meeting?

If no one responds, facilitators could add:

▷ That’s okay, how about you and I talk about some options after the meeting is over.

**Dominating Members**

Sometimes a group member dominates the discussion, but appears unaware of taking more than his or her fair share. One approach to address this imbalance is by saying, “Let’s give the quieter members a chance to talk.” If that doesn’t work, group leaders might want to take the person aside after a meeting. They can mention that they noticed he or she has a lot of interesting things to say, but are concerned that others in the group are silent or not opening up as much. They can ask the individual to engage other group members by suggesting he or she ask more questions of others.

If a group member is really dominating and appears unable or unwilling to control his or her enthusiasm, leaders may need to set some limits. They can suggest a finite number of times the individual in question may comment in the group, 4 times per meeting, for example, or that she or he speak only for a specific length of time per meeting, say 5 minutes. Usually people who tend to dominate the discussion feel embarrassed about this tendency and are actually grateful if it is brought to their attention. Most people really want all participants to share equally.
CHAPTER 12. FACILITATING SUPPORT GROUPS

Conflict between Members

Sometimes group sharing and discussion can reveal disagreement in opinions and cause conflict between group members, or can even bring up differences in deeply held values. Sometimes comments from one person can trigger old resentments or upsets that a second person ascribes to insensitivity, but are actually just a reminder of something painful from long ago. At times, even a casual comment can be misinterpreted as oppressive, sexist, racist, or in some way discriminatory.

Group members may also make thoughtless comments, oppressive jokes, or reveal unawareness and be unable to apologize sufficiently to defuse an upset. These upsets can snowball in the group, as other members are made uncomfortable by the tension and may react emotionally themselves. Upsets can occur even if the focus of the group is intended to be benign sharing.

Experienced group leaders can anticipate conflicts between group members and stay relaxed and encouraging. The most productive attitude for leaders to take is that conflict is not necessarily detrimental to the group’s process. Moreover, if handled with relaxed and reassuring guidance, working through conflicts can help group members connect more deeply with each other and promote growth, increased trust, and a greater willingness to share.

Why Conflict Arises

A certain degree of conflict in an ongoing group is inevitable. For some people, a support group seems to be a natural trigger for upset feelings and subsequent conflict. All of us find ourselves at times annoyed or ticked off by others, often people we have a close relationship with, but sometimes by strangers, co-workers, or casual friends. This process of “getting our buttons pushed” can be explained in the following, simplified way: We have all been hurt earlier in our lives. Important needs did not get met in our families of origin. Insults and injuries have occurred throughout our lives, and while some were aimed specifically at us as individuals, others were more systemic mistreatment, such as sexism, racism, or disability discrimination.

This backlog of previous hurts is not typically present in our consciousness, but it is waiting to surface. We all have an unconscious desire to recall these old injuries, reveal them to others, and get help with recovering to the point of reframing them from an adult perspective. But until we get a chance to elicit those old hurts and reflect on them repeatedly, they will continue to
arise as raw emotional pain. We are usually not aware that the current situation is just triggering old pain, because it flashes back as if it were fresh. And since typically we first experienced the pain as a victim targeted with mistreatment, we often tend to repeat that stance, blaming someone else for causing us pain.

In a support-group setting, the casual comment or interaction triggering our old pain to resurface is generally benign. Even if the content is less than thoughtful, it likely will not warrant a strong reaction from us in the present. However, since the present occurrence reminds us of some distant, unconscious distress, we do react. Indeed, for most people and most upsetting incidents, the old pain lurking in the unconscious greatly distorts many of our interactions in the present, even if the current interaction was in some way “off” (meaning unsatisfactory or inappropriate), for example. The old pain makes it much more difficult to sort out what is really going on in the present. Yet bringing it to the surface can be a growth-promoting experience if it is handled well.

A support-group setting can become a productive arena for this process of defusing old pain. It invites people to share and reflect on their experiences, positive as well as negative, and to express their feelings in an environment that is meant to be caring and thoughtful. Yet two challenging developments may take place:

1. People may unconsciously decide to feel emotionally safe and eager to show their old pain to this unusual gathering of people who offer to listen and care.

2. The interactions in a group will not always go smoothly, because people are people. We all have our ragged edges, history of hurts, and areas of unawareness, and we are not always sensitive to everyone’s needs. Thus, old disappointments arise from early family life, where our own loved ones sometimes failed to offer unconditional caring and respectful listening.

These two factors can create a “double whammy” of an unexpected safety to feel and express typically hidden emotions, potentially pleasing as well as alarming to participants, and a setup to feel disappointed that the “perfect (unconditional) caring” we’ve always hoped for isn’t here either.

With some groups, these factors can be discussed and explored in advance, so that members are better prepared when their buttons get pushed. If the focus of the group is charged or controversial, upsets are even more likely to happen. Participants will inadvertently remind each other of painful experiences they may have forgotten or repressed, and the level of upset is likely to be high when sharing a fair amount of painful experiences.

In most community support-group settings, particularly those run by inexperienced leaders, this potentially turbulent process may seem mysterious and overwhelming. The new relationships being formed in the group may not yet be strong
I'm not much for religion, but because of a neighbor, Walter, I started going to a church down the road. Walter would come over on Sundays and pick me up to go to the church. There were a few other oldtimers there like myself. They would ask sometimes, “How’s it going living with your family?” I didn’t want to say anything. Then a lady named Louise came over and said she could tell it wasn’t going that well, because there are signs. Luke said, “What are the signs?” I don’t know. She said they could help me find a better living situation. She also told me about the Senior Center, and that they could send a van over to pick me up. So I started going there once or twice a week. They have programs, entertainment, and BINGO...I usually eat in the dining room with the other oldtimers. We watch movies or play cards, using the jumbo cards for the ones who can’t see anymore and the cardholders and shuffle machine for the ones like me who can’t handle the cards. We get a few laughs. So, I can’t complain. (David Dugigian in “Luke’s Granddad”)

CHAPTER 12. FACILITATING SUPPORT GROUPS

Tips on Handling Conflict

Here are some techniques leaders can use to help ease conflict:

- Rather than ignoring the conflict, it is better for the group leaders to openly acknowledge that the conflict exists and is difficult for them, too. They can say something like, “This tension is difficult for us, too. Please bear with us while we try to handle this appropriately.”

- Remind other group members to offer relaxed, generous attention and request that they try not to get pulled into the conflict.

- Don’t take sides. Suggest to members that a conflict is potentially an arena for insight and growth, not a debate about who is right or wrong. Feelings are not right or wrong, feelings are feelings.

- Adhere to positive regard for all involved. Remind all group members that people are doing the best they can.

- Ask the members in conflict to hold off the debate until after the meeting, or alternatively, to consider just letting it go. If someone refuses to comply or insists on demonstrating control through shouting or demands, the meeting must end, as discussed on page 163.

- Do not attempt to resolve the upset while group members are still agitated, because it often leads to further conflict. People do not think clearly when they

enough to handle such intense emotions and conflicts, which sometimes can seriously disrupt the group. Leaders can prepare in advance by role-playing possible scenarios and incorporating the suggested responses in the following section.
are angry and they may end up making further provocative comments.

- Never attempt to remove one member engaged in the conflict and continue the meeting with the rest of the participants. This is too upsetting for everyone and has a potential for serious repercussions. If upset members seem likely to regain their composure, then leaders may proceed with the meeting.

- Do not accept other members’ attempts to negotiate, but let them know that the main task is to help their fellow participants calm down, so they can think and act more rationally. Those not involved in the immediate conflict can help the participants in disagreement by modeling a calm and thoughtful temperament.

- Suggest the group as a whole take a 5-minute cool-off break to help defuse the tension. The cool-off break will give group leaders a moment to think or strategize about what to do after the break. Leaders can ask the other group members to keep the following in mind during the break so that they can help keep the group together:

  - To focus their attention on something neutral, move around a bit, or get a drink of water or some fresh air.
  - Not to roll their eyes or make comments in support or disparagement of either or both the sparring members. Remind participants that upsets happen, and that they need to hold positive regard for everyone.

When the group reconvenes, leaders can suggest an exercise, a guided meditation or deep breathing exercise, a reading, poem, or song—something that changes the tone. They might say something like, “We know this may seem a bit contrived, but given the upset, we find it helpful to refocus on something lighter to remind us of our goals here.” Leaders need to prepare in advance activities that will help diffuse conflict and redirect the group’s attention.

Dealing with Troublemakers

If group members seem prone to getting into conflicts, leaders can use subtle ways to facilitate a relatively positive attitude change. If possible, they can sit near the individuals, make frequent eye contact, offer an occasional positive comment, or suggest a logistical task that gives them a visible role. Leaders should not avoid contact with someone who seems disruptive. This will backfire. Sometimes individuals who seem to be looking for trouble will respond well
to additional appreciation, validation, and inclusion. They might even be able to relax a bit, decide they belong, and rise above their usual difficulties with relationships because they feel cared about. Leaders need to value members who may be typically regarded as marginalized people. They are precious. Their presence reassures everyone that all are welcome and important. They are specifically the individuals group facilitators wish to benefit from the group’s support and resources. Leaders need to avoid holding an “us and them” attitude towards anyone in the group. We are all “us.”

**Apology is Powerful**

One of the greatest resources to help people when they are upset is apology. People who feel hurt want acknowledgment of that hurt. Just saying, “I’m sorry that what happened just now was painful,” can sometimes defuse the difficulty. Sometimes people resist apologizing because they didn’t do anything wrong. Using an apology does not necessarily mean an admission of guilt; it is an acknowledgment of the other’s hurt. Group leaders can model relaxed and forthright apology in the group.

**Brief Listening to Upset Members**

If one or two participants engaged in the conflict are extremely agitated, group leaders can try to arrange to listen to one or the other for a finite time, five or ten minutes, for example. They need to make sure to time the responses and stop the persons at the end of the allotted time. Leaders should not ask or expect people in disagreement to listen to each other, especially not right away. That rarely works. If there is only one leader, he or she can suggest the parties involved each take a 5-minute turn. If a relaxed, skilled listener is among the other members, the leader might enlist him or her in the listening role, not as a negotiator or problem solver, but as a neutral listener who will help defuse the upset.

Group leaders need to be careful not to get pulled into listening, either individually or as a group, to one person’s upset for a lengthy time period. Some people may try to maneuver others into listening to a long diatribe. This is rarely productive.

**If the Meeting Must End Early**

If an upset member insists on refocusing on the upset or is demanding a resolution, leaders should not comply. They can stop the meeting and inform the upset member that they will speak to him or her at another time when tempers have cooled off. If necessary,
CHAPTER 12. FACILITATING SUPPORT GROUPS

Group leaders can suggest intervention from a more experienced facilitator. Leaders do not need to listen to someone rail at them. Instead, they need to walk away, saying, “We’re really sorry, but this feels unproductive and hurtful to us.”

If the group leaders feel significantly challenged by the upset, they can remind themselves to use “I” statements (non-judgmental comments framed as “I feel scared/ confused/ uneasy/ unclear, etc.”), which reduce inflammatory or blaming behavior by requiring individuals to take responsibility for how they feel, rather than holding someone else responsible. Leaders should avoid saying anything judgmental, which could imply that a specific individual was the main or only cause of the upset.

Group facilitators benefit from apologizing to the other members for shortening the meeting and suggesting that they try not to take sides or gossip with each other about what happened. Leaders can suggest that if group members feel upset about the conflict, they might want to debrief with someone outside the group. Group facilitators also need to remind all present to adhere to the confidentiality agreement: not to share names or disclose other group members’ personal information. Leaders can encourage participants to focus on past upsets that might have been triggered by the current conflict.

If the Leader Gets Hooked

Group leaders can also have their old feelings triggered by interactions in the group and may end up making inappropriate comments. If this happens occasionally, it is important that they apologize to the group for getting triggered. It is not wise to pretend it didn’t happen. This will backfire and the group will likely dissolve. It is best for the group to understand the simple truth that everyone can get pulled in sometimes, and then move on. Modeling apology is a powerful lesson for the group. The possibility of leaders getting triggered reinforces the advantage of co-leaders. If one gets pulled in, chances are the other can remain calm and continue to think clearly.

However, if group facilitators often get triggered, if they find themselves deeply upset and dwelling on the interaction, if they get into conflicts with their co-leaders, or if they allow their upsets to threaten the safety or continuity of the group, they may not yet be ready to be group leaders. Similarly, group leaders who blame others in the group for their emotional reactions need more experience observing experienced leaders—and observing and working on their own personal history and emotional reactions. It’s part of the growth process and doesn’t mean they won’t become good leaders.

Check-in After an Upset

Before the next meeting, leaders can check-in with the individuals who experienced conflict and listen to them for a few minutes to find out if they are able to move beyond the upset. Facilitators can also encourage the individuals to reconnect with the person with
whom they had the conflict, without having to necessarily resolve all of their differences.

**Asking Someone to Leave**

Unfortunately, some individuals hold on to their upsets, pinning them onto others in the group. Their presence in the group may make other members’ participation impossible. If that occurs, group leaders may need to make the difficult decision about whether the upset person can remain in the group or if it is better for all involved if he or she takes a break from the group. If leaders must ask someone to leave the group permanently or temporarily, doing so in person and outside the group meeting time will be best. Group leaders need to be prepared to listen, within limits, and then adhere to them. They can also offer to refer the individual to another community resource, if possible.

**Difficulties Can Be Useful**

Group leaders should not be discouraged by difficulties. Although the difficulties described in the previous paragraphs are rare, they do occur sometimes. Leaders should not assume any given group will be immune from conflict. Even the nicest people get upset in relationships. Leaders can view facilitating a group that experiences conflict among its members as an opportunity for their own growth as leaders and human beings.

Sometimes difficulties arising in group settings can be rewarding and enlightening to participants. For example, some group members may be able to break through their agitation and actually thank each other for helping them uncover and clarify old hurts. Other group members can learn from witnessing upsets and exploring their sensitivity to them. Leaders need to be careful not to assume that the occurrence of disagreements and tensions means the group is not successful. It may be a sign of success! The facilitators’ attitude that conflict can be positive will help the group ride out the difficulties and reach for more closeness, deeper sharing, and growth.

**Evaluation**

Leaders can evaluate the group’s successes and challenges in order to learn from the experience and plan for the next group. Evaluation can be done by leaders alone or with input from group members. Evaluations can be solicited on anonymous feedback questionnaires or informally in discussion. If feedback is requested, leaders can ask participants to frame their answers as constructive suggestions rather than as disappointments.
Possible questions for constructive feedback might include the following:

- What went well in this group?
- What were the benefits for you?
- What were your favorite parts?
- What might be done differently the next time?
- What suggestions do you have for future groups?

Rewards of Leading Support Groups

Support groups have changed millions of people’s lives for the better. Participants can open up, realize they are not alone, heal old hurts, set new goals, learn new skills, take charge of their lives, and become leaders themselves. For many people, a support group is the best arena for these kinds of changes. Support-group leaders can feel great pride and satisfaction in facilitating these opportunities for participants. The rewards are worth the challenges. With experience, leaders can become more effective and powerful in facilitating positive changes in participants’ lives.
Movies of all kinds, whether dramas or comedies or documentaries or educational films, can be wonderful resources in helping to empower people with disabilities. They raise issues of disability awareness and stimulate productive discussion about abuse prevention. The wide availability of movies for home and educational use makes them a great catalyst for discussions, support groups, workshops, and individual viewing.

“Movie therapy,” or “cinema therapy,” is used by educators, librarians, and other resource people to help students and clients grow emotionally and learn new skills. Viewers identify and explore experiences and emotions they would otherwise be unable to address or discuss. Movies can even help build or restore communication between family members after they have experienced tragedy or trauma.

Movies are a true example of how art imitates life. To begin the journey, all you need to do is to identify those movies that apply to your individual life problem or those that will help you to self-nurture and grow. The movies will help you experience healing yourself and/or supporting family members and friends along their own healing path. Gilbert P. Mansergh, Movie Critic

Documentaries and other kinds of educational movies offer information within a relatively short time. Though hundreds of excellent films about disability issues have been made, they are not as easily available as Hollywood movies. Yet web and library access is rapidly increasing for this genre, with numerous web-based movie guides including the category of disability.
CHAPTER 13. MOVIES FOR EMPOWERMENT

in their search mechanisms. There are also many books that analyze the use of disability in film. We offer a list of web and print references below. CAPE offers readers an annotated list of widely available movies addressing the issues of abuse and disability. We also have suggestions for discussion questions for these and for any of the thousands of possible movies that can be used for abuse-prevention and empowerment education and training.

The Positive Value of Movies

Through oral traditions, myths, and fables, stories and storytelling have been a part of cultural and emotional growth throughout history. The modern medium of film allows these historic tales to be vividly refashioned. Movies have the power to elicit intense emotions, such as sadness, fear, anger, outrage, hope, joy, and awe, in ways that reading or listening or even observing everyday life cannot easily evoke. Special effects enhance the magic of movies and the impact on the viewer by creating images of experiences we could previously only imagine.

Watching characters in a movie allows viewers an intimate glimpse into someone else’s emotional life experience and gives them access to shifting and nuanced perspectives not usually available in everyday life. Seeing an entertaining or funny movie can also offer a needed break from emotional stress or real-life problems. While watching a movie can be a form of “escaping” from the seriousness of reality, it can also provide another point of view for evaluating old or rigid values or outworn attitudes. Movies have the power to bring tears and laughter, while simultaneously enhancing creative thinking about new options and possibilities.

Cautions about Movies

Movie viewing has its limits as well. Watching movies should not become a substitute for productive interaction with others: family, friends, peers, mentors, and the whole panoply of resource people. Movies can become time-wasters, even an addiction, for people who are isolated or fearful of or limited in interaction with others. Care should be given to prescreening films, and facilitators must be thoughtful about the use of movies, particularly for vulnerable viewers, such as those who have experienced abuse, and for children and adolescents.

Unfortunately, many films portray disability in stereotypical ways. Much writing has explored the use of disability in film as a metaphor for evil, pathos, tragedy, and adversely, for saintliness or courageous inspiration. Group leaders can help participants be on the lookout for these stereotypes in popular movies. If you choose to use or recommend a particular movie despite its use of stereotypical portrayals, be sure to explain that these representations of disability are not the whole picture, so that discriminatory attitudes will not be reinforced.

Watching violent movies can be a frightening, even traumatizing, experience for individuals who are sensitive to violence, but especially for people with a history of abuse. Likewise, children who view movies
that are inappropriate for them can be frightened or traumatized. Everyone has his or her own limits when it comes to the level of violence in films scenes. Yet violence on TV, in movies, and in the news media has become so commonplace that we as a nation have become desensitized to it. We must persist in re-thinking the effects of this everyday violence on our psyches. For additional perspectives on violence, see CAPE’s Chapter 7, Confronting Violence.

Guidelines for Selecting Movies

Thoughtful movie selection is essential for your audience. One way to make sure the movie is appropriate is to preview the entire film with your participants in mind. Don’t just assume that reading the movie rating or a review, or asking others for ideas or opinions of particular movies, will suffice in your selection, including the ones recommended below. Movies may have scenes or themes that are not mentioned in reviews and that could upset, confuse, or distract particular participants. Likewise, friends might not tell you about a movie’s violence or suggestive interactions that could be potentially upsetting to some participants. Sometimes “upsets” can be productive, but they must be thoughtfully gauged for the audience.

You might consider previewing the movie with another facilitator or co-worker to discuss possible reactions from participants. Consider the following issues during the screening process:

- Are the characters and storyline(s) sufficiently relevant to group participants?
- Is there a significant degree of compatibility or resonance with ethnic and cultural values of the group and group members?
- Are new values introduced in a thoughtful and meaningful way?
- Does the movie offer good role models of disabled people reaching for empowerment, help, insight, and connection?
- To what extent does the movie employ charged issues, such as sexuality, crime, violence, strong emotions, alcohol, tobacco, or drugs?
  
  ▷ If a given movie includes any or all of the aforementioned issues, is there a productive way to address them in a follow-up discussion?

- Are you keeping in mind that caution should be taken with some populations of disabled people who may be confused or frightened by unrealistic situations or bizarre circumstances?

For help in finding a movie, see the annotated movie list included in this chapter. Just suggesting watching the movie doesn’t necessarily help educate or enlighten the viewer. To be empowering, movie-viewing must be part of a larger process which involves reflection, discussion and perhaps laughter or even tears, and sharing animated interaction with others.
References to Websites Discussing Disability in Movies

- Films Involving Disability [http://www.disabilityfilms.co.uk/]
- Physical and Mental Disabilities in the Movies [http://www.lib.berkeley.edu/MRC/disabilitiesbib.html]

References to Books Discussing Disability in Movies


Additional Considerations

Another important aspect of using movies to educate or empower the audience is planning the movie viewing event. The viewing event, along with the movie, should fit the needs of the participants. Prepare discussion questions or activities before participants view and discuss the movie.

Consider these issues:

- Is the movie length workable for the attention span of participants?

- Can they view the entire movie and have attention for discussion as well, or would it be better to watch the movie over two or more sessions, with time in between for discussion and reflection?

- Should the movie be the main focus of the event or part of other activities?

- Should there be snack food, which would generate a party atmosphere? This could be an advantage or a disadvantage depending on the goals of the event.
Would an academic-type focus be better for the group and the particular movie?

Considering Accessibility

You also need to consider access for individuals with vision and hearing loss. Many people who are blind or have low-vision regularly enjoy movies. Audio-description may be included with the audio of some movies, with a narrator verbally describing visuals along with the dialogue and narration of the film. The use of audio-description is still limited, mostly to films about disability issues, but it is gradually increasing. Some visually impaired people enjoy informal audio-description by requesting that a sighted person in the audience describe visuals out loud as the film evolves. Others don’t opt for this feature, and it is appropriate to ask blind or low-vision participants if this would be useful for them. For viewers with hearing loss, be sure to check if the film is captioned. The vast majority of recent Hollywood films available on DVD provide the option of subtitles in English as well as other languages, but older films on VHS may not have this option. If a particular film is not available with closed or open captioning or subtitles, try to find a movie that has these features. Another idea is to show the movie and provide realtime captioning, or Communication Access Realtime Translation (CART).

For individuals with hearing loss who use American Sign Language (ASL) as their primary means of communication, sign language interpreters may provide interpretation. You may also inquire whether your hearing-impaired viewers could make use of an assistive listening device (ALD) if they have access to one, or if you might have to obtain it for them.

CAPE’s chapters 11 and 12 describe training event and support group facilitation and provide more ideas for planning movie-viewing activities. Have fun!

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2 Open caption means the captioning is visible to all viewers. Captions usually offer more description than subtitles, such as non-speech elements of the audio. Closed captions must be activated in the media device to make it visible.

3 Communication Access Realtime Translation (CART), or realtime captioning, is a word-for-word translation of spoken English onto a laptop or notebook computer by use of realtime software and a steno machine. Setup time is moderate and the CART reporter usually provides the necessary equipment. Retrieved January 30, 2009, from http://www.disabilityresource.uic.edu/viewer.asp?tab=2&label=Captioning%20Services

4 Information on assistive listening devices can be found at http://www.betterhearing.org/hearing_solutions/listeningDevices.cfm
CHAPTER 13. MOVIES FOR EMPOWERMENT

Annotated List of Movies about Disability Issues

At First Sight (1999)  
Blindness  
Director: Irwin Winkler  
With: Val Kilmer, Mira Sorvino, Kelly McGillis  
United States – 128 minutes  
A young woman falls in love with a blind massage therapist and persuades him to undergo an experimental treatment to cure blindness. The difficult road to understanding the visual world tests their relationship when the man begins to lose his sight once again.

Babe (1995)  
Genetic Predisposition  
Director: Chris Noonan  
With: Christine Cavanaugh, Miriam Margolyes, Danny Mann  
Australia – 89 minutes  
This film is about a piglet who finds himself on a strange farm. Confused and sad, Babe is adopted by a friendly dog and slowly adjusts to his new home. Babe devotes himself to becoming a useful member of the farm by learning how to herd sheep, despite the skepticism of the other animals.

Beauty and the Beast (1991)  
Deformity  
Directors: Gary Trousdale, Kirk Wise  
With: Paige O’Hara, Robby Benson, Richard White  
United States – 84 minutes  
An animated adaptation of the well-known fairytale, the film is about a prince who is cursed to beast form. The only way he can break the spell is to love another and earn her love in return. Beautiful Belle finds him trapped in the castle. The two soon taste the bitter-sweetness of unconditional love, and have to learn, change, and accept.

Born on the Fourth of July (1989)  
Paralysis, Paraplegic  
Director: Oliver Stone  
With: Tom Cruise, Raymond J. Barry, Caroline Kava  
United States – 145 minutes  
A film based on the memoirs of Ron Kovic, who grew up in the 1950s. The patriotic Kovic joins the Marines, goes to Vietnam, and comes home a paraplegic in 1970s America.
The hostility toward veterans is accurately captured as the film follows Kovic on his long journey to self acceptance.

**Children of a Lesser God (1986)**  
Deafness

Director: Randa Haines  
With: William Hurt, Marlee Matlin  
United States – 119 minutes  
In this film two adults working at a school for deaf students fall in love. The conflict between James’s preference to speak orally and Sarah’s preference to use sign language is a central part of the ensuing tension. Sarah is played by Marlee Matlin, a deaf actress who won the Academy Award for Best Actress for her portrayal.

**Dear Frankie (2004)**  
Deafness

Director: Shona Auerbach  
With: Emily Mortimer, Jack McElhone, Mary Riggans, Sharon Small  
United Kingdom – 105 minutes  
A single mother, Lizzie, and her deaf nine-year-old son Frankie constantly move from town to town to escape his abusive father. Rather than tell him the painful truth, Lizzie tells Frankie that his father is a sailor who is away on exciting trips. Lizzie is eventually forced to decide whether to tell Frankie the truth.

**Dumbo (1941)**  
Deformity

Director: Ben Sharpsteen  
With: Edward Brophy, Sterling Holloway, Verna Felton  
United States – 64 minutes  
An animated film about an elephant cruelly nicknamed Dumbo and ridiculed because of his truly enormous ears. His only friend is a mouse, Timothy, who helps Dumbo achieve his full potential and become a hero, using his big ears as wings to fly.

**Dying Young (1991)**  
Leukemia

Director: Joel Schumacher  
With: Julia Roberts, Campbell Scott, Vincent D’Onofrio  
United States – 111 minutes
CHAPTER 13. MOVIES FOR EMPOWERMENT

When Victor Geddes discovers that he has leukemia, his wealthy family hires pretty, young Hillary O’Neil to help nurse him through his chemotherapy treatment. They fall in love and attempt to make the most of their time together.


Directors: Andrew Stanton, Lee Unkrich
With: Albert Brooks, Ellen DeGeneres, Alexander Gould, Willem Dafoe
United States – 100 minutes
An underwater animation, Finding Nemo is an adventure story about a single father fish, his mildly fin-impaired son, Nemo, and Dory, a fish they meet who has a significant short term memory loss. They encounter many challenges in their quest to reunite and return home to Sydney, Australia.

Forrest Gump (1994) Learning

Director: Robert Zemeckis
With: Tom Hanks, Robin Wright Penn, Gary Sinise
United States – 142 minutes
An Academy Award winning film about the life of Forrest Gump, a man considered to be of low intelligence who finds success in his epic journey through life, meeting historical figures, influencing popular culture, and witnessing historic events. In each case he far exceeds what anyone imagined he was capable of.


Director: Julie Taymor
With: Salma Hayek, Alfred Molina, Geoffrey Rush, Antonio Banderas, Edward Norton
United States – 123 minutes
Frida Kahlo has mild post-polio and then a nearly fatal accident which leaves her with pain and multiple disabilities. She deals with them by painting to express her intense pain and grief – physical and psychological. The film follows Frida through her tumultuous relationship with muralist and political activist Diego Rivera.


Director: Andrew Niccol
With: Ethan Hawke, Jude Law, Uma Thurman, Gore Vidal, Ernest Borgnine
United States – 106 minutes
A film that takes a look into the near-future, where genetic predisposition is the determining factor in a person’s fate. The protagonist wants to work on the space program, but is barred as genetically "unfit." Another young man has had a spinal cord injury and uses a wheelchair. The movie follows their scheme to get the protagonist into the space program.

**Girl Interrupted (1999)**  
Borderline Personality Disorder

- Director: James Mangold  
- With: Winona Ryder, Angelina Jolie, Clea DuVall, Brittany Murphy  
- United States – 127 minutes  
- Based on Susanna Kaysen’s 1993 memoir about her two-year stay in a mental institution in 1967. She spends more than a year struggling on the border between normal and crazy. Once she realizes how difficult it is to be released once committed, she attempts to reclaim her life.

**Jenseits der Stille (Beyond Silence) (1996)**  
Deaf-Mute

- Director: Caroline Link  
- With: Sylvie Testud, Tatjana Trieb, Howie Seago, Emmanuelle Laborit  
- Germany (German and German Sign Language with subtitles in English) – 109 minutes  
- The film follows the childhood of Lara, whose parents are both deaf-mute. Lara handles translation to and from sign-language for her parents so that they can communicate with others. Lara is faced with deciding how to balance her own dreams with her parents’ desires.

**K-Pax (2001)**  
Mental Health

- Director: Iain Softley  
- With: Kevin Spacey, Jeff Bridges, Mary McCormack  
- United States – 120 minutes  
- The movie tells the story of Prot, a mysterious patient at a mental hospital who claims to be from a distant planet called K-PAX. Prot demonstrates an outlook on life that ultimately proves inspirational for not only his fellow patients, but also for his psychiatrist.

**The Little Girl Who Sold the Sun (1999)**  
Polio

- Director: Djibril Diop Mambety  
- With: Lissa Balera, Taorou M’Baye, Oumou Samb, Moussa Balde, Dieynaba Laam  
- Senegal (French with subtitles) – 45 minutes
Sili is disabled and develops the remarkable ability to sell newspapers on the streets of Dakar. She faces intimidation from some older male bullies, but she succeeds in earning money for her family and entertaining other street kids.

**Love! Valour! Compassion! (1997)**

*AIDS, Blindness*

Director: Joe Mantello  
With: Jason Alexander, Stephen Spinella, Stephen Bogardus  
United States – 108 minutes  
Eight gay friends grapple with life in the era of AIDS. They spend three weekends in the country over the course of a summer as they explore their sometimes conflicting attitudes about love, sex, friendship, life, and death.

**Mask (1985)**

*Lionitis*

Director: Peter Bogdanovich  
With: Eric Stoltz, Cher, Sam Elliot, Laura Dern  
United States – 120 minutes  
Based on the true story of Rocky Dennis, a boy who has “lionitis,” a fatal and disfiguring disease. Rocky is a teenager in high school and his mother is a freewheeling biker. Her biker friends accept Rocky, but his classmates ostracize him. The movie follows the challenges that Rocky faces with his classmates and his family.

**The Mighty (1998)**

*Learning, Neuro-muscular*

Director: Peter Chelsom  
With: Kieran Culkin, Elden Henson, Sharon Stone, Harry Dean Stanton  
United States – 100 minutes  
Two adolescent boys team up to support each other and slay the dragons in their world. One boy is emotionally wounded and perhaps learning disabled, the other is physically limited by a progressive neuro-muscular disease. Together they make a single unbeatable hero: “Freak the Mighty.”

**Niagara, Niagara (1997)**

*Tourette’s Syndrome*

Director: Bob Gosse  
With: Robin Tunney, Henry Thomas, Michael Parks, Stephen Lang  
United States – 93 minutes
Two emotionally scarred young people, Marcy and Seth, meet while shoplifting at the same department store. Seth is the son of an abusive father and steals out of rebellion, while Marcy has Tourette’s Syndrome. The two find a common ground in each other, and they decide to hit the road.

**Of Mice and Men (1992)**  
**Cognitive Impairment**

Director: Gary Sinise  
With: John Malkovich, Gary Sinise  
United States – 116 minutes  
Two close friends work on a ranch in the 1930s. George is the sly and intelligent guy, while Lennie is considered cognitively impaired. Though he means no harm, Lennie often gets into trouble. This is the story of the two men’s friendship and their hope to live a better life.

**One Flew Over the Cuckoo’s Nest (1975)**  
**Mental Health, Paralysis**

Director: Milos Forman  
With: Jack Nicholson, Louise Fletcher, William Redfield  
United States – 133 minutes  
This Academy Award winning film is set in a mental hospital. Playing crazy to avoid prison work detail, Randle McMurphy is sent to the state mental hospital for evaluation. Expressing his basic human rights and impulses, he protests against heavy-handed rules - leading to his own lobotomy.

**Passion Fish (1992)**  
**Paralysis, Addiction**

Director: John Sayles  
With: Mary McDonnell, Alfre Woodard, David Straithairn  
United States – 135 minutes  
A former soap opera starlet slowly accepts the changed realities of her life after becoming paralyzed in an auto accident. May Alice Culhane retreats from New York City to a solitary life in the plantation-like home on the bayou where she was raised. Chantelle, an attendant/nurse, has lived through enough pain to remain unmoved by May Alice’s rants and self-pity. The film portrays the experience of recovery from paralysis and addictions.
The Piano (1993)  Communication

Director: Jane Campion
With: Holly Hunter, Harvey Keitel, Sam Neill, Anna Paquin
Australia/New Zealand – 121 minutes
An Academy Award winning film about a passionate woman who does not speak. She finds expression through her piano, writing, and sign language. Her young daughter serves as interpreter. Set in the mid-19th century in New Zealand, the film explores the darker emotional sides of human beings.


Director: John Madden
With: Anthony Hopkins, Hope Davis, Gwyneth Paltrow, Jake Gyllenhaal
United States – 99 minutes
This film raises issues of sexism in academia, and grief, loss, and caregiving. Robert, a mathematical genius, becomes emotionally and cognitively disabled later in his career. His grown daughters care for him. Kate sacrifices her education to live with her father through his long illness, while Claire’s job pays the bills. A graduate student’s search through Robert’s notebooks ends up revealing Kate’s contributions to the field of mathematics.

Scent of a Woman (1992)  Blindness

Director: Martin Brest
With: Al Pacino, Chris O’Donnell, James Rebhorn
United States – 157 minutes
Frank Slade, a blind retired army colonel, hires a poor college student to take care of him over Thanksgiving. Frank reveals his plan to visit his family, have a few terrific meals, sleep with a beautiful woman, and finally, commit suicide. The film follows the mismatched pair as they learn about life through their series of adventures.

Shower (1999)  Developmental

Director: Zhang Yang
With: Wu Jiang, Quanxin Pu, He Zeng, Xu Zhu
China (Chinese with subtitles) – 92 minutes
A film about a Chinese man and his two sons in their thirties, one of whom is developmentally disabled. The family runs a Chinese bathhouse in the midst of urban
renewal. The focus is on tradition and modernity. When the old man dies, the non-disabled brother gently takes over the father’s role.

**The Station Agent (2003)**

- **Dwarfism**
  - Director: Thomas McCarthy
  - With: Peter Dinklage, Patricia Clarkson, Bobby Cannavale
  - United States – 88 minutes

  The film revolves around a man with dwarfism who moves into an abandoned railroad shack he inherited. There he gets involved in the lives of a couple of people and the three become supporters of each other. On the surface the film is about alienation, but it is humorously punctured by human warmth.

**Stuck On You (2003)**

- **Conjoined twins**
  - Directors: Bobby Farrelly, Peter Farrelly
  - With: Matt Damon, Greg Kinnear, Eva Mendes, Cher
  - United States – 118 minutes

  A couple of athletically gifted, working class guys who live on Martha's Vineyard and run a burger joint happen to be conjoined twins. The plot is charged with outlandish humor as the disabled central characters encounter a range of oppressive attitudes and deftly overturn them. The movie includes several minor characters with disabilities who have small yet significant roles played by disabled actors.

**A Woman Under the Influence (1974)**

- **Mental Health**
  - Director: John Cassavetes
  - With: Gena Rowlands, Peter Falk
  - United States – 155 minutes

  A drama chronicling the emotional breakdown of a suburban housewife and her family’s struggle to deal with it. People come away from the movie questioning whether there is indeed anything wrong with the woman.

**The Wild Child (1970)**

- **Communication**
  - Director: François Truffaut
  - With: Jean-Pierre Cargol, François Truffaut, Jean Dasté, Françoise Seigner, Paul Ville
  - France (French with subtitles) – 83 minutes
Based on a real-life case study, Dr. Jean Itard, a doctor working at Paris’s Institute for the Deaf and Dumb, takes on the challenge of Victor, a nonverbal "wild boy" found abandoned in the woods. Dr. Itard brings the boy to his own home, hoping to establish communication through kindness and compassion, and to imbue the boy with a sense of morality.
Additional Movies Portraying Disability Issues

- The Bone Collector (1999) (Quadriplegia)
- The Elephant Man (1980) (Neurofibromatosis)
- Extreme Measures (1996) (Paralysis)
- Inside I'm Dancing (also known as Rory O'Shea Was Here) (2005) (Muscular Dystrophy)
- Mac and Me (1988) (Spina Bifida)
- The Other Side of the Mountain (1976) (Spinal Cord Injuries)
- Resurrection (1980) (Spinal Cord Injury)
- The Sea Inside (2004) (Quadriplegia)
- Wait Until Dark (1967) (Blindness)

Documentaries

- Absolutely Positive (1990) (AIDS)
- Access to Medical Care: Adults with Physical Disabilities (2006)
- Angel on My Shoulder (1997) (Cancer)
- Being Different (1981) (General)
- Best Boy (1979) (Mental Retardation)
- Born Freak (2004) (Physical Birth Defects Caused by Thalidomide)
- Breathing Lessons (1996) (Paralysis)
- Children of Gaia (1998) (Deformity)
- The Collector of Bedford Street (2002) (Learning Difficulty)
- Crazy Love (2007) (Disfigurement)
- Dance of Partnership (2006) (Cognitive Disability)
- Darius Goes West (2007) (Muscular Dystrophy)
- The Devil and Daniel Johnston (2005) (Depression)
- Educating Peter (1992) (Down Syndrome)
- Going To School (2001) (Inclusion)
- Grace (1984) (Alzheimer’s)
- Graduating Peter (2001) (Education)
- Grizzly Man (2005) (Bipolar disorder)
- Hurry Tomorrow (1975) (Mental illness)
- In the Realms of the Unreal (2004) (Learning difficulties)
- Jupiter’s Wife (1995) (Mental Illness)
· King Gimp (1999) (Cerebral Palsy)
· My Flesh and Blood (2003) (Disabled Children)
· Normal for Us (2008) (Spinal Muscular Atrophy)
· On a Roll (2003) (Muscular Dystrophy)
· People in Motion (1995) (Mobility)
· People Say I’m Crazy (1989) (Schizophrenia)
· Praying with Lior (2007) (Down Syndrome)
· Spit It Out (2004) (Stuttering)
· Twitch and Shout (1993) (Tourette’s)
· Unknown White Male (2005) (Amnesia)
· Us and Them (2005) (AIDS)
· When Billy Broke His Head (1994) (Head Injury)
CHAPTER 14

PAS Scenarios for Men about Handling Abuse

In our studies of men and personal assistance abuse, we found that men encountered abuse by personal assistance services providers (PAS), but hesitated in confronting assistants and family members. They felt stuck with low-quality care, but were reluctant to disclose abuse or talk to others about it. To the male focus group participants, women PAS users seemed better able to be direct and clear about abusive situations with caregivers. (See the section on disabled men in Chapter 9, Populations: Women, Men, Elders, Youth, High Risk Disabilities.)

The scenarios outlined below were developed for use in training and support sessions for directing personal assistants and avoiding abuse. As indicated in the results section of the PAS Quiz on the Multimedia CD, participants can seek more information about PAS from Independent Living Centers and resources on the web, including the Center for Personal Assistance Services. Using the scenarios is an effective introduction for a group training session or for an individual one; participants may eventually be more willing to share their own most challenging or embarrassing problems in managing PAS. Allow enough time for participants to feel safe with the group setting and the discussion topic to be able to share what it is really like for them to face tough problems with PAS. Some participants may be enthusiastic about sharing their own stories, while others may take weeks or months to feel comfortable enough to open up.

All of the scenarios present challenging situations for male PAS users. They all require intervention and direction from the disabled employer to prevent abuse by personal assistants or family members. It is important to keep in mind and bring


2http://www.pascenter.org

183
to participants’ attention that there are no “right answers.” These situations could be handled in many different ways. Also, each PAS user must establish his own criteria regarding comfort or level of satisfaction with his PAS worker. The skills in Chapter 3 and the Empowerment Wheel offer help with developing more assertive approaches to dealing with difficulties.

Suggestions for Trainers and Facilitators

Choose one or two scenarios per training session. Avoid presenting all of them at once. The goals are to raise awareness and encourage discussion of common challenges in managing personal assistants, without overwhelming participants with discouragement or fears of possible difficulties. Introduce potential difficulties encountered with PAS workers in ways that are motivating and relevant to disabled men’s lives.

Also, recognize that men need to laugh while they learn! Don’t discourage or thwart cynicism or joking in these discussions. It’s a natural and expected aspect of working through challenges. Joking around allows participants to more deeply explore their own concerns. Some men may want to make up worst-case scenarios, even horror stories, of what might happen. This can be useful if handled with levity and in balance with positive options. Keep asking yourself how the discussion can be fun yet remain relevant to real-life situations these men may experience.

Once you have chosen and presented the scenarios, pose one or more of the questions below for discussion:

- What do you think the individual could or should do in this situation? What would you do if it were you?
- Which of the Empowerment Skills described in the Empowerment Wheel are important for each scenario?
- What assistance, information, or training would help these men with the difficulties?
- How could they get this information or training?

Have participants create success stories as outcomes for these problematic situations. Identify positive steps which, taken in advance, could improve communication, aid assertive direction of PAS workers, give access to useful community resources, and deliver other helpful interventions.
Various PAS Scenarios

Dave is a quadriplegic from a spinal cord injury and has lived alone in an apartment since his accident five years ago. The last attendant he hired through the want ads seemed pretty good for a while, but lately he’s been arriving late for work. He also seems distracted, making a lot of non-work related phone calls on the porch. When he comes back in, he is agitated, but won’t say what’s going on. One day the attendant didn’t show up at all, and Dave had to call his sister to drive an hour to come over and help him. He felt like he didn’t have anyone else he could call. Dave is afraid to fire the attendant because it is so hard to find a replacement. Dave knows that there’s an Independent Living Center in town, but he has not called them.

Derek is divorced and has been living alone for a year. He walks with crutches due to polio and sometimes uses a wheelchair. He is independent with his care routine. He also works full-time, but experiences fatigue sometimes and knows he shouldn’t overdo it. After experiencing increased pain and fatigue, he hired a woman to help him out for a couple of hours a day to clean and shop and prepare meals. He gives her cash and a grocery list and she shops and leaves prepared food in the fridge to heat up. Several days in a row, Derek noticed that the grocery money change wasn’t right and suspects she is cheating him. It’s just a few dollars here and there, but it’s adding up.

Jake has spina bifida and uses a wheelchair. He lives in an apartment with two bedrooms because he needs a live-in attendant. He is having a hard time finding someone he feels comfortable or safe with. The last guy who lived with him was loud and annoying and didn’t really do the jobs he was hired to do, such as cleaning up and helping him with laundry and some personal care. Then he moved out without giving any notice, taking Jake's CD player and some of his other belongings with him. Jake doesn’t know what to do next, but he knows he needs help.

Ron has cerebral palsy and lives with his family. He wants to save money to get his own apartment. Ron is a student and needs to be ready to go at 8:30 a.m. to get to school. Because of his cerebral palsy, he needs about two hours help in the morning and an hour at night. But his mother and brother, who help him, don’t always get up on time in the morning. His brother also sometimes acts resentful that Ron needs help, making snide comments and handling him roughly when helping him get dressed. Ron hasn’t mentioned this to his mother because he feels bad enough for having to depend on them. He is just waiting to move out of the house.

Melek has a cognitive and physical disability. A few months ago he moved out of a group home and into his own apartment, which he shares with a roommate. In the group home his care was directed by the
staff. But now, while learning to live on his own, Melek tries to direct his own care as much as possible. However, Lou, his roommate and primary support person, is an ex-employee of the group home and continues to tell Melek what to do. When Melek voices his own opinion about choices and decisions, Lou yells at him and tells him he’s not smart enough to make decisions for himself. Melek is not sure what to do.

Mike has muscular dystrophy and uses a wheelchair. He hired a new attendant, Pat, to work his night routine: getting undressed, a brief wash up of his groin, genitals, and bottom areas to make sure his catheter hadn’t leaked and he doesn’t have any skin lesions, and then getting into bed. Pat worked out well for the first few weeks, then Mike began to notice that Pat sometimes seemed to sort of stare at him in an unsettling way.

One night Pat showed up wearing a gauzy shirt that was unbuttoned and scented with some strong cologne. Mike tried to act casually, but he felt uncomfortable. While helping Mike get washed up, Pat said in a sort of hushed tone of voice, "You seem tense, Mike, how about a little massage?" Mike interpreted this as a sexual come-on and felt awkward and trapped. He had no interest in sexual contact with Pat. When he said, "No, no thanks," Pat started sulking and acting rejected. Mike doesn’t know whether to just fire Pat, or if he must explain his feelings to Pat.

Will had a stroke a few years ago, uses a walker, and has somewhat slurred speech. He hired Jan to fix meals for him and do housework three days a week. The other day, Will was looking in his closet and found some things moved around. He realized that Jan had been going through his stuff, especially some of his art books with nude photos. Will found his vibrator and some lubricating cream taken from a drawer and put somewhere else. Will feels very embarrassed to say anything to Jan, but he is also angry that these items were moved.

**Multicultural Tip #15: Learning about Cultural Barriers**

Explore cultural barriers to access and accommodation for disabled people within the specific populations and communities you work with. This may require some research for services providers from outside the community. Ask your participants to educate you about their communities’ attitudes and practices.

For more tips, see Chapter 10.
Frequently Asked Questions about Abuse, Abuse Prevention, and Empowerment

These questions and answers explain the fundamental issues covered in the Curriculum on Abuse Prevention and Empowerment (CAPE). They are divided into three categories: Abuse, Abuse Prevention, and Empowerment. This chapter should be copied and distributed as a handout for trainings and classes.

Abuse

1) What Is Abuse?

Abuse is any hurtful, inappropriate, frightening, insulting, oppressive, or demeaning behavior directed at one person by another. It includes physical abuse, such as violence, throwing things, rough handling, pushing, hitting, slapping or any other use of force, with or without weapons. Abuse can include verbal or emotional mistreatment, such as making threats, putting someone down, calling someone names, or keeping someone isolated or limited by jealousy or suspicion. Abuse may range from forced or pressured sexual activity to financial mistreatment, including the theft of medication or material possessions.

Abuse can mean doing something, but it can also mean not doing something. Because many disabled people need assistance or other resources, withholding or ignoring needed resources can result in harm. Withholding needed assistance, medication, equipment, communication facilitation, or other resources are all abuse, as is the violation of privacy or autonomy. Anyone can be an abuser, including strangers, family members, spouses, informal or paid assistants, associates, and services providers.
2) Are Disabled People Particularly Vulnerable to Abuse?

Some abusers seem to specifically target those disabled people who appear weakest, those unable to disclose abuse because of communication impairment, or those not likely to be believed because of low credibility due to cognitive, emotional, or physical impairment.

Thus, many people assume that individuals with disabilities are especially vulnerable to abuse because of impairments that limit mobility, strength, or communication. However, vulnerability, disability, and needing assistance do not cause mistreatment. Mistreatment is caused by the values and actions of the abusing individuals and our society.

3) What Factors Can Cause an Individual to Abuse?

Violence and abuse directed at disabled people is influenced by a complex interaction of factors, including:

a) the abuser’s personal history of violence and mistreatment, including his or her own experiences of being targeted with abuse as well as witnessing abuse in the family, neighborhood, and community;

b) the abuser’s deeply held attitudes about disabled people as being “burdens,” “unworthy,” “inferior,” and often deserving of blame for their own or their family’s difficulties;

c) the abuser’s and the community’s values about who should be in charge in relationships with disabled people;

d) caregiver stress, alcohol and drug abuse, and limited resources available to families and communities to meet the real needs of disabled people.

4) What Societal Factors Lead to Abuse?

Societal factors that can influence and contribute to abuse include:

a) discriminatory practices that objectify, disrespect, or marginalize disabled people, including architectural barriers, discriminatory attitudes, and lack of appropriate accommodations and services;

b) lack of choice of providers in some agencies and Personal Assistance Services systems (PAS);

c) lack of community support for family caregivers and low wages for PAS workers, which reduce the pool of qualified workers as well as the retention of experienced PAS workers.

5) Why Might a Disabled Person Not Report Abuse?

It is crucial that people with disabilities, human services providers, and concerned family members come to appreciate the complexity of factors that may influence individuals to not report abuse:
CHAPTER 15. FREQUENTLY ASKED QUESTIONS

Disabled people who were raised in institutions or have been disabled from early childhood may have a limited sense of personal boundaries and may not understand that certain kinds of mistreatment are unacceptable.

Parents with chronic illness or disabilities may fear losing custody of their children if abuse is revealed.

Disabled people may feel low self-esteem and embarrassment at needing help and about their bodies. They feel like a burden to family members and other caregivers and therefore settle for unsatisfactory care in order to avoid dealing with these issues.

The bureaucratic process of reporting abuse to authorities, police officers, or social workers is painful and humiliating.

People may feel ambivalent about or even terrified of reporting abuse because they don’t want to implicate the provider whom they depend on or care about.

Disabled individuals may fear institutionalization, loss of autonomy, or retaliation by the provider if they disclose mistreatment.

Societal values not directly related to disability also block individuals from seeking help:

In general, men, including disabled men, feel that squealing on anybody is unacceptable behavior and therefore resist recognizing or disclosing abuse.

Disabled women are acculturated to low self-esteem and low expectations and feel unable to assert their wishes or boundaries in abusive situations.

Gay, lesbian, or transgender individuals with disabilities may feel they have to hide their identities or circumstances or may be forced to do so and thus fear revealing mistreatment.

People from diverse backgrounds may have caregivers who misunderstand or invalidate their cultural values. The fear of invalidation keeps them from revealing abuse.
Abuse Prevention

6) What Is Abuse Prevention?

Abuse prevention for the long-term includes programs and activities that help people with disabilities live safely and free from the threat or the realities of abuse and violence. A range of organizations and communities are involved in this effort across the United States and the world. These include domestic violence prevention organizations, Independent Living Centers, developmental and physical disability organizations, self-help organizations, rehabilitation programs, violence prevention organizations, programs for elders and youth, and the criminal justice system. Many of these groups work with services providers and families to protect people with disabilities from abuse and violence by addressing policy issues and monitoring the provision of care and quality of life.

7) I Think I Am Being Abused. What Should I Do?

Get help! Connect with someone you trust, like a friend, neighbor, family member, spiritual leader, nurse, doctor, or social worker, for example. If you don’t know whom you can trust, call someone at a disability services agency, such as an Independent Living Center or Senior Center; or an abuse hotline, such as the National Domestic Violence Hotline, 1-800-799-SAFE (7233), 1-800-787-3224 (TTY), or an appropriate hotline in your area. If you can’t contact anyone else, call the police and tell them you are a disabled person and that you are being abused.

If you are afraid to contact anyone, do it anyway! Get more information to increase your confidence to resist abuse. First, realize that you deserve to be treated well. Then, think of ways to reach out to others who can help you. You don’t have to be alone in dealing with an abusive situation. Indeed, you need and deserve help to change your situation.

8) What Can I Do to Help a Disabled Person Being Abused?

If you suspect that a person with a physical impairment, mild cognitive disability, or chronic illness is being abused, do something about it. Approach that person alone in a relaxed setting. Express your concern for his or her safety and well-being and your respect for his or her autonomy and self-direction, and affirm your high regard for the person’s
CHAPTER 15. FREQUENTLY ASKED QUESTIONS

compence and ability to live independently. Offer your support by assuring the individual that s/he can handle the situation in his or her own way. What you can provide are good listening skills, information about abuse prevention, and referrals to community resources, such as counseling from clergy or social services and peer support. Suggest to brainstorm on alternative sources of personal assistance until the abusive situation is clear, articulated, and moving towards positive resolution.

Pressuring someone to act quickly or displaying a patronizing attitude may undermine the disabled person’s trust in you. Be patient and allow the individual to learn to take control of his or her own situation and develop new avenues of support. You may have to modify your own standards of care in consideration of the disabled person’s right to autonomy. If the individual appears unwilling or unable to take action on his or her own, or has a significant cognitive disability and does not grasp the situation, you may have to consider contacting the police, Adult Protective Services, or other resources without his or her consent. But be aware that immediate removal of a care provider with no alternative plan may threaten the disabled person’s survival. Discuss your thoughts with skilled resource people who have knowledge of disability community resources and an understanding of abuse prevention.

9) What Should I Do If I or Someone I Know Is in Immediate Physical Danger?

Call 911 without delay. Tell the police operator that someone is in danger and provide the address.

10) How Can Disabled People Stay Safe and Avoid or Resist Abuse?

Disabled people can learn to protect themselves and decrease their risk of harm or abuse by learning about their rights, being more assertive and in charge of their own lives, and becoming more connected to others in their communities. Personal assistance management skills and support can help improve the quality of the help disabled individuals receive.

First steps towards abuse prevention and empowerment include realizing that everybody deserves to be treated well, everybody can say no when he or she does not want something to happen, and everybody should have trustworthy people in their lives who can be told about mistreatment. Other steps include improving communication skills, building awareness and knowledge of community resources, using criminal background checks when hiring services providers, installing door-locking systems that can easily be changed, utilizing secure banking systems that protect against theft, and learning about fire and hazard prevention and emergency preparedness.
Empowerment

11) What Is Empowerment?

Empowerment is enabling people to take more initiative in their own lives and act effectively on their own behalf. Empowerment activities are a necessary and integral complement to abuse prevention activities. They assist and support people with disabilities to take greater control of their own lives, make their own choices, and become involved in and lead in arenas that are important to their well-being.

12) Why Are Abuse Prevention and Empowerment Education Necessary?

The vast majority of abusive incidents occur when disabled people are alone with one other individual. Even though disabled individuals may not be able to physically resist certain kinds of abuse due to impairments, empowered disabled people know they do not deserve mistreatment, know they have some degree of power through communication, such as the ability to communicate “No,” and know that they can disclose abuse and get help, if not immediately, then soon. Empowered people with disabilities are connected to others in their families and communities, and expect that they will be aided when they need help.

Empowerment activities teach and reinforce these ideas and skills. An educated and empowered disabled person is his or her own best resource in self-protection and safety. People with disabilities themselves must lead the abuse-prevention movement.

13) Shouldn’t Someone Else Take Care of Safety and Abuse Prevention for Disabled People?

Some researchers and services providers think disabled people should not have to participate in their own safety and protection; that other people should take care of it. Stereotyped views of disabled people regard them as helpless or as victims. The Independent Living philosophy contends that disabled people living independently or those who want to become independent can and must be included in their own safety planning and protection from abuse.

Families, mentors, services providers, community resources, and public policy must be oriented to help disabled people end abuse and violence directed at them. Disabled individuals unable to live independently can still participate in a team effort that
ensures their safety and engagement with the community. Of utmost importance to abuse and violence prevention is disabled people being supported to become the directors and facilitators of their own safety and empowerment planning and implementation.

One of the most important ideas to emerge from the disability movement in recent years is the credo, “Nothing about us without us.” Abuse prevention activities must be done with, not for people with disabilities.

14) Doesn’t Raising Abuse Issues Unnecessarily Scare Disabled People?

Some people are concerned that the ideas of recognizing abuse and learning safety and self-protection unnecessarily scare people with disabilities, or make them afraid of seeking assistance. The fact is that disabled people are already aware that they are at risk for abuse. Most disabled individuals have already experienced mistreatment. Disabled people have to face discriminatory attitudes regularly, and studies suggest that a majority of people with disabilities have already been abused physically, verbally, or sexually.

15) What Helps Disabled People Learn about Abuse Prevention and Empowerment?

Educational materials that are interesting, attractive, and motivating are best suited to help disabled individuals learn about abuse prevention and empowerment. Additionally, they need to be readily accessible and meaningful in terms of cultural background, age, and disability. For example, these materials may include stories of disabled people confronting and handling abuse, movies, comic book scenes, quizzes, and games—in formats that learners already regard as fun and entertaining.

Unfortunately, many existing abuse prevention materials are presented as tips or advice, or use scary stories of disabled people being victimized, in formats which are not motivating. Abuse is serious and its effects can be devastating, but learning and empowerment activities must be fun and accessible to be effective.

Multicultural Tip #1: Becoming Aware of Multicultural Issues and Disability

Offer diversity training and awareness events for staff and membership about ethnic, cultural, and racial issues, addressing where they intersect with disability issues. Regularly ask staff, clients, and members which issues concerning diversity and cultural sharing they would like to learn more about.

For more tips, see Chapter 10.
Safet y and Abuse-Prevention Tips for Games and Events

Seniors living independently want and need to discuss safety, personal assistance needs, and crime and abuse prevention. Don’t assume elders only want to talk nostalgically about old times and pleasant issues. The real difficulties of life are often on the minds of older people. They will welcome the opportunity to discuss these issues. Senior Centers, faith groups, health fairs, and other community events are good places to address these important topics.

Sometimes framing the discussion as “ways to help a friend” can allow individuals to think aloud and share their concerns, confusions, and fears about abuse issues. If you are a senior or friend or advocate of a senior, insist that community programs address these issues regularly. Remember, printed handouts are not enough! People need to talk and share in order to learn and remember. People of any age can benefit from openly discussing safety, personal assistance needs, and crime- and abuse-prevention strategies.

The questions and tips below can be used in many ways: as talking points in discussions, or combined with BINGO, card games, or other activities to add fun and motivation. Laughing, joking, and silly prizes help people learn! See CAPE training and support group guidelines for further suggestions in Chapters [11] and [12].

Safety Questions

What helps you to safely navigate stairways?

- Inside and outside stairways need good lighting, railings, and non-skid surfaces.
- Have outside steps regularly cleared of snow or leaves.
- In winter use salt or sand in places where ice is a danger.

What are common causes of falls for seniors?
CHAPTER 16. SAFETY AND ABUSE-PREVENTION TIPS

BINGO for Safety

BINGO is a popular game among seniors. Here’s how to incorporate safety tips and abuse and crime prevention into an existing BINGO game:

1. Print out the list of questions and answers below in large print for reading aloud.

2. Cut the list into slips to be drawn from a hat or envelope.

Before each BINGO number is drawn, draw or select a slip with a safety question and answers from a hat. The question can be read aloud by the leader or participants can take turns. Invite participants to brainstorm together and discuss answers. There are many right answers to each question. Sometimes confusions or disagreements lead to good discussions. Right answers and enthusiastic ideas get points or small prizes, such as whistles or pens. Points can add up for a bigger prize. Rotate participants in the role of judge to assign points. Alternate safety questions with calling out BINGO numbers to keep the game going. Invite participants to make up new questions and answers. Starting with safety tips can open the door to discussing abuse prevention and other important issues.

- Scatter rugs; they can slip.
- Small pets haphazardly running about can trip people.
- Long robes or belts hanging down can be tripping hazards.
- Wearing loose slippers; they can fall off and trip people.
- Unsecured electrical cords can trip people.
- Wet or slippery floors.

What can help you avoid falls at home?

- Remove scatter rugs.
- Clear up clutter.
- Hold the railing(s) when going up and down stairs.
- Never use both hands to carry something (like a laundry basket) down the stairs.
- Get help or transfer whatever you need to carry to a bag you can carry with one hand.
- Small dogs should be trained to walk behind you.
- Don’t wear long robes. Securely tie up belts, so they are out of the way.
CHAPTER 16. SAFETY AND ABUSE-PREVENTION TIPS

- Wear nonskid shoes that stay on your feet.
- Keep electrical cords from path of travel.

How can you avoid fires?

- Don’t use old or damaged extension cords. Regularly check that they are in good shape.
- Don’t run an extension cord under a rug.
- Don’t run too many appliances on the same circuit.
- Check that the wattage of light bulbs matches the fixtures they are used in.
- Don’t leave burning candles or cooking food unattended.
- Be careful when you use your microwave. It’s easy to type in 60 minutes instead of 6.
- Check smoke alarms regularly. If you have a hearing loss, make sure to have a smoke alarm that will alert you in an appropriate way.
- Call 911 if a fire starts. Don’t wait!
- Leave the house and call from a cell phone or neighbor’s house.
- Get a fire extinguisher and know how to use it. Practice!

How can you avoid electric shocks?

- Keep appliances away from water.
- If an appliance falls into a tub, sink, or bucket that holds water, do not touch it.
- Don’t use that appliance until it is checked by an electrician.

How can you avoid hot water burns in the bath tub?

- Check bathtub water temperature carefully, hand up to the wrist first, before entering.

How can you avoid slipping in the bathroom?

- Put nonskid mats in the shower or tub.
CHAPTER 16. SAFETY AND ABUSE-PREVENTION TIPS

- Install grab bars in or near the shower or tub and next to the toilet.
- Wear nonskid shower shoes and nonskid slippers.
- Have a phone nearby.

Crime Prevention Questions

How can you avoid crime when you are at home?

- Have a deadbolt and/or chain-door guard installed.
- Check that locks on doors and windows are secure.
- Do not open the door automatically if someone knocks.
- Use a peephole, and speak to the person through the door. Ask who they are.
- If you are unsure, tell them you are busy with a friend. Don’t tell them you are alone.
- If you observe suspicious activity inside your apartment building or outside of your home or if you feel scared, call 911.
- Don’t tell a caller you are home alone, or when you will be alone.
- Don’t give money or personal information to someone who phones, knocks, or sends you email, no matter who they claim to be.
- Check that your house number is visible from the street for law enforcement officers or emergency personnel.

How can you avoid crime when you are not at home?

- Remember it is always better to be embarrassed and safe. It is never worth taking risky chances to avoid feeling embarrassed.
- Never leave a note on the door saying you are not home.
- Turn on a few lights or the radio when you go out at night or use an automatic timer.
- Don’t hide your keys under the door mat, over the door jam, or in another common location.
- If you hide a key for friends or family, place it where the individual can retrieve it out of view of the street.
- If you suspect someone is in your home when you return, don’t go in! Call 911.
- Likewise, if you return to your home and sense that anything is amiss, like the front door is ajar or a light is on inside and you know you didn’t leave it on, do not enter your residence. Go to a safe place and call 911!

How can you stay safe when on a bus?

- Sit by the bus driver.
CHAPTER 16. SAFETY AND ABUSE-PREVENTION TIPS

- Pay attention to your surroundings.
- Keep valuables out of sight.
- Keep your belongings close to you.
- Don't get off the bus if you feel you are being followed. Tell the driver.

What should you do if you are mugged or attacked on the street?

- Make a lot of noise! Yell for help!
- Carry a whistle in your pocket. Blow long and hard if you feel there is a problem.
- If you go out at night, go with someone else and stay in well-lit and well-traveled areas.

How do you avoid getting your wallet or purse snatched?

- Keep your wallet or purse close to your body, not in a bag with a long strap.
- Never leave your purse, wallet, or bag unattended.
- Carry only the cash you will need.
- Pay attention to your surroundings at all times.

How can you avoid crime while in your car?

- Put your purse on the floor on the passenger side, not on the seat.
- Put packages in the trunk, not on the back seat.
- Check the back seat of your car before you get in.
- Use direct deposit for Social Security checks. Some crooks find out when government checks are sent out and steal them from recipients’ mailboxes.
- Lock your doors.
- Don't roll down your window when someone approaches and indicates he or she wants to ask you a question.

How can you avoid fraud?

- If an offer sounds too good to be true, it most likely is a fraud. Don’t be gullible.
- There are no free prizes, free vacations, magic cures, or perfect investments.
- Never respond to pressure to “buy now.” Think it over first. Talk to someone you trust before making a decision
- Get estimates or offers in writing.
- Use direct deposit for checks whenever possible.
- Never give personal information such as your social security number or credit card number to someone offering a reward or prize. If you are contacted by phone, ask that a written application be mailed to you. If they refuse, hang up.
CHAPTER 16. SAFETY AND ABUSE-PREVENTION TIPS

- If you suspect something is wrong with a deal or offer, call the police, the Better Business Bureau, or the National Consumer League Fraud Information Center, 800-876-7060.

- If you feel you have been cheated or scammed, call the police.

Why are older people targeted by scam artists?

- Older people may have limited incomes and need money.

- Older people may be alone or lonely, and scam artists pose as friendly and helpful.

- Sometimes memory problems make people gullible.

- Older people may have less confidence in their own thinking, or be afraid of looking foolish, and so they go along with a scam artist’s pressure.

- Older people are more likely to have hearing loss and misunderstand deceptive offers.

Abuse Prevention Questions

What can you do if someone threatens to hurt you?

- Call the police! Call 911.

- Tell someone you trust: your nurse or doctor, a clergy person, or a friend.

- Don’t put up with abuse! Get help!

When a friend shows signs of abuse or neglect, can you spot them? What are they?

- Bruises on face, arms, or legs.

- Broken eyeglasses or frames.

- Changes in personality or behavior.

- Unusual weight loss or dehydration.

- Unkempt appearance or a dirty house.

- Sudden change in financial situation.

- Items or cash missing from home.

What can you do if you suspect abuse or neglect of a friend?

- Express your concern for the individual’s safety in a calm, patient way.

- Offer to help, but don’t try to take over. Be respectful of his or her way of doing things.
CHAPTER 16. SAFETY AND ABUSE-PREVENTION TIPS

- You can keep your friend’s trust by being relaxed. Offer to brainstorm options for help.

- If the person has dementia or refuses to change a bad situation, tell someone you trust, like a friend, nurse or doctor, clergy person, or social worker.

- If you suspect physical or sexual abuse, call 911.

What is not okay for a family member or personal assistant to do?

- Get into personal possessions without permission.

- Yell, scream, threaten, or say insulting things.

- Make negative comments about someone’s disability.

- Steal money, checks, credit cards, medication, or other personal belongings.

- Show up for work drunk or high.

- Neglect or ignore needs or withhold medication.

- Pressure a disabled person to eat fast or go to bed early in order to leave sooner.

- Prevent a person from controlling his or her wheelchair, phone, or other equipment.

- Control where someone goes, what she or he does, or whom the person can see.

Multicultural Tip #5: Using Examples to Clarify Unfamiliar Concepts

Use many examples as a way of clarifying concepts when confusing or complex technical terms are introduced. Even people who speak English well and native English speakers may not be familiar with the terms used within the disability community.

For more tips, see Chapter 10.

- Gossip, threaten, blackmail, or manipulate.

- Hit, kick, slap, or hurt the person in any way, including rough handling.

- Pressure or touch someone sexually in unwanted ways.

- Keep a person from being as healthy or independent as he or she could be.

For more information, see the section and resources about Elders in Chapter 9 on page 116.