# *Journey of Self-Discovery*

## *A Study Guide for Trauma Survivors*

June 1, 2007

N P W
NEW
PARTNERSHIPS FOR
WOMEN

**New Partnerships for Women**
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# ACKNOWLEDGEMENTS

The *Consumer Curriculum Handbook* was initially developed for New Partnerships for Women (NPW) by an ad hoc collaborative work group whose members met for over a year between April of 2001 and June of 2002. The work group's members included: Jessica Barton, NPW; Lori DeGayner, Survivor; Heather Dunn, Cornucopia and Yahara House; Mary Beth Forsythe; Nancy Lee Fowlkes, Phi Beta; Dianne Greenley, Wisconsin Coalition for Advocacy (WCA); Cindy Harrington; Heather Hazelwood, NPW; Barb Hennings, NPW, Yahara House; Karen Herro, Cornucopia; Anne Ivey, NPW, Families United Network; Lori Kinnard, Cornucopia, NPW, Grassroots Empowerment Project; Lori Luebke, NPW, Employment Resources, Inc.; Ellen Magee, Catholic Charities; Karen Milstein, Cornucopia, Yahara House; Carin Mizera; Joy Newmann, University of Wisconsin-Madison School of Social Work; Alyson Petrick; Ruth Roshke, Consumer; Jolanda Sallmann, NPW; Anne Sullivan; and Kimberlee Wright, Domestic Abuse Intervention Services (DAIS).

The *Handbook* was revised and renamed in 2007 in response to several years of feedback from women who had participated in trainings and our desire to ground it in more recent empirical findings about the nature and effects of trauma. It also represents an attempt to incorporate material that has broad appeal to women of diverse ethnic and racial backgrounds and includes a new chapter on self-advocacy skills produced by Disability Rights Wisconsin. The Consumer Curriculum Revision Committee, chaired by Joy Newmann, included: Donna Erickson, Annette Felice, Mary Beth Forsythe, Lori Kinnard, Sherrill Sellers, and Alev Wilk. Others were added to the group in the final review process, including Yolanda Bohorquez, Jeanne Boydston, Emma Earl, Dianne Greenley, Julie Holfelz, and Marie Sarto.

We thank workgroup members for their selflessness, insight and humor! Without your hard work, knowledge, and expertise, this *Study Guide* would not have been completed. We also thank the agencies and programs that many of our workgroup members represent for supporting the efforts of NPW by donating the time of their staff during the initial development of the Handbook. We especially thank the YWCA of Madison for both housing and believing in the goals of the New Partnerships for Women project since its inception. Gayle Ihlenfeld, the project supervisor in 2001-2 deserves special thanks for her considerable help and support. The 2007 revisions were completed with the guidance and leadership of Annette Felice, our project coodinator during the years NPW incorporated and moved to the Rape Crisis Center of Dane County. We thank Rape Crisis and its Director, Kelly Anderson, for continuing to offer support to the project these past three years.

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# INTRODUCTION

*All of the information helped to reinforce the things I have been learning in therapy and life. It's good to talk about things and remember that I am powerful and have choices.*

*This is such a good reminder of how far I've come in healing and for when I get stuck.*

*I'm not alone!*

*~Evaluation comments from women who attended the NPW Consumer Curriculum Training Series*

## New Partnerships for Women

Welcome to the *New Partnerships for Women Study Guide for Trauma Survivors entitled: Journey of Self-Discovery*. The *Study Guide*, as we will refer to it subsequently, was originally designed as a *Handbook* to accompany the *New Partnerships for Women Consumer Curriculum*. The *Curriculum*, and its accompanying *Handbook*, was developed over the course of several years by a collaborative workgroup launched in 1998 as part of the Women and Mental Health Study Site of Dane County (WMHSS) and continued under the auspices of New Partnerships for Women, Inc. (NPW). The purpose of NPW, which was a direct outgrowth of WMHSS, is to continue to build the capacity of the community to promote healing and recovery for women who have histories of trauma and mental health or substance use problems, or both. Capacity building efforts include: (1) training activities, (2) consumer involvement and empowerment activities, (3) dissemination of information from the needs assessment of Dane County women, and (4) advocacy activities on behalf of these women.

The idea for the *Curriculum* was initially developed by an ad hoc consumer group organized within WMHSS. Drawing on findings from the needs assessment study, the group identified four focal topics to be covered in the *Curriculum*: (1) scope and impact of trauma on women's lives; (2) management of symptoms and substance use; (3) meeting women's basic needs; and (4) advocacy. A collaborative workgroup, including consumers, providers, researchers, and educators in the areas of trauma, mental health, and substance use, was subsequently developed within NPW to complete the design of the *Curriculum* and the *Handbook*. In its original version, the *Handbook* covered the first three topics noted above while the fourth was covered in a separate advocacy manual developed under the guidance of the Wisconsin Coalition for Advocacy (WCA). The 2007 revised version of the *Handbook*, which we refer to subsequently as a *Study Guide*, includes an advocacy chapter developed by

Disability Rights Wisconsin (formerly Wisconsin Coalition for Advocacy) as part of its *Advocacy Tool Kit.*[1]

The *Curriculum* was created specifically for women with histories of abuse who have a mental health or substance use problem, or both, and who may be confronting other life challenges. Moreover, it was originally designed as a series of consumer trainings for which this *Study Guide* was a supplement. We believe that any woman who is living with one or more of these issues may benefit from material in the *Study Guide*.

Trauma is all too common in the lives of women and plays an important role in the development of mental health and substance use problems, as well as many other life problems. Here we share one woman's conceptions of these relationships:

> *I mean the trauma and the substance abuse cause your mental health to be weakened. It's a triangle, . . . 3 circles inner-connecting so that they're connected and they influence each other. I like the three-circle idea. I have to draw it to be able to talk about it. So let's put mental health in the middle, and substance abuse over here, and ah trauma here. Mental health alone would be wellness, but with trauma and substance abuse, mental health is, you've got illness then. So you need treatment. You need the treatment for your substance abuse. You need treatment for trauma. You need treatment for the mental health. And otherwise I don't think you can get better, unless your trauma and your substance abuse is minor, maybe then you can get better on your own. But if you got moderate to severe, I don't think so. I think you need treatment of some kind. So yeah, they're intertwined. There's a connection, and it takes a long time. People have to be patient, work hard.*[2]

Although we acknowledge that this is very difficult work, we believe that healing and recovery are possible. For many women, this is a process of self-discovery, rather than recovery or healing, especially if the abuse started early in life. That is why we chose the title—***Journey of Self-Discovery***—for this *Study Guide*. We think it more aptly reflects the process that most women engage in following abuse experiences.

Many women will pursue this journey without professional help. Whatever pathway you may choose, we hope you find the material provided in this *Study Guide* useful to you in your own recovery or self-discovery process. Our ultimate goal is to help women like yourself appreciate areas of resilience in your life and develop the self-confidence and personal strength to make life changes that are important to you.

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[1] For more information on the *Advocacy Tool Kit* or other resources from Disability RightsWisconsin , please visit DRW's web site located at www.disabilityrightswi.org or by telephone at 608-267-0214 (voice/TTY) and request a brochure of available resource materials and videos.

[2] Excerpt taken from: Nadine Nehls and Jolanda Sallmann (August 1, 2001). *FORGING NEW PARTNERSHIPS WITH WOMEN: Listening to Women's Voices.* The Women and Mental Health Study Site of Dane County, School of Social Work, University of Wisconsin-Madison.

## Women and Mental Health Study Site

The WMHSS was one of 14 sites around the country that was funded by the Substance Abuse and Mental Health Services Administration (SAMHSA) in 1998 to study and improve services for women with histories of trauma and co-occurring mental health and substance use problems. The WMHSS undertook three primary tasks as a part of this study, each of which had significant implications for the development of this *Curriculum*.[3]

The first task was information gathering through a three part needs assessment. Computer assisted personal interviews were conducted with over 200 women who had received services from the publicly funded mental health and substance use treatment systems in Dane County. A subset of thirty of these women, who reported histories of trauma, mental health, and substance use problems, were invited to participate in a second in-depth interview.

The goal of this two stage interviewing process was to determine the number of women with trauma histories and co-occurring mental health and substance use problems who enter systems of care. Additionally, we hoped to learn about women's experiences with the treatment systems, what they found helpful or harmful, and what resources they felt they needed to improve the quality of their lives. In addition, a series of forums or focus groups was held to reach women who may struggle with these problems but not feel they have access to existing systems of care, e.g. women living in more remote areas of the county and women of minority group status. The information collected through these three needs assessment activities has been incorporated throughout the curriculum. For more information about some of the primary findings from this study, we have included the executive summary from the study site's final report in this manual (Pp. 8-23). More recent publications are noted below.[4]

**Suggested Reading:**

- *Forging New Partnerships with Women: Executive Summary* by Joy Newmann, Anne Ziege, and Jolanda Sallmann

The second task was to bring together a collaborative team of consumers, providers, funders, administrators, academics, and advocates to learn from the needs assessment

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[3] The following description was taken from the WMHSS report *PROM* *CONSUMERS: An Experiential Report and "How To" Guide* (March 21, 2001). Dianne Greenley, Jessica Barton, Barbara Hennings, Lola Barrientos Marquez, and Peg Michaelis. The Women and Mental Health Study Site of Dane County, School of Social Work, University of Wisconsin–Madison. Available through the Disability Rights Wisconsin (formerly Wisconsin Coalition for Advocacy). For more information, please visit their website at: www.disabilityrightswi.org or contact DRW by telephone at 608-267-0214 (voice/TTY).

[4] Newmann, Joy P., & Sallmann, Jolanda. (2004). Women, Trauma Histories, and Co-occurring Disorders: Assessing the Scope of the Problem. *Social Service Review, 78* (3), 466-499. Nehls, Nadine, & Sallmann, Jolanda (2005). Women living with a history of physical and/or sexual abuse, substance use, and mental health problems. *Qualitative Health Research, 15(3)*, 365-381.

and each other's perspectives, and to develop plans for improved services for women struggling with these issues. The New Partnerships for Women Consumer Curriculum Development Workgroup continued in this spirit, collaboratively developing the *Curriculum* and *Handbook*.

The final task of the study site was to train consumers and providers. A major goal of the project was to raise community awareness of the impact of trauma on the lives of women, including its impact on the development and course of mental health and substance use problems. In the words of the Substance Abuse and Mental Health Services Association (SAMHSA), we hoped to create a "trauma informed" community. Thus, training was provided for the entire array of community service providers on the impact of trauma, trauma assessment, treatment approaches, working with co-occurring mental illness and substance abuse, and parenting issues for women with a history of physical or sexual abuse. Training was also provided for consumers on several topics of their choice, including advocacy and boundary issues.

Now that we have provided you with some background on the development of this *Curriculum*, we would like to introduce you to the different chapters of the *Study Guide*.

## The Nature and Scope of Trauma in Women's Lives

The first chapter of the Study Guide begins with a definition of trauma and highlights the scope of trauma in women's lives. We focus, in particular, on a specific subset of traumatic events, namely physical and sexual abuse, and discuss the scope of such forms of interpersonal violence in women's lives. We believe that exposure to such events, which frequently first occurs during childhood for many women, can have long-lasting and extremely adverse effects.

## The Effects of Trauma in Women's Lives

In chapter two, we draw on women's stories to highlight the distinction between short-term and longer lasting effects of exposure to sexual and physical abuse with a special focus on the question: What are the pathways through which exposure to interpersonal violence and abuse can lead to mental health and substance use problems for adult women? Further, we ask: What resources—both personal and situational—can protect against the development of such problems or help a woman with her recovery process?

We believe that answers to these questions can help women open a door to a happier and healthier life. Thus, the chapter ends with a few exercises to help you identify some of the ways trauma may be affecting your own life. We view such self-knowledge as an important beginning step in better managing your symptoms, securing needed resources, and advocating for yourself. These topics are developed in the following chapters of the *Study Guide*.

## Symptom Management

The purpose of this chapter is to help you better understand your symptoms and their relationship to traumas that may have occurred in your life. It also includes some management tools for your own recovery process. We begin by defining "symptoms" and "symptom management" in relation to coping mechanisms women often use to survive or deal with abuse in their lives. We view many symptoms as behaviors and emotions that helped women survive and cope with past traumas, although they may have outlived their usefulness and contributed to other life problems. Symptom management is the diverse set of skills and techniques that we use to ease the intensity of a symptom. Given our uniqueness as individuals, both symptoms and the ways we manage them are different for each person. The rest of the chapter is dedicated to providing you with an assortment of skills and activities to choose from to help manage your own symptoms.

## Meeting Women's Basic Needs

A major finding from the WMHSS is that economic adversity (experiencing poverty) and its consequences are major problems with which women need and want help. This chapter is intended to give you a general understanding of how economic adversity may be one of the pathways through which histories of trauma can lead to mental health and substance use problems. It is also designed to provide you with some skills in locating resources in your own community and to introduce you to several resources in Dane County dedicated to helping women meet their basic needs.

## Skills and Strategies for Effective Self-Advocacy

The final chapter of the *Study Guide* was developed by Disability Rights Wisconsin under the leadership of Dianne Greenley. It is part of a larger Advocacy Tool Kit (2007) that is available through DRW and we thank them for allowing us to include it here. It focuses primarily on self-advocacy skills, although the full tool kit includes peer advocacy as well. We suggest that you contact DRW if you are interested in learning more about it (608-267-0214).

## Before Getting Started

We view the *Study Guide* as a self-help toolkit. It is not intended as a replacement for therapy or treatment. You might find that reading through the materials triggers thoughts, memories, feelings, or emotions related to abuse or other traumas you may have experienced. If you find yourself overwhelmed by your feelings or emotions, or physically reacting to what you are reading, we suggest that you seek professional assistance. If you do not know where to go for help, check your local Yellow Pages under such listings as: "Crisis Intervention Services," "Domestic Abuse Intervention and Treatment Centers," "Rape Treatment Centers," and "Suicide Prevention Services." Many phonebooks also provide a listing of "Community Services" in the front; this usually includes several 24-hour hotlines as well as trauma, mental health, and substance use services. At the end of this Study Guide there is information about "211," a referral service offered by the United Way of Dane

County. There is also information on New Directions Information Center, a program of the Mental Health Center of Dane County that helps Dane County residents find mental health and substance abuse resources.

Before you begin reading through this Study Guide we have a few suggestions for you. Although this is very hard work, we believe that healing and recovery is possible for everyone. We urge you to start with the view that you are an expert on yourself. Listen to what your mind and body is telling you about how much work you are able to do in the area of trauma.

**We encourage** you to work through this Study Guide at your own pace. Feel free to take breaks or to set the Study Guide down for as long as you need to, even if that means setting it aside for several months.

**We encourage** you to pick and choose articles and activities that feel most relevant to your life and experiences and disregard those that do not feel as though they apply to you.

**We encourage** you to work through this Study Guide in a place that feels safe and comfortable to you. You may find that this means dedicating quiet time alone to do this work, or you may find that you would like to have someone else with you. Remember, there is no right way to do this work. Find what fits best for you.

**We encourage** you to have a support system available. This could be a friend, neighbor, support group, or professional counselor. Use this system, not only if you find yourself in crisis, but also if you just need a little extra support while working through these difficult issues.

**We encourage** you to take good care of yourself. Become aware of what makes you feel good. Try to do at least one good thing for yourself each day and make sure to reward yourself for all of the hard work you are doing.

Finally, **we encourage** you to have hope for the future. We ask you to share our belief that healing and recovery *are* possible. We have seen these changes in our own lives and believe that you can also effect positive change in your life through using the information and skills we have provided in this Study Guide.

# Chapter Two

# The Nature and Scope of Trauma In Women's Lives

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## Introduction

Welcome to Chapter Two of the *Study Guide*: The Nature And Scope Of Trauma In Women's Lives. Our purpose in this chapter is to define what we mean by trauma, highlighting the distinction between life adversities that women face and their personal responses to those adversities. We then discuss the scope of a particular set of life adversities that we believe, and studies have shown, are important in the development of mental health and substance abuse problems among women—exposure to interpersonal violence and abuse.

## Definition of Trauma

You might wonder what we mean by the term "trauma." The term can be confusing because it is often used to refer both to events that are considered to be extremely stressful (traumatic events) *and* to the responses (psychological trauma) that develop from having experienced such events. When we speak about the "effects of trauma on women's lives," we are referring to *both* the effects of actual traumatic events *as well as* the effects of the psychological trauma that the events can create.

**Suggested Reading:**

- *What is Psychological Trauma?* by Esther Giller

As noted in the excellent article by Esther Giller, a person experiences *psychological trauma* as a result of exposure to an extremely stressful life event or enduring conditions that ***overwhelm his or her perceived ability to cope with the circumstances***. This definition reminds us that ***it is not only the actual event or enduring conditions that are traumatic; it is also our perception of those life circumstances and our capacity to deal with them***. What makes such events or circumstances so overwhelming is that we may fear that our inability to cope with them can have life threatening consequences-we may fear for our lives, our sanity, our physical safety, even our economic survival. This could also mean that we fear we will lose the love of a parent or significant other, or fear they will leave or abandon us. In a sense, then, our reactions to traumatic events are uniquely determined in that they depend on our own individual perception of the event or circumstances, and their consequences for our well-being.

However, there are certain life events or enduring circumstances that most people would perceive as extremely adverse and life threatening and likely to induce a state of psychological trauma in almost everyone exposed to them. Such traumatic events include powerful one-time incidents like accidents, natural disasters, crimes, surgeries, deaths, and other violent events. Equally, and sometimes more traumatic, are chronic or enduring life circumstances such as child abuse, neglect, combat, urban violence, concentration camps, battering relationships, racism and discrimination, and enduring economic deprivation.

This Study Guide will focus on a specific set of traumatic life events believed to play a causal role in the development of mental health and substance use problems in women; that is, exposure to interpersonal violence or abuse. We will focus in particular on histories of physical and sexual abuse experienced at any point in the life course of women. As shown in our review of the scope of trauma in women's lives, such events begin early and recur across the life course for many women. Moreover, physical and/or sexual abuse often co-occurs with other life adversities for many women, creating stretches of life that have an unrelenting battlefield quality.

## Scope of Trauma in Women's Lives

**Suggested Reading:**
*Prevalence, Incidence and Consequences of Violence Against Women: Findings from the National Violence Against Women Survey* (Tjaden and Thoennes, 1998)

You may ask, how common are such experiences in women's lives? Community studies of the number of women who have been exposed to histories of physical or sexual abuse are typically the best source of such estimates in that they sample women from the general population. Although there have been a number of smaller community studies, some focusing on physical abuse, others on sexual abuse, one of the largest and more recent studies that focused on both forms of abuse is the National Violence Against Women Survey (NVAW). Sponsored by the National Institute of Justice (NIJ) and the Centers for Disease Control and Prevention (CDC), the study involved telephone interviews conducted in 1995-1996 with a nationally representative sample of 8000 women and 8000 men. Major findings of the study are highlighted below:

- 52% of American women said they were physically assaulted either as a child by an adult caretaker or as an adult by any type of perpetrator. Such assaults included a range of behaviors, from slapping and hitting to using guns.
- 18% of women surveyed said they experienced a completed or attempted rape at some time in their life involving forced vaginal, oral or anal intercourse.
- Combining responses to both types of abuse, the study found that 55% of women had experienced either physical or sexual abuse in their lifetimes.

These are sobering findings in that they show that over half of adult women are victimized either sexually or physically. Moreover, many become first-time victims during childhood or adolescence—an experience that is associated with a higher risk of physical and sexual assaults during adulthood.

- More than half of the female rape victims (54%) were under 18 years of age when they experienced their first rape—22% of women who disclosed rape were under 12 years of age when it first happened; 32% were first raped between 12 and 17 years of age
- Over three quarters (76%) of the women who reported some form of physical abuse in their lifetimes reported having been physically assaulted by a caretaker as a child or adolescent
- Each form of childhood victimization experience is linked with twice the risk of being an adult victim of sexual or physical assaults compared to

women who did not report being physically assaulted by a caretaker or raped as a child or adolescent

But, you might ask, what makes this a women's issue? Aren't men also victims of violence? Yes, men are victims of violence. In fact, in the NVAW study, more men than women reported experiencing physical assaults in their lifetime—66.4%. Moreover, over 80% of men who reported such victimization experiences said they were physically assaulted by a caretaker as a child or adolescent. However, there are several features of the experiences of women and men that seem to be quite different:

- Women are six times as likely as men (18% vs. 3%) to report being sexually assaulted and/or raped in their lifetime
- Such victimization experiences often first occur in childhood in the context of one's own family for girls and are more likely to involve *both* sexual and physical abuse than is the case for boys
- As girls become young women or adults, they are at significantly greater risk than men of being assaulted by an intimate partner
    - 25% of women compared to 8% of men reported being raped and/or physically assaulted by a current or former spouse, cohabiting partner, boyfriend or girlfriend, or date in their lifetime
    - Moreover, gender differences in rates of physical assaults by an intimate partner become greater as the seriousness of the assault increases
- Women are stalked (followed by someone who induces a high level of fear) in disproportionate numbers compared to men (8% vs. 2%) and their stalkers are often current or former intimates
- Violence against *adult* women is primarily intimate partner violence
    - 64% of women who reported being raped, physically assaulted, and/or stalked since age 18 were victimized by a current or former husband, cohabitating partner, boyfriend, girlfriend, or date
    - By contrast, only 16.2% of the men who reported being raped and/or physically assaulted since age 18 were victimized by such a perpetrator
- Violence against *adult* women, and men, is primarily male violence
    - 93% of women and 86% of men who were raped and/or physically assaulted since the age of 18 were assaulted by a male
    - By contrast, 11% of women and 23% of men were assaulted by a female

These findings, which have been reported in studies around the world and across racial and ethnic groups, have led the Center for Health and Gender Equity (CHANGE) to conclude that violence against women and girls is gender-based violence that must be recognized as a major public health concern and a violation of human rights (1999). They note:

It is often known as "gender-based" violence because it evolves in part from women's subordinate status in society. Many cultures have beliefs, norms, and social institutions that legitimize and therefore perpetuate violence against women. The same acts that would be punished if directed at an employer, a neighbor, or an acquaintance often go unchallenged when men direct them at women, especially within the family.

In short, whether you are black, white, Asian, Latina, Native American, or some mixture of these racial or ethnic identities, if you are a woman, the odds are over 50% that you will have experienced some form of physical and/or sexual violence in your lifetime, according to findings reported by the NVAW survey. Although there is some variation in rates of different types of violence across these groups of women, the overriding conclusion is that violence against women—particularly violence perpetrated by men--is a cross-cultural experience.

Does this mean that women are never violent or abusive toward others? No it does not. In fact, we encounter many women who describe experiences of childhood abuse and cruelty that are perpetrated by mothers or female caretakers, and who, themselves, have either neglected or emotionally, physically or sexually abused their own children. Unfortunately, community studies, such as the NVAW study, do not provide a breakdown of rates of childhood abuse of different forms perpetrated by men versus women. The National Child Abuse and Neglect Data Systems (NCANDS), which summarizes reports by states on the numbers of children who enter the public child welfare system, do show that child maltreatment that comes to the attention of authorities occurs primarily at the hands of parents, and especially mothers. In its most recent report of findings from 2003 maltreatment statistics (U.S. Children's Bureau, 2005), 12.4 children per 1000 were maltreated and most of the perpetrators (80%) were parents. Moreover, women comprise a larger percentage of all perpetrators than men—58% compared to 42%. Again, because most child maltreatment does not come to the attention of authorities, these numbers are much smaller than numbers from community studies, such as the NVAW survey. Moreover, they show that the most common form of maltreatment is neglect (60% of victims), followed by physical abuse (20%), sexual abuse (10%), and emotional maltreatment (5%).

You may, in fact, be a victim of some form of abuse at the hands of a woman, perhaps your mother, or you may have victimized your own children. This should not surprise any of us as women do most of the caretaking of children. Moreover, sometimes women do not protect their children from abuse at the hands of men, whether fathers, step-fathers, or boyfriends. Often they do not protect themselves from such violence and children suffer from witnessing it. It is, in fact, violence against adult women that the NWAW Survey was primarily designed to investigate. The finding that most adult violence that women experience is perpetrated by men, usually a date, boyfriend, partner, or spouse, does not mean that *only* men are perpetrators. Nor does it mean that all women are in intimate relationships with only men.

Tjaden and Thoennes (2000) asked if men and women who reported ever living with a same-sex partner as a couple experienced more or less violence than men and women who had only lived with an opposite-sex intimate partner. Their initial findings suggested that same-sex intimate relationships were more violent than opposite-sex relationships:

- 39.2% of women with a history of same-sex cohabitation and 21.7% of women with a history of opposite-sex cohabitation reported being either raped, physically assaulted, or stalked by an intimate partner at some point in their lifetime
- 23.2% of men with a history of same-sex cohabitation and 7.4% of men with a history of opposite-sex cohabitation reported being either raped, physically assaulted, or stalked by an intimate partner at some point in their lifetime

However, when they analyzed the data separately for male and female perpetrators, they found a significant gender difference in patterns of partner violence for men and women in same-sex relationships:

- Only 11.4% of women with a history of same-sex cohabitation had ever been victimized by a female co-habiting partner, while 30.8% had been victimized by a male co-habiting partner
- Conversely, 15.4% of men with a history of same-sex cohabitation had been victimized by a male co-habiting partner, while only 10.6% had been victimized by a wife or female co-habiting partner

These findings suggest that intimate partner violence is perpetrated primarily by men, whether against male or female partners.

The NVAW survey also found that women of color are exposed to more partner violence than white women (28.6% vs. 24.8%). However, victimization rates differ significantly by racial identity status:

- 15% of Asian Pacific Islander women reported being victimized by an intimate partner in their lifetimes--the lowest rate of all the groups
- 37.5% of American Indian/Alaska Native women reported being victimized by an intimate partner in their lifetimes—the highest rate of all groups
- Women of mixed racial backgrounds and African American women reported comparable rates of intimate partner victimization—30.2% and 29.1% respectively

Finally, the NVAW survey found no significant difference in rates of partner violence for Hispanic and non-Hispanic women—23.4% of Hispanic women and 25.6% of non-Hispanic women reported being victimized in their lifetime by an intimate partner.

In summary, while there is some evidence that rates of partner violence vary across racial and ethnic groups, it is clear that intimate partner violence is a major risk for women who enter into intimate, co-habiting relationships. In an analysis of what increases the risk of such violent experiences for women, independent of race or ethnic identity, the NVAW survey identified several risk factors:

- having been physically abused as a child by a caretaker
- having a higher educational level than one's partner
- cohabiting or living with a partner
- having a partner who is jealous or possessive
- having a partner who is verbally abusive

You may be asking yourself, "Why is it important for me to have to learn these unpleasant facts about women's shared victimization experiences?" We think there are four reasons. First, there is a growing body of evidence that histories of physical and/or sexual abuse are linked with a wide range of personal problems in women's adult lives. In a follow-up study of the health impacts of violence based on the NVAW survey, Thompson and her colleagues (Thompson, Arias, Basile, and Desai, 2002) found that both physical and sexual victimization in childhood were significantly associated with women's poorer perception of general health, sustaining a serious injury, acquiring a mental health condition, and using drugs and alcohol in adulthood. Similarly, the Adverse Child Experiences (ACE) study, conducted with over 19,000 enrollees in the Kaiser Permanente Health Plan in California, has concluded that abuse and household dysfunction during childhood increases the risk of a range of health problems among adults (Felitti et al., 1998). Such problems include a higher risk of cigarette smoking, obesity, physical inactivity, alcoholism, drug abuse, depression, suicide attempts, sexual promiscuity, and sexually transmitted diseases. You may be grappling with one or more of these problems, but not considered the possibility that abuse experiences in your life may have contributed to these problems. We think it is important for women to know about, and reflect on, these larger patterns as a beginning step in self understanding and self-caring, as well as collective actions.

Second, in our experiences in talking with women who participated in the Women and Mental Health Study Site (WAMHSS), we were struck by how common physical and sexual abuse is in the lives of women who enter the alcohol, drug, and mental health (ADM) systems of care. As shown in the suggested reading (Newmann and Sallmann, 2005), 88% of the women interviewed reported having experienced either physical or sexual abuse in their lives—a much higher percent than shown for women in the general population (NVAW Survey). Although these findings reflect the epidemic nature of violence in women's lives, many women, including a number of us involved in drafting this document, have often felt very alone in experiencing abuse. We thought that we were the only ones this was happening to. In fact, many women told us after the interview that it had been a relief to be asked, and to be able to report, their abuse experiences, since so many women had never had it publicly acknowledged in their lives. Equally important, it was a relief for many women to discover that other women had had similarly painful and difficult life experiences, because it helped them feel less alone. So one of our goals in sharing these findings with you, which are reported in more detail in the suggested reading, is to help you take stock of your own experiences and, if you have

**Suggested Reading:**
*Women and Trauma Histories: Assessing the Scope of the Problem in the ADM System* (Newmann and Sallmann, 2005)

experienced such traumas in your life, understand that you are not alone. Nor are you without support and resources to cope with such realities.

A third reason we think it is important for you to become familiar with information about violence in women's lives is that gender-linked violence goes beyond experiences of physical and sexual abuse. In the WAMHSS study, we discovered that three quarters of women report experiences of emotional abuse or neglect; that is, affirming the experience of being frequently shamed, embarrassed, ignored, or repeatedly told that they were no good. Over a third of the women have been separated from a child against their will (through loss of custody, or visitation or kidnapping), close to 60% have been sent to jail and more than 70% report having had serious money problems, for example, not enough money for food or a place to live. In short, these are women who face many adversities on a daily basis, including sexual harassment in the workplace or job (48%) and violence even at the hands of service providers—30% of the women report having been strip-searched, forcibly restrained, or held against their will by a provider of mental health or substance abuse services. We note these traumas, and will discuss them further as we progress through the curriculum, as a number are particularly troubling for women.

Fourth, in the chapter that follows, we will review several prominent theories, and related evidence, about how such abuse experiences and related life adversities may be linked to mental health and substance use problems, as well as to their co-occurrence, among adult women. We will also highlight sources of resilience and strength in women's lives that can help prevent the development of such problems. We believe that a better understanding of such processes, pathways and "protective" mechanisms will be helpful in developing your own theory of risk and protective factors in your life, and ultimately empower you to move forward in your own healing and recovery. We think it will also help you seek the help you may need from care providers who are both "trauma-informed" and who can offer "trauma-specific" services, if and when you feel you need them.

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# Chapter Three
# The Effects of Trauma In Women's Lives

N P W
NEW
PARTNERSHIPS FOR
WOMEN

## The Effects of Trauma on Women's Mental Health and Substance Use

There are many theories linking trauma and mental health or substance use problems among women. They differ in a number of important ways that shape what we know about the effects of trauma in women's lives. One difference among theories is in whether they are focused on short-term reactions to trauma, or reactions occurring over a longer period of time. Another difference is in the pathway or pathways they view as important in understanding the trauma-mental health link.

In this chapter, we begin by reviewing a prominent theory of the immediate, or short-term, effects of trauma exposure on men and women's lives, which assumes that most people recover in the short-term from such exposures, although some go on to develop more long-lasting mental health problems. We then share the stories of several women for whom traumatic experiences are longer lasting and ask, what is it about their lives and experiences that made it difficult for them to recover in the short-term? Drawing on these stories, along with findings from community studies of trauma exposure and consequences, we develop a general theory of the pathways through which exposure to traumatic life events may lead to a mental health or substance use problem, or both. We also consider some of the resources and strengths of women that help them prevail in the face of great adversity.

## Short-term effects of trauma in women's lives:

As Edna Foa and her colleagues (2006) note in *Common Reactions to Trauma,* exposure to traumatic life events or experiences may cause many emotional problems in the short term. In fact, many of these changes following a trauma are normal and most people who experience a major life trauma have severe problems in the immediate aftermath. Here we highlight some of the more common problems adults experience in the wake of a traumatic life event, which are described in more detail at the website for the National Center for post traumatic stress disorder (PTSD) (see reference for site).

**Suggested Reading:**
- *Common Reactions to Trauma* by Edna B. Foa, Elizabeth A. Hembree, David Riggs, Sheila Rauch, and Martin Franklin (2006)

- *Fear and anxiety* are common and natural responses to a dangerous situation and may continue, if not recur long after the trauma has occurred, sometimes being triggered by places, times of day, smells or noises, or other situations that remind you of the trauma.
- *Re-experiencing the trauma* through unwanted thoughts, flashbacks, or vivid images are also common.
- *Increased arousal* is another common response to trauma, which may be accompanied by feeling jumpy, jittery, shaky or irritable. Such arousal reactions are due to the fight or flight response in our bodies in the face of danger—we, like animals, protect ourselves from danger by fighting or running

away. This requires more energy than usual so our bodies pump out extra adrenaline to help us get the extra energy we need to survive. Over long periods of time, such states of arousal and vigilance can be very uncomfortable. Another variation of this state is *freezing*, much like a deer caught in the headlights.

- *Avoidance* is another common response to managing trauma-related pain. We may avoid situations associated with the trauma or even push away painful thoughts and feelings resulting in *numbness* or the deadening of any feelings.
- *Anger or irritability* commonly follow traumatic experiences and can be extremely uncomfortable, especially if experienced on the spur of the moment in relation to people you are close to.
- *Guilt and shame* may also follow exposure to traumatic life events, particularly if one feels somehow to blame for what happened or is made to feel that way by others.
- *Grief and depression* are also common reactions to trauma and can include feelings of hopelessness and despair, sadness, and crying, or feeling that life is not worth living.
- *A negative self-image or view of the world* can also develop following a traumatic life experience. You may decide "I am a bad person and deserved this." Alternatively, you may conclude that you can't trust anyone or anything. Both feelings can co-exist and are often part of the package of guilt, shame, grief, and depression.
- *Sexual relationships* may also suffer after a traumatic experience. For many, a loss of interest in sex is common, particularly if the trauma involves a sexual assault.
- *Increased use of alcohol or other substances* is also not uncommon in the wake of a traumatic event.

Foa and her associates note (2006) that it is not unusual for a number of these reactions to occur in combination following exposure to a traumatic life experience. However, for many people, such thoughts, feelings, and behaviors typically diminish, or completely disappear, over a two to three month period following exposure to a traumatic life experience. Others recover more slowly while some may have recurring problems for years following the trauma. **An important question is what makes the difference between those who do and those who do not recover in the short term?** And what are the factors that protect against the development of mental health or substance abuse problems in the wake of exposure to traumatic life events, particularly events involving physical and or sexual abuse? To address these questions, we turn first to women's stories.

## Listening to women's stories

In the course of our earlier study and our community work and trainings, we have invited women to give accounts of major life traumas they have experienced. We have also invited them to tell us about the impact of such events on their lives in the short term, as well as over time. Finally, we inquired into their own recovery process, asking what they found helpful or harmful in coping with these traumas and their emotional consequences. We share some of these stories below using pseudonyms to protect our story tellers' identities. We begin with Y'kana's story:

> I was molested by my friend's father when I was 14. This molestation went on for 3 ½ years. One time he tried to take my virginity, but I was too small to enter. The last time, when he was going to try again, I shook my head 'no.' A month later; he was dead during an operation. I was 17 and went to the wake for my friend's sake.

Initially, Y'kana reacted with a range of feelings, emotions and physical revulsion: "My immediate response, besides shame, guilt, worry, was to become physically ill, nauseous. When I went home, I stayed isolated in my room for two days, not even coming out for meals." Over time, Y'kana's feelings changed to hate, anger, and more guilt: "I had a choice—stay home and get hit or terribly ridiculed or seek refuge at my best friend's house, though it meant getting sexually abused. Since what he did didn't hurt like getting hit (except the one time he tried to take my virginity), it was like the lesser of two evils. I guess it did hurt emotionally in that my curiosity made me feel very guilty." Now 45 years old, Y'kana reflects on the help she received from her therapist and from reading the book, *Courage to Heal*. She also reminds herself, "He's been a skeleton in a box in the ground for almost 30 years now. I remind myself that my body responding doesn't make me sinful or bad."

Although Y'kana feels she has made much progress in her recovery from this difficult stretch in her adolescent years, she notes that she still has a lot of problems with sex and intimacy. Her friend, with whom she still has contact, has similar problems and she wonders: "I still suspect that he also sexually abused my best friend, but I don't want to trigger her trauma by asking her or telling her what he did (to me)."

Mary's story is in some ways similar to Y'kana's, although she relates a series of traumatic life events: (1) rape at 13, (2) parental physical abuse (which started most of her problems, she says); (3) divorce due to husband's ongoing infidelity, and (4) physically abusive relationship. She recounts that the physical abuse by her parents lasted for years and went as far back as she could remember. "I felt unwanted and unloved—I ran away from home numerous times as a teen. Bruises were noticed by my best friend. I couldn't leave the home as I had to protect my brother." Over time, Mary's feelings changed to rebellion although she suffered from low self-esteem. She notes: "I was afraid to be a parent fearing I would continue the cycle." With the help of "lots of counseling," in addition to "having friends who understand," Mary has made good progress in her recovery. Now at age 56 she notes: "I am bi-polar and suffer from depression, but I am not suicidal any more."

Although Mary has little to say about the impact of her marital problems and abuse on her current well being, Tries to Catch Moonbeams With a Net, as she refers to herself, focused primarily on her relationship abuse. It began when she was 32 years old. We refer to her subsequently as Moonbeams. She tells us: "My traumatic event(s) lasted years and began when my ex-partner escalated her emotional abuse of me by using the police to have me, or threaten to have me, placed in the psych unit." She notes that the police did not believe her side of the story "because I had a mental illness." One time, when she sustained a head injury during an argument and had to be taken to the ER, "even the ER doctor believed her [ex-partner's] version of the event." "I had no allies—I felt trapped, alone, and with no way out."

Moonbeams described her reactions to these relationship abuses as a difficult dilemma: "Mostly I was confused and I self-blamed a lot. I thought my illness was to blame. If only I wasn't 'crazy' this wouldn't be happening to me. I feared the police (I lived in a town of about 2,000 people) and felt watched. The police would sometimes stop and ask me how I was doing and if my medication was working for me. I was afraid to go out and afraid to stay home. I am still leery of police and ER situations."

Over time, her feelings and emotions grew more intense. "I began to self-injure and withdraw. I attempted suicide several times. When a therapist finally believed me, I began to feel better. I am still left with nightmares and I live alone—unsure that I can trust another to be intimate with." Despite these residual problems, Moonbeams feels there are ways in which she has recovered. "I no longer blame myself. I do/am able to get out and trust enough to have friends. I no longer injure myself—I am able to pursue my career and my creativity and my religion, which was denied to me because my partner saw Native Earth-based religions as pagan." Moonbeams concludes that what has been most helpful is: "Having a person who believed in me—and a new circle of women—most of whom have been affected by abuse and trauma. We have created our own community that is supportive and accepting."

Truth, now 26 years old, attributes her personal recovery to her religious faith, although much of her childhood and adolescence was spent in an abusive home: "I was raised in an abusive family for 18 years. My father emotionally, physically, and sexually abused my mother, brother, and me. In 1997, he beat the family dogs to death and was sent to prison. He was a teacher in my high school, so I was humiliated the day I went to school while my father's face was being broadcasted across the ---- area."

Truth's initial reactions were anger, depression, and anxiety, especially during college. "I was hospitalized in a psychiatric ward twice during that time for traumatic flashbacks and self-mutilation. I struggled with alcohol/drug addiction, eating disorders, and became promiscuous. I have worked with three different therapists since 1997." Truth has since had a remarkable recovery. She notes: "I am healed! In recovery→completely. No psychotropic meds, no addiction, healthy body, and good interpersonal relationships. I will be terminating my clinical relationships with my therapist and psychiatrist soon." Hopeful of soon completing her master's degree in clinical work, eventually marrying and having children, Truth believes that "Accepting Christ into my life" has been the most helpful thing in her recovery process. "The therapy, medication, education all helped, but God put all of these avenues into my life to help me find Him. In the Lord, miracles are a reality."

Lucy's story, which, like Truth's, involved early family violence, focuses upon the role of witness, rather than victim. "As a young girl, I witnessed my father beat my mother up, call her names, etc. He also abused animals." These experiences, which lasted for about 2 years from the time she was 9 or 10 years old, led to a number of personal problems for Lucy. "I have experienced post traumatic stress disorder, extreme startle response, depression, not knowing how to handle many situations, no ability to handle any conflict in my life, highly sensitive to yelling, flashbacks, aggressive behavior, abuse of drugs and alcohol. Feelings could include guilt, shame, fear, loneliness, lack of trust in males, and anger. It has made me highly independent, not having to rely on anyone to meet any of my needs."

Lucy, now 43, sees her own recovery as aided by the counseling she received. "With counseling I have been able to accept what occurred in my childhood and learn from it. As I get older, I tend to be able to tolerate more of other people's behavior. Strained relationships with (my) parents have healed. I am now able to use them to my advantage rather than them hindering my progress. I don't feel that the feelings have necessarily gone away, but the behaviors have changed. I think just time and forgiveness have lessened the feelings, as well as talking about it with both parents. Education has helped with the aggressive behavior, as I became a parent myself."

Lucy describes many ways in which she has recovered from her father's abusiveness. "I am not aggressive at all any more. I can actually talk about it without judgment or crying. I am able to help my younger siblings discuss their feelings about what we experienced. I no longer abuse alcohol. I no longer feel guilt, shame, or anger about the issue. I try to teach my kids how to handle anger appropriately. I don't resent my parents for my childhood trauma any longer. I have healthy relationships with both parents separately. I have set boundaries with my father to ensure my wishes and safety, as well as for my kids."

We conclude with Elizabeth's story—another story of family violence involving the role of witness and victim: "I was with a man for only 2 ½ months. In that time, he brutally beat my two children. Each of them had a broken leg. T. was in the hospital for 10 days with a broken collarbone and bruises on his face from him trying to crush his head. My daughter, R., was sexually abused by him. I also have a third child, which is his because he thought if he got me pregnant, I would never leave him. I also was physically and sexually abused by him."

In recounting her feelings, emotions, and behaviors in response to his abusive behavior, Elizabeth's key emotion was fear: "Fear...when this has never happened to you before and you have never known anyone that has experienced it, you are paralyzed by fear and you don't know what to do. My abuser made sure I was isolated from all my family and friends." Elizabeth and her children were terrorized, she notes, for "2 months and 14 days," at which point she apparently turned to a domestic violence shelter and ended the relationship. Explaining her changed feelings and actions, she noted: "The fear turned to anger and guilt—anger at him for what he did to us and anger at myself for being a fool. Also, I felt guilt that my children suffered so at his hand."

Elizabeth, in looking back at her own recovery process, notes that the most helpful thing she did was to seek out a good counselor who "...taught me how to forgive myself." She has used this experience "to help others out in similar situations." It has also helped her "teach my children a lot about abuse and what it is." As she continues to learn about healthy relationships through her counseling sessions, she is also actively involved in helping other women recover from domestic violence experiences.

## Making Sense of Women's Stories

In the discussion that follows, we are going to use these stories, along with findings from recent community studies, to begin to develop a theory of the long-term impact of trauma on women's lives. We invite you to take a break now from reading and begin to think about these questions in the context of your own life and experiences. When you feel you have the time and interest, and have taken a sufficient break from this difficult material, we ask that you read on.

### *Making Sense of Women's Stories*

Question 1: Looking at the list of common reactions to trauma (Foa et al.), which of the women's initial reactions to the trauma they describe include one or more of these feelings or responses *in the short term?*

Question 2: Are there other short-term reactions in these women's stories that you don't see on this list?

Question 3: Which of the women, if any, recovered completely in the short-term from exposure to their traumatic life situations?

Question 4: What do the women's stories reveal about the long-term consequences of exposure to such life traumas?

Question 5: In what ways do you see signs of hope and recovery in these women's stories?

Question 6: What resources do women find most helpful to them in their recovery process?

Question 7: What lessons, if any, can you take from these women's stories that might be helpful in your own growth and recovery process?

## Long-term Effects of Trauma in Women's Lives

The women's stories reviewed above reveal many long-term effects of trauma in women's lives linked with complicated histories of abuse. Their stories weave together themes of physical, sexual, and emotional abuse, and sometimes witnessing the abuse of a parent, sibling, or one's children, or favorite animals. Some are stories of childhood abuse experiences that lasted for years, others are stories of abuse at the hands of one's partner also lasting for years, and, in one instance, a story of abuse at the hands of one's parents and subsequently one's partner. In this chapter, we will focus on some of the pathways through which exposure to histories of physical or sexual abuse, or both, are linked with mental health and substance use problems. We start with a review of studies that have been conducted to investigate the link between childhood adversities, including abuse experiences, and adult mental health outcomes. We then turn to studies of the link between adult victimization experiences and mental health outcomes.

### *Childhood Victimization and Mental Health/Substance Use Problems*

We should note at the outset that not all women who have been exposed to childhood adversities develop mental health or substance use problems in adulthood. In fact, most do not. Thus, it is important to think of exposure to traumatic life events as "increasing the risk" of certain mental health and substance use problems over time. We will first explore which mental health problems are most commonly linked with abuse experiences. Then we will turn to an exploration of pathways and processes through which such increased risk occurs. Finally, we will conclude with a discussion of protective factors that prevent the development of mental health and substance use problems among women exposed to such adversities and discuss their implications for women's recovery efforts.

We begin with two large-scale studies that have attempted to investigate and compare the link between different forms of childhood abuse and adult mental health outcomes. Using data from the NVAW study (Thompson et al., 2002), Thompson and her colleagues showed that both childhood physical abuse and childhood sexual abuse were associated with an increased risk of women reporting a chronic mental health condition that started in adulthood. Women with a history of physical victimization were more than two times as likely as women with no such history to report a chronic mental health condition (2.15) and women with a history of sexual victimization were over 1 and a half times as likely as women with no such history to report a chronic mental health condition (1.77). Both forms of childhood victimization were also linked with an increased risk of drug use in the past month (1.57 for physical victimization and 1.55 for sexual victimization). Finally, physical victimization, but not sexual victimization was associated with a significantly higher risk of using alcohol on a daily basis over the past year (1.41 for physical victimization versus .95 for sexual victimization). Although these findings suggest that childhood physical victimization may have somewhat worse consequences for adult women's mental health and substance use problems than childhood sexual victimization, the authors note that women with the highest risk of adult drug use and a chronic mental health condition were those who experienced both forms versus one form of childhood victimization.

Similar findings have been reported for the Adverse Childhood Experiences Study (ACE) we discussed earlier. Summarizing findings of a study of over 8600 members of an HMO who completed questionnaires about childhood adversities, Edwards and his associates (2003) found that virtually all forms of childhood adversities were associated with poorer mental health (more symptoms of anxiety and depression). Using a cutoff score on the symptom scale to designate a probable mental disorder, Edwards et al. found that 9.5% of women with no abuse history were positive for a mental disorder compared to 11.9% of women with histories of childhood sexual abuse, 13.7% of women who witnessed maternal battering during childhood, and 17.8% of women with histories of childhood physical abuse. Again, rates were even higher for women with multiple forms of childhood abuse experiences. Twenty percent of women who experienced all three forms of adversity (physical and sexual abuse and witnessing maternal battering during childhood) were positive for a mental disorder; 18.9% of women who experience both physical and sexual abuse were positive for a mental disorder.

The Edwards et al. (2003) study also investigated the impact that emotional abuse had on the risk of adult mental health problems, apart from other forms of childhood victimization experiences. It concluded that emotional abuse during childhood was associated with an increased risk of adult mental health problems independent of other forms of childhood abuse experiences. Moreover, its presence with each of the other forms of abuse enhanced its link with adult mental health problems.

Other large-scale studies have investigated the link between childhood adversities and adult mental health and substance use disorders. Unlike the former, which were based on individuals' self-reports of symptoms or mental health problems, these community studies used diagnostic criteria developed by the American Psychiatric Association (1987, 1994, 2000) to estimate the prevalence of various disorders in the population and link such disorders with different risk and protective factors. Perhaps the best known of these studies is the National Co-morbidity Study (NCS), which involved interviews with a nationally representative sample of close to 6000 women and men between the ages of 15 and 54 (Kessler et al. 1994).

Several papers have been written with these data to show the link between childhood victimization experiences and the subsequent onset of different disorders (Kessler, Sonnega, Bromer, Hughes, & Nelson, 1995; Kessler, Davis, & Kendler, 1997). Such analyses show that interpersonal victimization experiences, particularly rape and sexual molestation, but also physical assaults, are among the most traumatic life experiences reported by women. Moreover, such events have a high probability of being associated with the subsequent onset of several disorders, including post-traumatic stress disorder (PTSD), manic depressive disorder, drug problems and dependence, major depressive disorder, alcohol problems, and other anxiety disorders (Kendler, Bulik, Silberg, Hettema, Myers, & Prescott, 2000; Molnar, Buka, & Kessler, 2001).

Such disorders typically do not occur alone but tend to covary. Indeed, the National Co-morbidity Study was commissioned by Congress to study the high rates of co-occurring disorders in the general population. Kessler and his colleagues (1994) found that a significant portion of the population, and particularly women, reported multiple disorders, including the co-occurrence of mental health and substance use disorders (Kessler et al., 1996). Further, findings show that co-occurring mental health and substance use disorders are more common among women with abuse histories than among women who have had not had abuse histories (Newmann and Sallmann, 2004).

### *Adult Victimization and Mental Health/Substance Use Problems*

With the exception of the National Violence Against Women Study discussed earlier, It is interesting that there have been fewer studies of the link between adult victimization experiences and mental health or substance use problems. Most that have been done focus on intimate partner violence (IPV). In an analysis of findings from earlier published studies, Jacqueline Golding (1999) concluded that women with a history of IPV are 4 to 6 times as likely as women without such a history to report mental health problems. Such problems included more symptoms of depression, a greater risk of suicidality, PTSD, alcohol abuse, and drug abuse. A more recent review of studies by Briere and Jordan (2004) concluded that studies of physical and sexual assault within and outside of marriage have been associated repeatedly with increased anxiety, depression, cognitive disturbance such as hopelessness and low self-esteem, posttraumatic stress, dissociation, somatization, sexual problems, substance abuse and suicidality. Moreover, they note that "...similar findings have been reported for victims of stalking, partner psychological maltreatment, sex trafficking, and in women who have experienced sexual torture" (p. 1254). Finally, a recent longitudinal study of men and women found that young adult women who became involved in an abusive relationship were more likely than other women (or men regardless of victimization status) to subsequently develop multiple disorders (Ehrensaft, Moffitt, and Caspi, 2006). The specific disorders they were at higher risk for included: a major depressive episode, marijuana dependence, PTSD, and generalized anxiety disorder.

In sum, as with child abuse experiences, women who are victimized as adults are at greater risk than women who escape interpersonal violence for a range of mental health and substance use problems. Moreover, the cumulative effect of multiple forms of intimate partner violence (physical, sexual, and psychological abuse), as with child abuse, seems to contribute to a greater risk of subsequent symptoms (Basile, Arias, Desai, and Thompson, 2004).

The finding of complex diagnostic histories linked with both childhood and adult victimization experiences has led to a good deal of debate about the utility of current diagnostic frameworks for capturing the full array of symptoms and/or disorders that are linked with abuse experiences. Two strands to the debate are worth noting, particularly in light of the stories of women we shared earlier. They are linked in a common critique of the diagnosis of post traumatic stress disorder (PTSD) as "the only or even the central posttraumatic response following exposure to potentially traumatic events, particularly if such events involve child victimization or chronic, severe interpersonal violence that occurs at any age" (Kilpatrick, 2005, p. 379).

One can see in the earlier accounts of women that the traumatic life experiences they reported are typically not single events, like a tornado, auto accident, or even the death of a loved one or a rape. Rather, they are periods of days, months, and years when one is held hostage in a situation that one is, in the short-term at least, unable to change. Typically, these are experiences that take place in one's own home, at the hands of parents, lovers, or neighbors—the very people whom one should be able to trust and rely on for care and nurturance.

Bessel van der Kolk and his associates (van der Kolk, Roth, Pelcovitz, and Spinazzola 2005) contend that such complex developmental traumas and their consequences are not adequately captured in the PTSD diagnosis. Thus, they argue for a new diagnostic category labeled *Disorders of Extreme Stress* to capture the full array of symptoms and behaviors typically associated with such experiences. Such responses include unmodulated anger and impulse control, problems with attention and dissociation, and difficulties negotiating relationships with caregivers, peers, and subsequently, marital partners. The authors note that complicated adaptations to severe and prolonged trauma are not confined to children. They are also characteristic of rape victims, battered women, and concentration camp survivors.

A second, and related, strand of work by Read, Van Os, Morrison, and Ross (2005) argues that symptoms considered indicative of psychosis and schizophrenia, particularly hallucinations, are at least as strongly related to childhood abuse and neglect as many other mental health problems. Their review of a number of studies supports this claim. Their work represents a fairly new and controversial area of inquiry—one that they assert has been minimized, denied or ignored for a number of reasons, including "adherence to a rather simplistic biological paradigm" and "fear of being accused of 'family-blaming' on the part of clinicians and researchers (Read et al., 2005, p. 331).

What we can conclude from this body of work is that exposure to traumatic life experiences of the sort described in women's stories noted above can be associated with an array of symptoms that increase the probability of several diagnoses. These include:

- Anxiety disorders, including posttraumatic stress disorder and disorders of extreme stress
- Affective disorders, including manic depressive disorder and major depressive disorder
- Substance use disorders, including both drug and alcohol disorders, and
- Psychotic disorders, including dissociative disorders and schizophrenia

This may not surprise you if you have experienced traumas in your own life and grappled with their aftermath. Moreover, if you have entered one or more systems of care for these problems, you are likely to have received multiple diagnoses organized around your symptoms. In the Women and Mental Health Study, we asked women "As far as you know, what was the diagnosis or diagnoses for which you last received treatment?" To our surprise, women's responses ranged from 1 to 9 diagnoses with an average of 2.5. Moreover, women with histories of abuse reported significantly more diagnoses for which they were being treated than women who did not have an abuse history.

We include a number of readings written from a "trauma-informed" perspective, many written by trauma survivors and/or survivor advocates. They address some of the most difficult symptoms and reactions that women who have been physically or sexually abused experience.

**Suggested Readings:**

- What is Post-Traumatic Stress Disorder (PTSD) *by Sidran Foundation*
- What are Traumatic Memories *by Sidran Foundation*
- Schizophrenia, Trauma, and Recovery *by Ellen Magee*
- Women and Self-Injury *by Bristol Crisis Service for Women*
- SIV: Roots and Reasons *by Ruta Mazelis*
- In Harm's Way: Suicide in America *by NIMH*

However, you may find it helpful at this point to take a break and check in on how you are feeling and what you need to do to take care of yourself. We include two exercises in our suggested readings for this chapter that many women have found helpful in getting in touch with their own experiences and feelings, including good things in their lives. We encourage you to take some time to review these exercises before you read on.

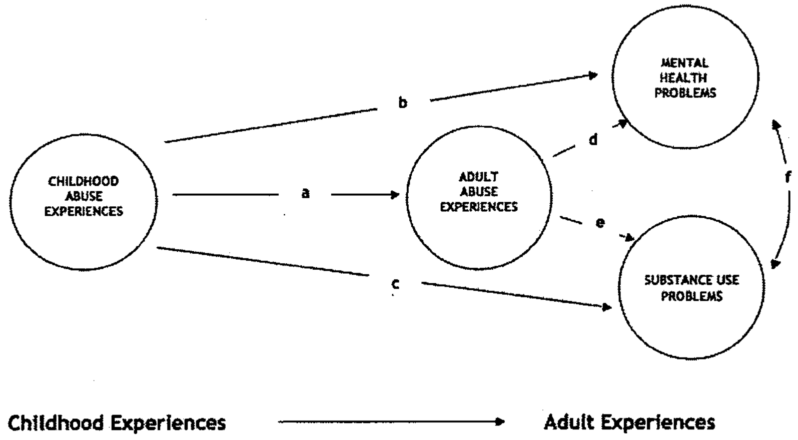
**Suggested Exercises:**

- *Understanding Trauma* by Mary Ellen Copeland and Maxine Harris
- *The Body Remembers What the Mind Forgets* by Mary Ellen Copeland and Maxine Harris

## Pathways linking abuse experiences and mental health and substance use problems

An important question is: What are the pathways through which abuse experiences, including childhood abuse experiences as well as adult victimization experiences, are linked with mental health and substance use problems among women? One hypothesis implied by the findings we discussed earlier from the National Violence Against Women Survey is that child victimization experiences increase the risk of being revictimized as an adult. Both, in turn, may increase the risk of adult mental health problems. A number of studies show support for this "revictimization" hypothesis, which we represent below in Figure 1 with a simple path diagram (Cold et al., 2001; Noll et al., 2003; Renner and Shook Slack, 2006; Schaaf and McCanne, 1998).

**Figure 1. Linking Trauma and Mental Health in Women's Lives: A Life Course Perspective**



The model presented in Figure 1 represents changes over the life course in relations among four different constructs or concepts, each represented by a circle. It represents relations we would expect to find if we had information on these four life experiences from large numbers of women. The paths or single headed arrows with letters on them represent earlier life experiences that are associated with later ones. These paths can be positive or negative, but in this example, we are concluding they are all positive. Thus, path a, which has a positive sign associated with it, says that childhood abuse experiences increase the risk of adult abuse experiences. Both forms of abuse, in turn, increase the risk of mental health and substance use problems (as shown by paths b and d to mental health problems and paths c and e to substance use problems).

Another way of expressing these relationships is: Based on the findings we have reviewed so far, the more complex and prolonged the childhood abuse experiences, the more likely a woman is to develop a mental health and/or a substance use problem as an adult. This is partly due to the fact that childhood abuse experiences increase the risk of revictimization as an adult, which, in turn, increases the risk of mental health and substance use problems among women. However, the model says that child abuse experiences also have a direct impact on the risk of adult disorders independent of its link with revictimization experiences. Finally, we show a double-headed arrow (f) between mental health and substance use problems to designate that they are likely to both be present. Further, we hypothesize that f is a positive value (+), meaning that the two often occur together, but we do not specify that one is causally prior to the other.

Now we are going to add other paths to the model to begin to fill in possible pathways that might link abuse experiences with adult mental health problems. We do so drawing on several different theoretical perspectives that are important for you to know as they shape different approaches to treatment, as well as different ways one might think about or approach one's own recovery efforts. We start with the concept of other life adversities that might occur across the life course.

### *1. Other Childhood Adversities*

Some investigators have hypothesized that childhood abuse experiences may be less important in the development of mental health or substance use problems than are other childhood adversities that typically occur in the lives of children who are also abused. For example, some studies (as well as some of the women's accounts discussed earlier) show that children who are abused grow up in families that are fraught with other adversities, including parental psychopathology, poverty, family disruption, and a host of other environmental adversities that may be as important as the abuse itself in contributing to the subsequent development of mental health problems. In the ACE studies as well as studies by Kendler and his associates (Kendler et al., 2000) and Molnar and her associates (Molnar et al., 2001), investigators found that even when you measure and control for such adversities, there is still a strong link between childhood abuse experiences and the onset of adult psychiatric and substance use disorders.

### *2. Other Adult Adversities*

A second and related explanation for the link between childhood abuse experiences and adult mental health and substance use problems has been proposed by Horwitz and his colleagues (Horwitz, Widom, McLaughlin, & White, 2001). They note that one of the theoretical deficiencies of most studies is "...the assumption that there is a simple causal direction leading from childhood abuse and neglect to mental health outcomes in later life" (p. 185). They argue that a "life course perspective" makes more sense in that it assumes that subsequent life changes, including the strength of adult marriages and other social relationships, as well as educational and occupational attainment, play an important role in determining whether childhood adversities will result in subsequent mental health problems. In their own study of abused and neglected children grown up, who were compared with a control group of non-abused children, both followed for a twenty year period, they conclude that the greater exposure of abused children to adult adversities is the key pathway accounting for their adult mental health problems (Horwitz et al., 2001). In Figure 2 below, we show a second model that incorporates both childhood and adult adversities as additional pathways through which abuse experiences may be linked with mental health and substance use outcomes.

**Figure 2. Linking Trauma, Other Life Adversities, and Mental Health in Women's Lives: A Life Course Perspective**

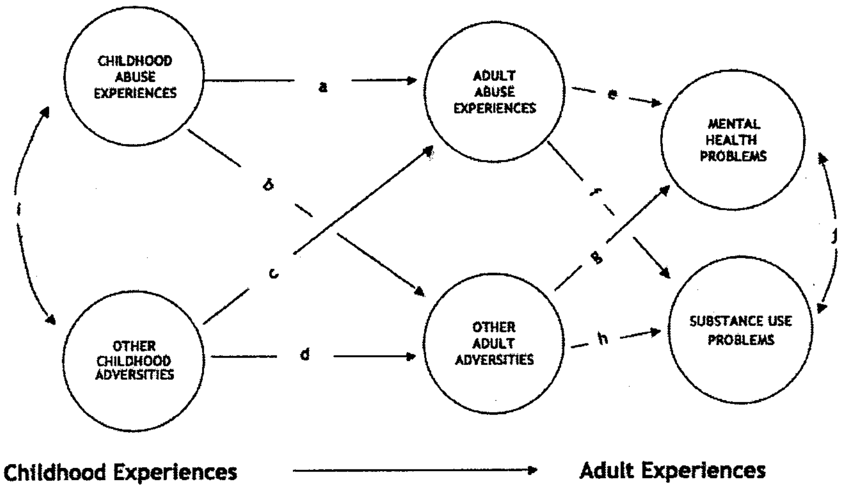


Figure 2 differs from Figure 1 in several ways, a key way being that childhood abuse experiences no longer have a direct effect on mental health or substance use problems among adult women. Rather, they are mediated (have effects that are indirect) entirely through their association with an increased risk of adult abuse experiences and other adversities. Similarly, other childhood adversities have effects that are largely indirect and mediated through pathways c and d—their association with an increased risk of adult abuse experiences and other life adversities.

## *3. Coping Resources and Resilience*

You may be wondering at this point what about a woman's actions or sense of personal control in all of this? Don't women, or girls, try to get away from bad situations or do something to prevent adverse circumstances from occurring? The answer is yes...they do many brave and courageous things to prevent bad things from happening to them. But for many reasons, they sometimes do not have the coping resources they need to protect themselves, or they cope in ways that are ultimately harmful to them. Indeed, when we asked women in the WAMHSS study what aspects of their lives they would like to change looking into the future, and what they would need to help them make those changes, virtually all of the women pointed to a need for what we called "coping resources." Below, we discuss three kinds of coping resources that women mentioned most frequently as critical in their personal growth and change goals. We refer to them as ***personal coping resources, interpersonal coping resources, and material coping resources.***

### *Personal Coping Resources and Resilience*

Much of the research, as well as writings of consumers, has focused on the individual's emotional and behavioral responses in the face of adversity that contribute to mental health problems over time. Indeed, as Laurie Ahern argues, one can think of mental illness as a coping mechanism (Ahern, 1999). Similarly, Carin Mizera, a practicing clinician and member of New Partnerships for Women, Inc. in its early phases, developed a model to explain the process whereby a traumatic life experience is confronted, dealt with, and resolved or unresolved over time. Using this framework, Theresa Swoboda (2002) described her own life experiences to illustrate both resolved and unresolved traumas in her life and how her own coping behaviors were effective in some instances and not in others, due in large part to the nature of the trauma. We include both of these readings because they offer consumer/survivors' perspectives on the role of personal coping behaviors in the development of mental health problems over the life course.

**Suggested Reading:**

- *Mental Illness is a Coping Mechanism* by Laurie Ahern
- *May the Circle Become Broken* by Theresa Swoboda

Personal coping responses are often conceptualized as ways we typically respond in the face of adversity. As we see in the women's stories, there are many examples of what we might think of as active problem-solving or what some refer to as "problem-focused coping"—Y'kana's going to her friends house to avoid physical violence at home, saying "no" to her friend's father's sexual advances; Mary's running away from home to escape physical abuse, Moonbeam and Truth's reliance on religious faith and practices, and virtually all of the women seeking the help and support of books, friendship circles, and counselors. At the same time, there are examples of self-destructive behaviors and what some have referred to as "emotion-focused coping," including self-blame, social isolation, suicidal thoughts and self-injury, promiscuity, eating problems, and abuse of substances.

The general assumption underlying much research on the link between abuse experiences and adult mental health problems is that abuse experiences erode effective coping behaviors which, in turn, contribute to more life adversities and a greater vulnerability to such adversities once they occur. Schumm and his associates (2005) refer to the "double-barreled burden" of child abuse and current life stressors on adult women as a "kindling effect." Kessler, Davis, and Kendler (1997) offer a similar explanation for the link between childhood adversities and adult mental disorders: "One widely held notion is that childhood adversities create enduring intra-psychological vulnerabilities that heighten emotional reactivity to adult stress." (p. 1102).

What might account for this heightened emotional reactivity or kindling effect? Penza, Heim, and Nemeroff (2003) suggest that childhood abuse experiences bring about neurobiological changes that are triggered in the face of adversity. Such changes involve neurotransmitters that are essential in coordinating behavioral, immune, and endocrine functions in the human stress response. A set of neurotransmitters that is well known to most people is adrenalin. Adrenalin has very powerful effects when released into the bloodstream in response to trauma and stress. These effects not only include a rise in heart rate and blood pressure, but also changes in gastrointestinal activity, decreased appetite, disruption of sleep, heightened startle response, fear conditioning and the enhancement of shock-induced freezing and fighting behavior. Such reactions, which were described earlier in the chapter, can become persistent and recurring resulting in a neurobiological vulnerability to the effects of stress later in life. But there are other explanations for such a heightened vulnerability to stress, which we discuss below.

### *Interpersonal Coping Resources*

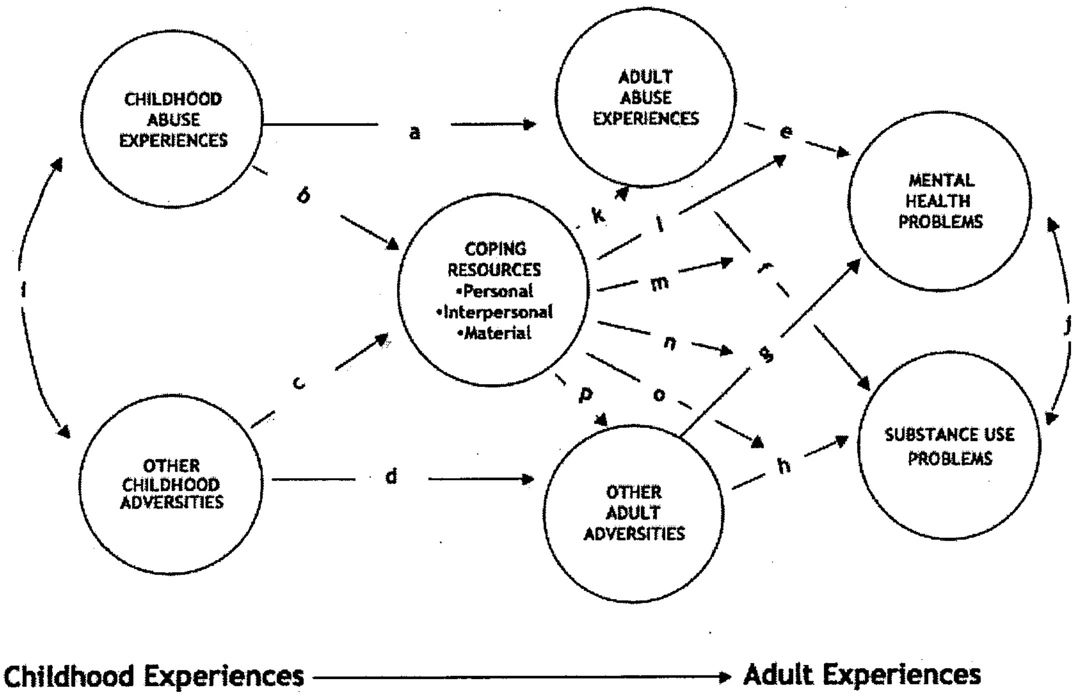
A second important type of coping resource is interpersonal support—the availability of people we can call on to provide us with advice, comfort and support, and physical, as well as material, help in times of difficulty. As Bromet, Sonnega, & Kessler (1998) note, adversity in childhood is often associated with frayed or inadequately developed parental bonds, which can further erode trust and the capacity to establish close relationships as an adult. Indeed, we see this in many of the women's stories about trust, intimate involvements, even the question of having children to care for. Schumm and his associates (2005) argue that childhood abuse experiences actually contribute to "psychosocial resource loss" involving both personal and interpersonal resources, which, in turn, place women at higher risk for a range of subsequent life adversities and undermine effective coping responses. A similar idea was suggested by Molnar, Buka, & Kessler (2001) who note that: "...childhood sexual abuse, which is threatening by nature, may interfere in a developing child's sense of security and ability to trust others, leading to increased anxiety and emotional distress. Guilty feelings may also play a role; survivors of childhood sexual abuse often report self-blame and difficulty trusting others." (p. 757). Thus, this pathway suggests that women who have experienced childhood abuse may have fewer adult intimate or trusting relationships than women who have not been abused as children.

### *Material Coping Resources*

Finally, we emphasize an important class of coping resources that emerged in our work with women who were survivors of childhood traumas—insufficient material resources. Women who use publicly funded mental health and substance abuse services are generally poorer than women in the general population, so it may not be surprising that over 60% of the women we interviewed in the WAMHSS study said the most important thing they wanted to change about their lives was to secure more material resources. In fact, most saw their own recovery as intimately linked with poverty and a need to climb out of poverty. We believe that childhood neglect and abuse, as well as adult victimization experiences, can erode a woman's earning potential through cutting short education and educational opportunities, interrupting preparation for the world of work and reducing access to needed material resources for self-care, recreation, and/or the purchase of help and resources to lead a full and happy life. This is such an important issue for many women who have been physically and/or sexually abused that we devote a chapter to the topic.

We present one final model below that incorporates personal, interpersonal, and material coping resources as mediators, and moderators, of the abuse-life stress-mental health link. Although we represent coping resources as one circle in the model, rather than three, we think it is important to recognize that such resources can make distinct contributions to well-being across the life course and can change in relation to one another over time. Moreover, we believe that learning and change can take place across the life course and much of our work together in subsequent chapters will focus on ways to change one's personal, interpersonal, and material coping resources. Let's turn now to the picture to show you what we mean by mediation and moderation—fancy terms that researchers use in their work and that clinicians are guided by as well.

**Figure 3. Linking Trauma, Other Life Adversities, Coping Resources, and Mental Health in Women's Lives: A Life Course Perspective**



Mediation means that something, such as coping resources, is the pathway through which a former concept (circle), like childhood abuse experiences or other childhood adversities, affects a later outcome like adult adversities or mental health outcomes. In general, coping resources are thought to be good or protective of mental health. This is done, in part, through reducing adult abuse experiences (path k) or other adult adversities (path p). If childhood abuse experiences and other childhood adversities erode coping resources, this becomes an important pathway through which early adversity affects later mental health.

Moderation means that something, again like coping resources, changes the relation between two other things. This is shown in Figure 3 by the paths labeled l, m, n, and o. Paths l and n show that coping resources reduce the risk of developing mental health problems among women who are abused as adults (path l) or who are exposed to other adult adversities (path n). Paths m and o show the same moderating process in relation to substance use problems. In other words, although adult abuse experiences and other life adversities increase the risk of developing a mental health or substance use problem or both, if you have good coping resources, you are at much lower risk because of their protective role.

One final note on the importance of coping resources and their interchangeability. Johnson and Lindblad (2006) studied a group of women who had experienced child sexual abuse and asked: What coping resources are most protective in preventing adult mental health problems? They found that women at high risk (because of the severity of their abuse) who had either good personal coping resources *or* good sources of social support had much better mental health scores than women at comparable risk but who had poorer personal coping resources or fewer effective sources of social support. Finally, when they included all protective factors in their final analysis, they concluded that self-esteem (a personal coping resource) and social supports (an interpersonal coping resource) were the strongest predictors of positive mental health.

## System Retraumatization

We want to address the significance of social supports, not only because the women's stories we presented earlier highlight the importance of social supports in their lives and recovery process, but also because finding caring and trustworthy sources of social support is, for many women, a long and difficult journey. In fact, many women with trauma or abuse histories have experienced retraumatization within service systems designed to provide care. This often happens because the service providers, such as the counselors and other caregivers in the mental health, substance use, or physical health care systems do not understand how a trauma or abuse history may affect a woman. We have included a number of women's stories about these kinds of experiences in your Study Guide and suggest you read through them for a better understanding of how a service system may be experienced as retraumatizing.

**Suggested Readings:**

- *Anna's Story* by Ann Jennings
- *K's Story* by Anonymous
- *A Couple of Barb's Stories* by Barbara Hennings
- *An Outrage of Institutions* by Anonymous

## Exercises for Understanding and Coping with the Effects of Trauma

We have provided you with a lot of information about trauma and the ways in which it may affect your life. We understand that the amount of information may seem overwhelming at first. We do want you to remember that we believe that it is possible to live happier and healthier lives by addressing the effects of trauma. We also want you to remember that we believe that healing and recovery are possible and have seen it happening in our own lives. Earlier we referred to two exercises that might help you understand trauma and some of the ways it may be affecting your life. If you have not taken the time to go through these exercises, you may want to do so before you read on. On the other hand, the chapters that follow are designed to give you additional tools to make progress in your own self-discovery process.

**Suggested Exercises:**

- *Understanding Trauma* by Mary Ellen Copeland and Maxine Harris
- *The Body Remembers What the Mind Forgets* by Mary Ellen Copeland and Maxine Harris

The next chapter of the *Study Guide* will focus on providing you with a variety of tools for how to manage some of the symptoms of trauma you may be experiencing within your own life.

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# Chapter Four
# Symptom Management

N P W
NEW
PARTNERSHIPS FOR
WOMEN

New Partnerships for Women

## Introduction[*]

This chapter has been written to give you a general understanding of symptom management and how you can improve the way you feel by using some simple tools. As we discussed earlier, trauma can have many serious consequences for those of us who have been exposed to it, whether as children, adolescents, or adults. Among those consequences is an increased risk of experiencing an array of symptoms, many of which can be quite disabling. However, we believe that it is possible to manage our symptoms and live happier and healthier lives. How we do that is partly a matter of trial and error and finding what works best for us.

Each of us is unique and therefore we may experience symptoms in different ways in our lives. This also means that certain symptom management techniques may work better for one person than for another. We have tried to provide a variety of different techniques that have worked for us in the hopes that each person will find something to meet her needs. You are the only expert there is on yourself. We encourage you to pick and choose articles and activities that feel most relevant to your life and experiences and disregard those that do not feel as though they apply to you.

## Definition of Symptom

Let us return for a moment to our definition of trauma. Psychological trauma occurs when an event overwhelms our perceived ability to cope in everyday ways. As the stories we reviewed earlier reveal, women use a number of creative strategies to survive the traumas they experience in their lives. We refer to these strategies as coping mechanisms. Coping mechanisms helped protect us when we were experiencing a traumatic event. They are the behaviors and emotions that developed in response to the trauma. But, these protective behaviors can sometimes become unhealthy in the present. These unhealthy coping mechanisms are what we are going to refer to as **symptoms**.

We use the term symptom broadly to also include the behaviors and emotions that have developed to help us cope with the overwhelming feelings that occur with unresolved trauma. For example, if we are triggered by some event or situation and start becoming anxious or experiencing a flashback, some of us may drink or use drugs in order to numb the bad feelings. Some of us deal with our pain by inflicting more pain on ourselves through cutting or burning. These are also coping mechanisms, they are ways we cope with feeling overwhelmed. We are also referring to these behaviors as symptoms. As time goes by, these symptoms can become routine ways of responding to distressing events or situations.

It may seem that these symptoms eventually become us - or at least we start to believe that is who we are. **But it is not who we are.** At the time we developed

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[*] Text written by Carin Mizera and Jolanda Sallmann based on the ideas generated by the NPW Consumer Curriculum Development Workgroup.

these behaviors and emotions, they helped us survive horrible things that were happening to us. But they may no longer be serving us well.

Here are a few examples of what we are talking about. While experiencing a traumatic event, an ***initial reaction*** may be to dissociate. Dissociation is when your mind leaves your body so that you do not mentally have to experience what is happening to your body. Sometimes you may even see what is happening to your body, a feeling of almost floating over and watching your body. This is a survival technique that allows you to survive the abuse that is happening. It becomes a symptom of trauma, or an unhealthy coping mechanism, when your brain cannot resolve the trauma and is triggered to dissociate by something that reminds you of the event.

There are so many other things we do in order to survive the overwhelming pain. We might overeat. We might have very intense emotions, or maybe not feel emotions at all. Maybe we starve ourselves to always feel empty. Maybe we isolate ourselves to not have to feel the pain of being with people. Whatever it is, we did it in order to survive. We all have our patterns of behaviors and emotions that we are not very proud of. We all have kept secrets about it because we have felt ashamed. But today we all can let go of that shame because we know that we did those things in order to survive.

**Review Readings:**

- *Mental Illness is a Coping Mechanism* by Laurie Ahern
- *What is Psychological Trauma?* by Esther Giller

A lot of people don't understand this at all. They would like to believe that we should just get over it. We hope that you are learning that "just getting over it" is not the answer. Remember, we believe that symptoms are the emotions and behaviors we have developed to help us cope and deal with the trauma we have experienced. For more information on the relationship between coping mechanisms and symptoms, please review some of the suggested readings from earlier chapters, along with the suggested exercises in Chapter 3. Here we offer another exercise to help you explore ways you are currently managing these symptoms in your own life.

**Suggested Reading:**

- *Psychological or Emotional Symptoms* by Mary Ellen Copeland and Maxine Harris

## Definition of Symptom Management

The good news is that there is hope. Just as there are as many ways to respond to trauma as there are people, there are at least that many examples of ways to manage our responses. This is what we call symptom management. We use the term "symptom management" to refer to a diverse set of skills and techniques that we use to ease the intensity of a symptom or get rid of it altogether. It is taking the best possible care of ourselves so we are no longer harmed by our trauma.

Although we each already have our own unique, creative ways that work for us, many of us could still use a few more tools. Additionally, since we are constantly growing and changing, our symptom management needs are also growing and changing. We also find that as we use a tool and get better at it, our needs change simply because we have changed the intensity of our symptoms. For example, we may have intense anxiety reactions. To deal with that, we may have taken an anti-anxiety medication and practiced daily relaxation exercises. We also may have used many affirmations in situations that made us anxious. Each of these is a symptom management technique. After doing this for a while, we may find that we do not need the medication anymore and that the affirmations that once seemed silly and false have become part of our normal thought process. We have succeeded in easing the intensity of the anxiety.

This of course is an ideal example of symptom management. It doesn't always happen that neatly! What usually happens is that we recognize small changes, such as noticing that our symptoms become less intense. Once that happens, we then need to find new ways to manage these different, less intense, feelings.

What is important in understanding symptom management is: ***You are your best resource***. You will get ideas from here and many other places, but you will be the one who will know what works best. We were all ***unconsciously creative*** in coping with our pain. Now we get to be ***consciously creative*** in our symptom management. In this way, symptom management is one method of taking back control over our own lives by realizing we have the ability to ease the intensity of our own symptoms.

Learning that we have the ability to change how we feel is also helpful for increasing our self-esteem. The term "self-esteem" refers to the value or worth that we see in ourselves. For most trauma survivors, our self-esteem has suffered. Many of us were told by our abusers that we were "no good," "ugly," "unloved," and responsible for the violence inflicted upon us. We heard this so many times that we began to believe these messages. Having low self-esteem sometimes means that we do not feel that we deserve to feel better. Luckily, just as we learned to believe those negative messages, we can teach ourselves ways to ***unlearn*** those messages. We can learn to find worth and value in ourselves and believe that we do deserve to feel better. For information on more ways to take back control of your life and increase your self-esteem after experiencing trauma, please see the suggested readings.

**Suggested Readings:**

- *Taking Back Control of Your Life* by Mary Ellen Copeland
- *Building Self-Esteem* by Mary Ellen Copeland

## *Safety and Prevention*

Let's review. Symptom management is the diverse set of skills and techniques that we use to ease the intensity of a symptom or get rid of it altogether. It is taking the best possible care of ourselves so we are no longer harmed by our trauma. This means that when we talk about managing our symptoms, we are talking both about how to keep ourselves as safe as possible while we are experiencing the symptoms and learning ways to identify what triggers our symptoms in order to reduce their intensity with the goal of eventually preventing them from occurring. Symptom management therefore focuses both on safety and prevention. Let's explore this a little more with some examples.

Some of us use drugs or alcohol to numb the pain we are feeling. This is one way we have learned to cope with unresolved trauma. Once we have identified that substance use is a symptom of trauma (it is a behavior we have developed in response to the trauma), we can find ways of reducing the harm it does to us. We can find ways of keeping ourselves as safe as possible while we are experiencing this symptom. This may mean that if we know we are going to drink heavily in order to cope with our pain, we decide to stay home where no one can hurt us while we are drunk. This could also mean that instead of scoring crack we smoke pot. Although these may not seem like the ideal goals we have for ourselves, they are little steps we can take to reduce the ways we are harmed by our symptoms.

Here is another example: Some of us have a history of cutting ourselves as a way of coping with our pain. In order to keep ourselves safe we may remove all of the razors or sharp knives from the house. Safety is about lessening the pain of the symptom and reducing the harm it does to us. In these examples we can see how safety strategies require us to be aware of the fact that we will be overwhelmed by intense emotions and find alternative ways of coping with the feelings in order to reduce the damage that they do.

Prevention, on the other hand, is about becoming more conscious of how and when a symptom is triggered so we can work up to not having it triggered at all. For example, you may notice that you want to use drugs or alcohol, or do some other self-harm, when you are feeling lonely and sad. You may notice that you feel lonely and sad when you are alone at night. In order to prevent the symptom (the urge to do self-harm or use), or lessen its intensity, you find ways to not be home alone. This could mean calling a support line, sponsor, or friend. It could mean going to a support group meeting, a social group, or some free event in town. It might even mean getting a fish or a bird so we feel less alone. In these examples we have found new skills and techniques to prevent our symptoms from being triggered.

## Symptom Management Tools

Symptom management is about more than just having a few good exercises for dealing with specific symptoms. Symptom management is a lot of hard work. The work can be made easier by finding ways of taking care of you and having a good support system in place. For some of us, the use of prescription medications is also a form of symptom management. We will explore each of these areas in this chapter.

### *Taking Care of Yourself*

Dealing with the effects of trauma on our lives and learning how to manage our symptoms is very hard work. It is therefore important that we make sure we are taking care of ourselves throughout this process. Just as continued stress and more traumas can worsen the biochemical effects of trauma, so too can they increase the severity of our symptoms. In other words, our symptoms can become more severe when we are under a lot of stress or have been traumatized again. However, positive life changes, positive thinking, and other healthy choices can help to reduce the severity of our symptoms. Learning what things we need each day to take care of ourselves is one of the skills we can develop to help us manage our symptoms.

One thing we realized while creating this study guide is that taking care of ourselves is not "rocket science." Each one of us already has a number of things we do, many of them unconsciously, because they make us feel better. The tricky part is to set some time aside each day to do at least one thing that makes us feel good. What follows is lists of things we developed while creating this study guide of things that make us feel good. You may already do several of these things. You may discover new ideas that sound good to you. We encourage you to add additional ideas of your own to this list. You may even find it helpful to tape the list to a wall at home or at work to remind you to do something good for yourself each day.

**List of Things You Can Do to Take Care of Yourself**

- Write/journal
- Tell your story
- Exercise
- Educate yourself
- Dream/hope
- Sing
- Make music
- Listen to music
- Pray
- Meditate
- Relax
- Play
- Have fun
- Get a hobby
- Take risks
- Dance
- Make art
- Enjoy nature
- Eat well
- Meet basic needs
- Raise plants
- Seek help
- Name the abuse
- Read or listen to books on tape
- Watch sunrises and sunsets
- Take vacations
- Weigh your options
- Protect yourself
- Live "one day at a time"
- Use affirmations
- Watch movies
- Do what you enjoy
- Say no
- Find listeners
- Set boundaries
- Feel safe
- Play with animals
- Laugh
- Talk

Several other suggestions for ways to take care of you can be found in the suggested readings, including information on safety planning. Safety planning is particularly helpful for women who are currently in abusive relationships or who have recently left one. We believe that safety planning is an important tool for taking the best possible care of ourselves.

**Suggested Readings:**

- *Building Self-Esteem* by Mary Ellen Copeland
- *Collections* by Karen Milstein
- *10 Ways to De-Stress Your Life* by National Empowerment Center
- *Safety Planning* by Domestic Abuse Intervention Services

## *Support Systems*

Having a good support system is a very important part of symptom management. We really need a lot of different kinds of support to get through this. A support system helps us get our needs met. In this way, it is also one of the ways we can take good care of ourselves.

The term "support system" basically refers to those people, other than ourselves, whom we go to for different kinds of assistance, encouragement, and aid. Because we are each unique, our need for support, and the people available to us, are going to differ. Several of the suggested readings discuss qualities to look for in a support person, or support system, as well as personal stories about the importance of a good support system.

**Suggested Readings:**

- *Someone Who Believed in Them Helped Them to Recover* by Daniel B. Fisher
- *The Importance of Hope* by Judie Robson
- *Recovery is Worth the Hard Work* by Anonymous

There are two main types of support systems that can be helpful for symptom management. These are informal and formal support systems. The term "formal support system" refers to the professional kinds of help we seek to help us manage our symptoms, such as a counselor at a rape crisis center or domestic violence shelter, a mental health or substance use counselor, a social worker, psychologist, or psychiatrist. For many people this may also include someone like a massage or dance therapist. In the suggested readings, several articles offer helpful suggestions for choosing a formal support system for help in dealing with trauma. Although the articles are focusing specifically on the treatment of PTSD, we feel that many of the suggestions are also helpful for thinking about how to seek other kinds of formal support, such as finding a substance use or mental health counselor who understands the effects of trauma on women's lives.

**Suggested Readings:**

- *Therapy for Post-Traumatic Stress and Dissociative Conditions: What to Look for and How to Choose a Therapist* by The Sidran Institute
- *Treatment of PTSD* by National Center for PTSD

The term "informal support system" refers to non-professional types of support. This can include, but is not limited to, friends, family members, neighbors, romantic partners, church or other social groups, and peer or other support groups.

Although many of us would really like to have friends included in our support system, we may have difficulty developing friendships as a result of the traumas we have experienced. The suggested reading offers information on both what to look for in a friend and how to be a good friend. It also offers suggestions for how to build and maintain friendships.

**Suggested Reading:**

- *A Wellness Tool: Developing and Keeping a Circle of Support* by Mary Ellen Copeland

Whether we are seeking support from a formal or informal system, it is important for us to understand what we are looking for in a support system. It may be helpful for you to spend some time making a list of all the things you think are important in a support system. This can include a list of qualities, such as "someone who is nonjudgmental," as well as examples of desired support systems, such as a friend, counselor, or support group. You may then want to review the list, putting a circle around each item that you have right now and are satisfied with. Then, go through the list a second time and place a star next to the ones you don't have but would like to have. We have found this exercise to be helpful for knowing how to use our support systems as a part of our symptom management as well as for setting goals about how to expand our support systems in areas where they are weak.

### *Medications*

Although we firmly believe that the use of prescription medications can be a useful part of symptom management for many women, we also have reasons to be alarmed about some of the problems women encounter in getting good medication management from their providers. In the WMHSS survey of women who use publicly funded ADM services, a critical area where women feel their voice is not heard and their choice compromised is in the area of medications. Over two thirds of women using mental health or substance abuse services at the time of the interview were currently taking a prescription medication for a mental health or substance use problem. When we asked women whether they had any choice in "picking medications that are right for me," 46% stated that they did not. Other queries about medication management suggest that significant numbers of women are not happy about this aspect of their treatment. Fully 30% of the women disagreed with the statement: "The medications I received were right for me." Further, almost 20% of the women felt their complaints about medication side effects were not taken seriously, and similar numbers reported that they had not been told what side effects to watch out for. Thus, one of the major

**Suggested Readings:**

- *Reclaiming Your Power During Medication Appointments with Your Psychiatrist* by Patricia Deegan
- *How to Talk with Your Doctor about Your Medications* by WCA
- *Taking Medication Safely* by Mary Ellen Copeland
- *The Myriad Medication Mistakes in Psychiatry: A Consumer's View* by Betty Blaska

areas of needed improvement in services is a system that is more responsive to women's perspectives on the use of medications.

Ultimately, each woman must make an informed choice about whether or not the use of prescription medications is right for her. Part of making that choice is finding a prescriber who is also a good listener, respectful, informed, and supportive. We know of many women who have found such a physician, psychiatrist, or psychologist and for whom medications have been a critical tool in their recovery process, along with a good therapist. We have included several readings in this manual that are helpful resources for deciding (1) whether or not medications are right for you, (2) how to use medications as a part of your recovery or self-discovery process, and (3) how to advocate for your needs during medication appointments with your doctor.

We suggest you try the following exercise. On one side of a piece of paper list all of the things you can think of that medications *can* do (such as help you sleep, alleviate anxiety, etc.). On the other side of the page, list all of the things you can think of that medications *can't* do (such as cure mental illness, fix relationship problems, etc.). This exercise is intended to help you think realistically about what kinds of change you can expect from the use of prescription medications.

In conclusion, even though we have concerns about some of the ways we have seen prescription medications misused in the lives of women, this does not mean that we are against the use of medications as a part of symptom management. Rather, we believe that women should be empowered to make an informed choice about the use of medications and have an understanding of both the positives and negatives they can expect from the medications.

## *Flashbacks*[*]

Flashbacks are a common symptom experienced by many trauma survivors. A flashback is a re-living of a past experience, usually a traumatic experience that feels as though the experience is happening again. Right now. With all the physical and emotional feelings that the person felt when the event originally occurred. It is not a memory. It is not like watching a movie. It is a re-living. It can be very intense and can come on very suddenly, often "triggered" by some seemingly innocent word or object that is associated with the original traumatic event. We may either consciously or unconsciously know these triggers.

Flashbacks are often one of several PTSD symptoms. A full re-experiencing of the traumatic event is what people think of as a flashback. However, there are different degrees of severity of flashbacks. Heightened startle response or body memories are also types of flashbacks. Often when a traumatic experience happens to us we block out the memory in order to survive the pain and if these traumas are

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[*] *Flashbacks* was written by Barbara Hennings (2002) for the *NPW Consumer Curriculum*. Her piece is a reflection on the work of Kenna del Sol © 2001 found in the suggested readings.

not dealt with they can return in the form of flashbacks. However, even if you remember the traumatic event you can still have flashbacks.

Flashbacks can be a very scary experience. Luckily, like other symptoms, there are tools we can use to manage them. For more information on flashbacks, the symptoms of flashbacks, and suggestions for coping with them, please see the suggested readings. Many of us have also found it helpful to share this information with both our formal and informal support systems. It can be very difficult for our support systems to witness us having a flashback. Many people do not know how to be helpful. This information can help our support systems understand what a flashback is and provide the opportunity for us to talk about what kinds of help we need from our supports when we are experiencing a flashback. If you are looking for a professional caregiver, we suggest finding one who is experienced in dealing with flashbacks. Even trained professionals may not know how to treat trauma survivors and you may have to teach them how best to help you. You know best what helps. Remember, this is not "one size fits all" therapy. What works for you may be different than what works for others.

**Suggested Readings:**

- *Coping with Flashbacks* by Kenna del Sol
- *Ideas for Coping with Flashbacks* by Bristol Crisis Service for Women

**Suggested Readings:**

- *Guide to Developing a WRAP – Wellness* Recovery Action Plan by Mary Ellen Copeland
- *Developing a Wellness Toolbox* by Mary Ellen Copeland
- *A Wellness Tool: Developing and Keeping a Circle of Support* by Mary Ellen Copeland
- *Crisis Planning* by Mary Ellen Copeland

## Symptom Management Plans

As we stated earlier in this chapter, symptom management is about both keeping ourselves safe while experiencing a symptom and working to eventually prevent our symptoms from being triggered. We believe that the best way to approach managing our symptoms is proactively. The term "proactive" refers to acting before a crisis occurs. When we are in crisis we are already dealing with feeling overwhelmed. During crisis is not the best time to think out how to best manage our symptoms. We believe that a symptom management plan is a helpful tool for managing our symptoms. It should be written when we are not in crisis and address how we should deal with crises when they happen. It should also address what we would like other people to do for us when we are in crisis.

We have chosen to provide you with information on how to develop your own Wellness Recovery Action Plan (WRAP), a symptom management plan developed by Mary Ellen Copeland.[3] This plan is a way of individualizing your own symptom

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[3] Mary Ellen Copeland has written many articles and books relating to the development of Wellness Recovery Action Plans (WRAP). If you are interested in ordering her books or finding more information on the topic, please visit her web site at http://www.mentalhealthrecovery.com.

management and the suggested readings will walk you through how to create one. By creating the plan, you will explore your own personal symptom triggers and techniques for managing them. You will also examine how to identify your own warning signs that a crisis is approaching. Additionally, the plan will guide you through developing an individualized crisis plan. A crisis plan is a proactive plan for what to do when a crisis occurs. This is helpful not only for yourself, but provides guidance for your caregivers and support systems by laying out what kinds of help you do and do not want while you are in crisis.

While we were creating this study guide, many of us felt that it would be very helpful to work on a crisis plan with our caregivers or other support persons, or at least make sure that we share this information with them once it is completed. That way we know that our support people are aware of our needs and are committed to helping us carry out our crisis plans to the best of their abilities. Keep in mind though, even the best thought out of plans do not *always* work out in the way we would like. The hospital we have chosen may be full. Our doctor may be on vacation and her substitute may not be familiar with our plan. Life is unpredictable. However, we still believe that a crisis plan is an effective tool for managing our symptoms. You may want to review an earlier reading that tells one woman's story about the importance of a crisis plan.

**Review Reading:**

- *K's Story* by Anonymous

We hope these tools provide you with a good start on your way to recovering from the effects of trauma and discovering new things about yourself. In the next chapter of this study guide we will provide you with some information on meeting basic needs. Having our basic needs met is another way of taking good care of us. In this way it is an additional tool we can use to help us manage our symptoms.

# Chapter 5

# Meeting Women's Basic Needs

NPW
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PARTNERSHIPS FOR
WOMEN

New Partnerships for Women

## Meeting Women's Basic Needs[*]

In the last two sections, we discussed how continued stress and adverse life circumstances could heighten psychological trauma and the severity of our symptoms. However, we also shared with you our belief that healing and recovery are possible and that positive life changes, positive thinking, and other healthy choices can help to reduce the effects of trauma in our lives.

Struggling to meet our basic needs, or not having them met at all, is a definite source of continued stress in many of our lives. We believe that struggling with poverty and its consequences are major problems with which women need and want help. This section provides information on how our experiences with trauma affect our basic needs and offers some tools for locating and securing resources to better meet those needs. We believe that meeting our basic needs is one way of taking good care of ourselves. Therefore, meeting our basic needs is another tool we can use to help us manage our symptoms, address the effects of trauma, and live healthier and happier lives.

## Definition of Basic Needs

The term "basic needs" is most commonly used to refer to food, shelter, and clothing. These are considered the *most basic* of needs because of their link to survival. We are going to use the term basic needs a bit differently here. When we talk about basic needs, we are referring to any need we may have that is necessary for either survival *or* a decent quality of life. We do not believe that it is enough just to ***survive*** in this life; rather we believe each person is entitled to ***thrive***—to have a quality of life that is worth living. As each of us is unique, we may each identify different needs as basic; in this way basic needs are subjective.

Using this framework for thinking about basic needs, the workgroup that developed this handbook identified several basic needs that seemed significant to our participants. These included food, shelter, clothing, transportation, medication, a decent income, meaningful work, education, training, and access to needed services, including dental and physical health care, and substance use, trauma, and mental health treatment. Our workgroup felt that each of these needs is basic to both survival and quality of life. We have provided you with readings and/or resources covering many of these topics in this handbook.

***It is important to understand that underlying all of these needs is the need for safety. We firmly believe that every woman, every person for that matter, deserves to be safe in her own home, community, or anyplace in the world.***

Since each of us is unique, we may each have different needs that we consider to be *basic* to our survival and/or general well-being. We hope that the information we have provided touches on a few of your basic needs and gives you the tools you can use to seek out other resources that we have not covered here.

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[*] Text written by Jolanda Sallmann and Heather Hazelwood based on the ideas generated by the NPW Consumer Curriculum Development Workgroup in 2001-2002.

## Economic Adversity and Basic Needs

As we discussed earlier, economic adversity and its consequences are major problems with which women need and want help. Many studies have found that poor people have higher rates of mental health and substance use problems than people who are not poor. Although there is debate about the causal nature of this relationship, we believe that the stress poor people experience in struggling to meet their basic needs significantly increases the risk of many mental health problems.

It is stressful enough to struggle to find housing, food, clothing, and transportation. But often, economic hardships prevent us from taking care of ourselves in other ways. Many of us do not have health insurance, or not enough coverage to practice good preventative care. Most of us have problems affording a dentist, or finding one who will accept Medicare or Medicaid. And, even if we can find free or low-cost mental health, substance use, or trauma treatment, we may find that not having enough money means not getting as much help as we would like for our problems. Because we do not have enough money, or insurance, to meet these needs, we are often forced to neglect our physical or emotional health. In these ways economic adversity prevents us from taking the best possible care of ourselves. Neglecting these needs obviously does not help the problems go away, rather it often increases the intensity of the symptoms we experience. For more information on some of the effects of economic adversity in women's lives, and women's suggestions for how the community can meet those needs, please see the suggested reading.

**Suggested Reading:**

- *Meeting Basic Needs: Addressing Economic Adversity in Women's Lives* by Joy Newmann

## Trauma and Basic Needs

Our experiences with trauma affect our basic needs in both immediate and long-term ways. Some of the initial, or immediate, basic needs we may have as a result of experiencing trauma include physical health needs related to the physical or sexual abuse we have experienced, such as bruises, broken bones, cuts, dental problems, or gynecological problems. If we decide to leave the abusive relationship or run away from home, we will need to find safe housing or shelter, a new job or source of income, childcare, and replacements for the clothing and furniture we were forced to leave behind. If we stay in the household, we have to address safety needs related to the possibility of more abuse.

We become more vulnerable to economic adversity when we run away from home or leave an abusive relationship. For many of us, our economic well-being and insurance are tied to our abusers' incomes or jobs. When we leave an abusive household, we lose that income, and oftentimes our health insurance. Even in cases where we may still be eligible to use that insurance, we fear that our abusers will be able to track us down if we submit insurance claims. We may even lose our social status and/or credit history. In these examples we can see how trauma both creates new needs that have to be addressed (we may need medical care, shelter, income, etc.) and leaves us vulnerable to not meeting our basic needs (a loss of income, insurance, housing, etc.).

Whether we stay or leave an abusive household, previous trauma may also make us more vulnerable to experiencing more trauma. If we stay, there is the risk that the abuse will continue. If we leave, we are more vulnerable to increased economic adversity. This sometimes means being homeless, living in a shelter, or finding housing in a poorer neighborhood—in each of these cases the housing may feel unsafe and expose us to more violence.

Trauma also has long-term effects that relate to our basic needs. In Chapter 3 we discussed the long-term effects of trauma on mental health and substance use problems. Trauma can also affect our physical health. Our bodies experience harm through physical and sexual abuse. Head trauma survivors may experience the long-term effect of what is commonly known as severe migraines. Many other after effects of trauma will cause various health risks that are often unnoticed by a regular doctor. Dental problems are a large concern. Grinding and clenching of the teeth because of anxiety and fear will harm the joints within the jaw. Some medications that are prescribed for mental health symptoms often have severe side effects on both the teeth and gums. If we are using drugs or alcohol to cope with our pain, that use may also be affecting our physical health. Additionally, we risk becoming addicted to these substances as we use them as coping mechanisms. Addiction itself brings along its own physical health problems.

Another long-term effect of trauma is that it has prevented many of us from addressing particular basic needs. Many of us have avoided going to our medical providers, not only because we didn't have the money to pay for services, but also because we experienced these appointments as retraumatizing. This means that the experience reminded us of past abuse. Two of the most common examples of this are going to the dentist or to the gynecologist. Both of these experiences can feel very intrusive for many trauma survivors and many of us have experienced flashbacks during these appointments. In these ways, the effects of trauma become a barrier to taking the best possible care of us.

Let us return for a moment to our definition of symptom management. Symptom management refers to a diverse set of skills and techniques that we use to ease the intensity of a symptom. It is taking the best possible care of ourselves so we are no longer harmed by our trauma. We can think of avoiding appointments with our doctors or dentists as one of the symptoms of the effects of trauma on our lives. Avoiding is one of the behaviors that we developed as a response to trauma. Learning to manage the overwhelming feelings we experience during these appointments is a form of symptom management. It is taking the best possible care of ourselves, by seeking the medical care we need to stay or become healthy, so that we are no longer harmed by our trauma. There are also some simple tools that many of us have found helpful in dealing with these experiences. The suggested readings offer suggestions for how to talk with your medical providers about the traumas you have experienced as well as techniques to help you get through a dentist or doctor's appointment.

## Prioritizing Basic Needs

We have a variety of basic needs that are important to us. We might be homeless, struggling with a drug or alcohol use problem, feeling suicidal, dealing with flashbacks, and trying to be good parents. Sometimes one or more of our needs can prevent us from getting the other needs met.

For example, if we are really being affected by our drug or alcohol use, we may not be able to hold a job. We may lose our housing because of constant altercations with the landlord or because of the police being called frequently. We may lose custody of our children because we have not been able to care for them. If this is the case, our unmet needs for substance use treatment are preventing us from meeting other needs that are also basic for our survival and well-being.

**Suggested Reading:**

- *Discussing Trauma and PTSD With Your Doctor* by Pamela Swales and Joe Ruzek
- *Information on PTSD for Women's Medical Providers* by Erica Sharkansky
- *Afraid of the Dentist?* by Patricia Deegan

On the other hand, if we are homeless or do not have adequate transportation, these unmet needs may prevent us from being able to schedule or make it to appointments with our mental health, trauma, or substance use providers. Trying to find affordable housing may be so stressful and time consuming that we do not have the time or energy to meet some of our other needs. If this is the case, then our unmet needs for housing and transportation are preventing us from meeting the rest of our basic needs.

Many of us have found it most helpful to have support systems, particularly formal support systems, that can help us find ways of meeting both our treatment and other types of basic needs at the same time. But, some of us have found that we really need to focus on meeting one type of need first, such as getting sober or finding housing, before we can focus on our other needs. Remember, you are the best expert on yourself. Trust yourself to know how to best prioritize your needs, but also remember to discuss your priorities with your therapist, care provider, and/or case worker, as well as with your support systems.

## Stigma and Shame

In the last chapter, we discussed the importance of self-esteem. Many of us were repeatedly told by our abusers that we were "no good," "ugly," "unloved," and responsible for the violence inflicted upon us. We began to believe in and "internalize" these messages over time. Low self-esteem, in turn, leaves us feeling perhaps we do not deserve to feel better. In a sense, the process of internalizing these terrible messages becomes an additional barrier to managing our symptoms.

Internalized messages can also prevent us from meeting our basic needs. Most of us have been labeled with one, if not several, mental health or substance use diagnoses. Oftentimes we have been treated differently than women who do not have these problems because people see our diagnoses before they see us. In this way, we often feel stigmatized, or branded, by these labels.

People do not always treat us in these ways because they want to be mean, rather they have often internalized many of the stereotypes that exist about mental illness and substance use. Some of these stereotypes are based on the assumption that persons with mental health or substance use problems are: "crazy," "irresponsible," "dangerous," "manipulative," "dumb," "weak," "liars," "untrustworthy," or "fakers," just to name a few. Many of us have repeatedly heard that we are "just doing that for attention" or "being manipulative" by people that don't have an understanding of how trauma has impacted our lives. When we hear these messages repeatedly, or feel that people are treating us differently because of our labels, we too begin to believe these messages about ourselves.

In this way, we feel the stigma of being a trauma survivor or of having a mental health or substance use problem—sometimes we may even feel that we wear a mark or brand that visibly identifies our problems to outsiders. When we internalize this stigma, we feel shame. We believe that there is a personal shortcoming that is responsible for our problems.

Both stigma and shame can prevent us from meeting our basic needs. Stigma often prevents us from meeting our basic needs because those in positions of power view us as undeserving (because they have come to believe the stereotypes). Shame prevents us from having our basic needs met because we have internalized these stereotypes and feel unworthy or undeserving. However, as we noted earlier, we can let go of this shame once we accept the fact that our problems are not a result of personal shortcomings. We developed these behaviors and emotions in order to survive. There is no shame in that! For more information about how stigma and shame affect our ability to meet our basic needs, please see the suggested reading.

**Suggested Reading:**

- *The Cause and Effect of Stigma and Shame* by Jessica Barton

## Basic Needs Resources

Now that we have discussed many of the barriers that prevent us from meeting our basic needs, we would like to provide you with some tools to help you identify resources in your own community or county to meet your needs. In 2002, our staff at NPW created a resource guide of agencies and programs in Madison, Wisconsin and other areas of Dane County that addresses many of the basic needs we have been talking about, either for free or at very little cost. We want to share with you the steps we followed in developing this resource list so that you can do the same in your state, county, or local community, perhaps with the help of friends.

The process of developing these lists is rather simple, it just takes some initiative, determination, and perseverance. Below, we describe the steps we took to develop a list of low cost dental services in Dane County as one example you might want to follow:

1) First, we asked service providers and consumers we work with if they knew of any existing resource lists for low cost dental clinic services in Dane County.

2) We received one list from Catholic Charities, a local organization.

3) We found contact phone numbers for each resource listed on the Catholic Charities sheet and called their offices. When we talked to each of them, we explained that we were updating and expanding a resource list for our project, we had them verify the services offered, and we let them know which other resources we had listed and asked if they knew of any others we should add.

4) We followed up by contacting the additional resources to clarify services they offered, making changes and additions as necessary to the existing resource list.

5) We then called the United Way of Dane County's First Call for Help line, 2-1-1, (608-246-7548 for out of area or cell phone callers), explaining our purpose and inquiring about additional resources we may have missed.

6) We contacted additional resources suggested by First Call for Help and found out about the services they offered.

7) We continued making changes and additions to our existing resource list until we felt confident we had a complete, up to date, and finalized list of dental resources.

We found that the process of developing these lists was not only educational, but also empowering. While each of us had felt that we knew little about basic needs resources as individuals, the more people we talked to, the more we learned about where and how to get our needs met. We know you can do it too in your community. We wish you good luck in the process.

## Some Closing Thoughts

We believe that trauma can have many serious effects on our lives, which we have discussed in the prior chapters. We do so with the goal of helping you examine and begin to deal more effectively with the adverse effects, while celebrating whatever good may have come from your experiences. This does not mean that this Study Guide is a replacement for professional therapy or treatment. Rather, it is a self-help tool.

We want to remind you that if the materials trigger thoughts, memories, feelings, or emotions that may be related to abuse or other traumas you have experienced, this can be a natural experience. If you find yourself feeling overwhelmed by your feelings or emotions, or find yourself physically reacting to what you are reading, we suggest that you seek professional assistance.

Please remember that the women who put this Study Guide together are just like you. We don't claim to be experts on anyone's lives but our own. If there is anything in this Study Guide that you have found offensive or feel does not apply to you, feel free to disregard it. We included it because it was important to someone in our workgroup.

We hope that you have learned, or nurtured, compassion for yourself by reading the materials in this handbook. Whatever coping mechanisms we have used, or continue to use, we developed in order to survive the traumas we have experienced.

Finally, we hope that we have succeeded in providing you with hope for the future, hope that your own healing and recovery *are* possible. Remember, we have seen these changes in our own lives and believe that you can also affect positive change in your life by using the information and skills we have provided in this handbook. Taking the initiative to read these materials is already a step you have taken toward taking the best possible care of yourself on your journey to recovery. We are glad that you have chosen to join us on this journey. Remember, this is hard, but very rewarding work and each of us is worth it.

We turn to our final chapter on self-advocacy. We hope it offers you a final set of tools to care for, and advocate for, the things you most need to lead a full and happy life.

# Chapter 6

# Skills and Strategies for Effective Self-Advocacy

N P W
NEW
PARTNERSHIPS FOR
WOMEN

New Partnerships for Women

# INTRODUCTION

## What is Advocacy?

"Advocacy" can mean many things, but in general, it refers to taking action. Advocacy simply involves speaking and acting on behalf of yourself or others. There are several types of action that a person can take:

- *Self-advocacy*: taking action to represent and advance your own interests;
- *Peer advocacy*: taking action to represent the rights and interests of someone other than yourself;
- *Systems advocacy*: taking action to influence social, political, and economic systems to bring about change for groups of people; and
- *Legal advocacy*: taking action to use attorneys and the legal or administrative systems to establish or protect legal rights. (Advocacy Training Manual. Wisconsin Coalition for Advocacy (1996), p. 1.)

This *Advocacy Tool Kit* provides individuals with information and skill building exercises to develop and enhance self and peer advocacy skills. The information contained in this Kit has been gathered and developed to assist individuals in Wisconsin, but may be helpful to those in other states as well.

The goal of this tool kit is to teach people with disabilities and others who are advocating for them, the skills and strategies necessary to be an effective advocate.

- *Skills* are techniques for becoming competent in an area.
- *Strategies are* plans for an approach to address an issue or solve a problem.

This Kit reviews Informal and Formal Advocacy Strategies. For the purposes of this Tool kit, **Informal Advocacy Strategies** are strategies that do not involve bringing in an outside decision maker. **Formal Advocacy Strategies**, on the other hand, typically involve an outside decision-maker. Examples of formal processes include court hearings, grievance procedures or complaint processes.

Although some of the sections in this publication are written with the self-advocate in mind, peer advocates (including family, friends and service providers) will benefit from the advocacy information and techniques throughout the publication.

## Why advocate for myself or someone I know?

Whether you attempt to get a service provider to listen and respond to a concern or you try to get a landlord to fix the broken light in a stairwell of your apartment building, advocacy is practiced by people for many different reasons. For people with disabilities, frequent interaction with service providers, family members, friends, colleagues and others who may not recognize you as a decision-maker can disempower you. Learning about and practicing self-advocacy and peer advocacy skills can enhance your role and confidence in making the decisions that affect your life.

While there's no guarantee, advocating for yourself is the most direct way to secure change. And that change can mean more than getting the stairwell light replaced. Self-confidence, a healthier self-esteem and newly-gained respect from others can all be surprising by-products of the advocacy process.

## How do I advocate for myself or someone else?

This *Advocacy Tool Kit* is designed to assist you in learning strategies and practicing some skills so that you feel comfortable and confident as an advocate. Everyone is different and has different life experiences. Because of these differences, there is not one magic formula that tells you how to be an effective advocate. Experiment with different styles and choose the ones that you feel are both comfortable and effective for you.

Now, turn the page and let's get started![1]

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[1] This *Advocacy Tool Kit* was originally developed in cooperation with the New Partnerships for Woman Project of Madison, WI in 2002. It was modified in 2007 to use as a training tool for people with disabilities, their families and friends to help build and support strong advocacy skills. We use it here because people with mental health and substance use problems are considered one of the disabled groups served by DRW. We thank Dianne Greenley and others who participated in its development through Disability Rights Wisconsin, the State of Wisconsin Department of Workforce Development, as well as the members of the Long-Term Support Subcommittee of the Brain Injury Advisory Council.
For more information on additional copies of the *Advocacy Tool Kit* or other resources from the Community Mental Health Protection and Advocacy project, please visit DRW's web site located at http://www.disabilityrightswi.org or contact DRW by telephone at 608-267-0214 (voice) or 888-758-6049 (TTY), and request a brochure of available resource materials and videos.

## BUILDING AN ADVOCACY STRATEGY

You've been introduced to various forms of advocacy; including self-advocacy, peer advocacy, systems advocacy, and legal advocacy. As a reminder:

- Self-advocacy is representing and advancing your own interests;
- Peer advocacy is representing the rights and interest of someone other than yourself;
- Systems advocacy is influencing social, political, and economic systems to bring about change for groups of people; and
- Legal advocacy is using attorneys and the legal or administrative systems to establish or protect legal rights (Advocacy Training Manual: Wisconsin Coalition for Advocacy (1996), p. 1.)

Effective advocacy, of any kind, requires building a solid **strategy** or plan and practicing **skills** to help you feel comfortable and confident in reaching your advocacy goals.

Why is having a plan so important? Because it allows you to take action as an advocate in a thoughtful way. By really thinking about what you want to advocate for and how your will take action, you are more likely to resolve the problem as quickly as possible.

This section focuses on building a strategy to identify what you want to advocate for, and four things you should do before you begin. The goal of a strong advocacy strategy and developing strong basic advocacy skills (discussed in the next chapter) is to help you resolve your complaint ***informally***, without legal or outside agency involvement. Generally, you should start your advocacy using these basic techniques.

There are times when starting with ***formal*** advocacy strategies are necessary. Formal advocacy strategies typically involve getting an outside agency, like a court or an investigator, involved in resolving your problem. Formal advocacy strategies are discussed in a later chapter.

In order to make your advocacy efforts effective you should:

1. Break down the problem
2. Educate yourself
3. Identify your rights
4. Develop a solution (goal) and strategy to address your problem

This planning process takes time. Sometimes even the best laid plans fail to achieve the identified goal. It requires that you clarify your goal, identify who you will communicate with to achieve your goal, determine what methods or strategies you want to employ and figure out what steps you need to take for follow-up.

Learning how to negotiate a compromise or can be an important components to effective advocacy. This section and the next section called Informal Advocacy Skills provides information and worksheets that you can use to build advocacy skills and try out different self-advocacy strategies.

## Informal Advocacy Plan - Step by Step

### Step 1: Problem Analysis

Questions to ask yourself:

- What is the problem or issue? If there is more than one, focus on one at a time.
- What is my goal?
- What facts do I know?

We all have been overwhelmed at one point or another by something or <u>somethings</u> that we want to change in our lives. All good advocacy starts with a good understanding of the problem. You have to understand *what* you want before you can do anything about it. It sounds simple, right? Well, not necessarily. Sometimes the problems can be complicated to break down.

First, it's a good idea to keep your issues separate. Have you ever heard the phrase "when it rains it pours?" Life is often complicated. There can be more than one problem at a time. For example, you might be frustrated because you boss denies your request to change your work schedule, your roommate is not paying her half of the utility bill, and your sister is not pulling her weight in caring for your older parents. When planning how to advocate for yourself on an issue, you should make sure that you notice each separate problem. To help you, you can complete a separate Advocacy Plan for each problem that you want to address.

Once you identify the basic issue, you may need to break down the problem even further. Let's say that you asked your boss if you could work from 9:00 AM until 5:30 PM instead of from 7:00 AM until 3:30 PM because the symptoms from your disability are worse in the early morning hours. Your boss is aware of your disability, but still denies your request, stating that he does not want to give you any special treatment over other employees. You have spoken to your doctor about your concerns, but you feel she has not taken you seriously. To make matters worse, your doctor has been out of town, and so you have not had a chance to talk with a medical professional about the change in your symptoms and you are feeling worse by the day.

The problems you are having at work can be broken down into smaller parts such as:

- Your request for an accommodation has been denied;
- You have not been feeling well;
- Your doctor is on vacation and your symptoms are getting worse;
- You feel your doctor has not been taking your medical concerns seriously.

To resolve the problem, you may choose to advocate for your employer to allow you to change your schedule, for your doctor to take your concerns seriously, or to be seen by another doctor right away. You also may want to change your doctor all together.

Once you clarify the problem you should ask yourself the question "what is my goal?" If your goal is to feel better, for example, you may decide to focus your energy on working with your doctor or finding a new doctor with whom you are better able to communicate, rather than to work with your employer to permanently change your work schedule, because once you feel better you hopefully will be able to function well in the early morning hours.

When deciding what aspects of your problem you want pursue, it is important to remember:

- Some problems are easier to resolve than others
- Not all problems can be solved, or easily resolved.
- You may decide you do not want to address all the problems that you identify, and that's ok. Remember, you should pick the battles that you want to fight.

**The key is to pick out the problems that are the most important to you and address those first.** In any event, breaking down the problem will help you to move on to the next stage in the advocacy process.

Once you know which problems you want to work to take action, you should **identify the facts** that you know. Identifying the facts you know is as simple as recalling what you know about the situation and outlining the events of what has happened so far. Using the example above, some facts of the problem are:

- You have told your boss you would like to modify your work schedule;
- Your boss is aware you have a disability, but you did not tell her that you want to change your schedule because of the symptoms you are experiencing;
- You spoke to your doctor about the increase in severity of your symptoms;
- Your doctor is out of town.

When you answer the question "what facts do you know?" you should avoid inserting judgments such as "my boss is a jerk," or "my doctor does not care about me" as facts of the problem. These statements are not helpful, and will distract you from focusing on what is most important -- resolving the problem you face.

Once you have outlined the problem, identified your goal, and identified the facts of your problem, you are ready to move on to the next step - information gathering.

### Step 2: Information Gathering

Questions to ask yourself:

- What additional facts or information might you need regarding this situation, such as laws, rules or policies?
- How can I go about gathering this information?
- Who are the decision-makers that I need to influence to solve this problem?
- Are there other people who can help me?

In order to be able to effectively advocate, you must have a clear understanding of the facts that you know, and also a firm grasp of what information you might need to gather. Educate yourself about the laws, rules, and, policies that apply to your situation.

## Identifying your rights

In the United States, we all have rights as citizens. As people with disabilities, we have often been led to believe that we don't have rights or should be afraid to exercise them. Some rights are governed by laws or rules, while others are not. Therefore the term "rights" can sometimes be confusing. It is important to understand the differences in the types of rights that you may have so that you can determine the best advocacy strategy. To do this, let's first identify different types of rights.

***Laws:*** Some rights that we have are legal rights, and therefore may be enforceable in a court of law or through a formal grievance procedure. There can be Federal, State, or local laws. For example, a federal law called the Health Insurance Portability and Accountability Act of 1996 (HIPAA) makes it illegal in most instances for a health care provider to share your private health care information with others. Therefore, according to this law, you have the right to private health care records.

***Contracts:*** You can also have rights under a contract that are enforceable through a court of law. One example of a contract is a rental lease. A lease outlines the rights and responsibilities of tenants. If you feel your rights under a lease have been violated, your case can be heard in small claims court.

***Rules and Policies:*** Sometimes there are rules or policies that outline your rights. The rules or policies may not be law, but may be governed by law or may simply be a set of guidelines that an agency or an individual claims to follow. In either case, if a rule or policy has been broken, there typically is a way to file a complaint or formal grievance to address your concern. For example, your doctor may have a policy that states that you have up to 30 days to pay the balance of your bill.

***Preferences and Social Expectations***: Every society has a set of social expectations or rules that are followed, and everyone has personal preferences in how they would like to be treated. *Preferences and social expectations are typically not illegal, and therefore are not the same as a right that someone has under a law or a policy.* It is very important to understand the differences between enforceable rights - rights that are governed by a policy or law - and things that we may refer to as being a "right", but that are not covered under any law or policy. For example, how often have you said or heard people say "I have the right to be listened to" or "I have the right to make a mistake." Although expressed as rights, the right to be listened to or the right to make a mistake are really preferences of how we would like to be treated, and they are not likely to be a right we have under a policy or law.

It is important to remember that not all behavior we don't like is against the law or a formal policy that can be enforced. This does not mean that you cannot address a concern you have about being treated rudely. For example, let's say you were stood up two times by someone who is coming to give you an estimate on painting your bedroom. Although they did not break any law by making you wait for them, you could call or write a letter to the owner of the business letting then know that you were dissatisfied with how you were treated. Writing a letter or placing a phone call may or may not change the painter's behavior.

## Exercise:

Can you pick out what might be considered a <u>law</u> versus <u>a social expectation or preference</u> versus a <u>rule or policy</u> versus a <u>contract</u>? There may be more than one answer to the question. Take a few minutes to complete this exercise:

1) The right to employment without discrimination based on disability, under the Wisconsin Fair Employment Act.
2) The right to be happy.
3) The right to be "treated with dignity and respect" by your physical therapist as identified by the rehabilitation facility where she works.
4) The right to have a painter complete painting your house, as identified in the agreement.
5) The right to not be abused by your home health care aide.
6) The right to say "I don't know".
7) The right to seek housing without discrimination based on disability, under the Fair Housing Amendments Act.
8) The right to choose your health care provider.*

* Answers:

1) The Wisconsin Fair Employment Act is a <u>law</u>.
2) The right to be happy is generally considered a **<u>preference</u>**.
3) The right to be treated with dignity and respect in a rehabilitation facility might be governed under a **<u>rule or policy</u>** set by the rehabilitation facility, and being treated with dignity and respect is also a **<u>social expectation</u>**.
4) The right to have a painter complete a job she or he promised in an agreement is governed by a **<u>contract</u>**.
5) The right not to be abused by your home health care aide is a right that is governed by a **<u>rule and policy and is against the law</u>**!
6) The right to say "I don't know" is considered a **<u>preference</u>**.
7) The Fair Housing Amendments Act is a <u>law</u>.
8) The right to choose your health care provider may be governed by a **<u>rule or policy</u>**, however, not necessarily. To some it may be considered a **<u>preference</u>**.

When you still have questions or need more information, how can you go gather additional facts. Finding an answer to your question is as simple as **contacting the right person**. You'll be surprised with the amount of progress you can make by placing a few phone calls. Even if the first person you call cannot answer your question, they are likely to point you in the right direction. Some useful places to start include: the protection and advocacy (P&A) organization for Wisconsin (Disability Rights Wisconsin); the Wisconsin Department of Health and Family Services; consumer groups; drop-in centers; and Social Security offices.

The **Internet** is another tool. You can search the Internet on various topics of interest, or use it to find phone numbers to local, state, or national resources. If you don't have access to the Internet at home, try a local library, many of which now offer Internet access. If you need help learning how to use the Internet, you can ask a librarian for help. Additionally, many disability-run organizations now offer both Internet access and training. If you are more familiar with how to use the Internet, you can also see if there is a coffee shop nearby that has Internet access. Many coffee shops offer free access. To learn more information about legal research, see the chapter called "Legal Research – The Basics" starting on page 203 of the Toolbox.

The next question is who are the key decision-makers in your situation? Often, going straight to a decision-maker can result in a decision without hassle. If you are not sure who has the authority to make the decision, ask!

Advocating for yourself takes effort. Surrounding yourself with people who can help you can make all the difference. Ask from friends, family, other advocates, professionals and others to support your efforts to navigate the system and can listen and give advice when you are frustrated.

## Step 3: Solution Analysis

Questions to ask yourself:

- What are some possible solutions to this problem/issue? (be specific)
- What are some barriers to these solutions?
- What do I expect the other side to do?

After you've figured out what your rights are and have broken down the problem, then you're ready to look for a solution. An old adage says that each problem has a unique solution. By using a systematic approach, you're more likely to find the solution that fits your problem.

Preliminary steps

First, consider what you want to happen. While consulting other people is extremely helpful, you must make up your own mind, rather than relying exclusively on suggested strategies or predicted outcomes. Ask yourself, "what do I need?" Do you have emotional needs, such as an apology, or do you need something concrete?

In researching your rights, you might have learned some of the possible solutions that are available. For example, if your advance directive is ignored, your state's law might allow you to sue for money damages in court. However, you might be more satisfied with an apology and the hospital's promise of future compliance than you would be with the expense and time of a trial that might not be successful.

While determining what you want to happen, you should definitely consult with other people. Ask questions and find out whether others have faced the same problem, and what happened in their cases. Ultimately, it is you who must decide what you want to get out of your self-advocacy efforts.

Often, you'll be able to score a partial victory even if you don't obtain your ideal solution. Ask yourself in advance what alternatives you would be willing to accept. This will help you determine the course of your self-advocacy efforts. For example, maybe, you make a request for a later starting time at work due to your disability. If, in this example, your supervisor says "no," then a lawyer might tell you that the Americans with Disabilities Act entitles you to such an adjustment in working conditions. (You are entitled to a "reasonable accommodation" if you can prove you need it as a result of your disability, and it won't harm your employer too much.) However, a lawsuit might not be worth your time or money; perhaps you'd be willing to accept a transfer to another supervisor instead.

After determining what you want to happen, you must identify which people you'll need to contact in resolving your situation. Try to follow the established "supervisory ladder": if you take your problem "straight to the top," then you run the risk that the person will say "no," and you'll be left with no recourse. Also, consider potential allies who might help you with your problem.

### Building your case

Once you decide what you want and whom to contact, you can begin building your case. Ask yourself about the strengths of your position: Have your legal rights been violated? Has an established policy or procedure been ignored?

Ask yourself what the other side has to gain from resolving the problem in your favor. Sometimes, the other side might want to avoid negative publicity or complaints to supervisors, and sometimes - if you are persistent enough with your efforts - the other side might decide to give you what you want rather than continue to hear from you. When dealing with managed care companies, you might choose to show how something you want might save them money, compared to the hospitalizations that might result if you receive substandard care.

Perhaps the most important part of building your case is collecting all of the documentation that your position. Although the relevant documentation will vary from situation to situation, you should always keep copies of documents concerning health care, insurance, benefits, or anything else involving money.
Examples of important documents might include:

- Letters of support from doctors, therapists, or case managers;
- Photocopies of laws or regulations;
- Insurance policies; or
- Pay stubs.

As you build your case, you also must look at the other side of the argument. Why is the other side acting the way it is acting? Is there a rule or policy that they are following? Acknowledging the other side's viewpoint as you advocate for yourself shows that you appreciate the other side's needs, and this will help you maintain relationships.

### Planning your strategy

There are usually a variety of ways to approach any given problem. Sometimes, there is an established procedure for resolving a problem, such as filing a particular form, but often you'll find that you need to "buck the system" to see results.

You don't need to plan your strategy alone. Consulting with others can help you plan more effectively.

You should also spend some time reflecting on what you plan to do before you do it. Before you make your first contact, sit back and think.

Plan how you are going to phrase your words when you talk to someone. Develop a concise story about what you need. Take out the parts of the story that may have been emotional for you, but might not be relevant to the resolution of the problem.

When Planning your problem-solving strategy, you should take into account the various methods that might be at your disposal, including:

- Making phone calls;
- Holding an informal meeting;
- Writing a letter of complaint; or
- Filing a formal complaint.

A sample Informal Advocacy Plan Worksheet follows and can help you develop your action plan for a specific self-advocacy goal you identify. The Informal Advocacy Plan is an adaptation from Teacher's Guide, Freedom Self-Advocacy Curriculum published by the National Mental Health Consumers' Self-Help Clearinghouse. In addition, information about the methods you can use to carry out your problem-solving strategies is discussed in the next section.

## INFORMAL ADVOCACY PLAN

**Sample Action Plan Worksheet**
(Adaptation from Teacher's Guide, Freedom Self-Advocacy Curriculum, National Mental Health Consumers' Self-Help Clearinghouse (April 2000 Pilot Version), p. 18.)

**What is the problem or issue? If there is more than one, focus on one at a time:**

**What is your goal?**

**What facts do you know?**

**What additional facts or information might you need regarding this situation, such as laws, rules or policies?**

**How can you go about gathering this information?**

**Who are the decision-makers that you need to influence to solve this problem/issue?**

**What are some possible solutions to this problem/issue (be specific)?**

**What are some barriers to these solutions?**

*Pick one solution and discuss the strategies and tactics you will use to achieve this solution. Complete the information below to assist you in initiating your action plan.*

I will call/meet with/write to ______________________________ by the following date: _____________.

If this person does not resolve the situation by the following date __________, then I will call/meet with/write to

_________________________________________.

<u>Documentation that I will need</u>:

<u>Other people who can help me</u>:

<u>What I expect the other side to do</u>:

<u>Strategies for what's next</u>:

<u>Debriefing: who will I call or how will I take care of myself following this encounter</u>?

*Keep in mind that the strategy you use to obtain the advocacy goal may not be successful. It is helpful to think about what you will do if you don't get what you want the first, second, or even third time around.*

*If your plan does not work, you may need to review your strategy, what went wrong and alternative ways to resolve your concern. You may want to revisit some of the information-gathering questions listed above and consider asking yourself the following questions:*

<u>What will I do if the strategy doesn't work? What is the backup plan?</u>

What went wrong? Why didn't the strategy work?

# INFORMAL ADVOCACY SKILLS

This section is a brief overview of some basic tools to help you to become a better advocate. You will find worksheets and tools to assist you in developing advocacy skills and taking action to address your concern. You will learn how to:

- Stay organized,
- Properly document and keep records, and
- Be an effective advocate on the phone, in writing, and in-person.

By understanding, practicing and using these skills, you will be better organized, prepared, and able to respond to unexpected things that come your way. Generally you should start your advocacy using these informal techniques; however, there are times when starting with formal advocacy strategies are necessary. Formal advocacy strategies and additional communication skills are discussed in other sections.

Before we begin, let's review some important tried and true advocacy tips. The following tips were originally created to address concerns within a treatment setting, but can be applied to most any advocacy situation.

***Exercise:*** After you review them, take some time to think about how you've used these strategies to advocate for yourself in the past. Were they helpful? What strategies might have helped you to resolve your problem sooner had you tried them?

### How to be an Effective Advocate

(Adaptation from Advocacy Training Manual. Wisconsin Coalition for Advocacy (1996), p. 26, from a presentation by Nina Gagnon, National Project Director, Mental Health Advocacy Training, National Paralegal Institute, San Francisco, CA.)

1. Try not to be intimidated by authority; learn to question responses with which you do not agree.
2. Try to resolve the dispute informally first. Why spend more time than you need to? Most of the time if you address your concern directly with a person who can do something about it your complaint will be resolved.
3. Find out what the authority is for the agency's decision. Ask the worker what regulation her/his decision is based on. Public agencies must follow written regulations and procedures. Members of the public have a right to see these regulations. Insist on checking the rule book yourself. Perhaps you can find it online.
4. Find out who in the bureaucracy has the power to make the change you want, and insist on dealing with that person. Don't give up because the person you are dealing with does not have the power to make the change you are requesting. Find out who does, and go up the "chain of command."

5. Use your imagination to come up with solutions to problems. If, for example, you cannot locate a document you need, think of alternate ways to prove the fact. Use a declaration (sworn statement) or an affidavit (sworn, notarized statement).
6. Take full advantage of all appeal rights. Request decisions in writing and inquire specifically about methods of appealing unfavorable decisions. Be aware that deadlines exist for filing appeals. Be sure to read the small print carefully in any official notices received.
7. Always get the name of any person within an agency with whom you deal. Keep accurate notes of dates, content of conversations, and the identity of the worker who gave you the information. If questions arise later, this is your proof that the conversation you remember did, in fact, take place.
8. When possible establish and nurture contacts within the agency with people you find helpful. Try to deal with or get helpful information from workers with whom you have established a cooperative, friendly relationship. They can be of great assistance.
9. Utilize other existing advocacy resources in your community. Locate other organizations advocating for low income, elderly, and people with disabilities. Establish contacts with other advocates in your community, and explore the possibility of setting up training together. When you are stymied or confused as to what to do next, call a more experienced advocate for advice.
10. Use all available methods for increasing your legitimacy as an advocate.
11. Remember that it takes time to develop highly skilled advocacy approaches. Even the best advocates don't always win; losing may be as much a reflection on the target system as on the advocate. Evaluate your activities periodically. Give yourself credit for good, effective approaches, and outline areas of your advocacy skills in which you would like to heighten your skills. Remember that change is a long, slow process, but that all contributions to progressive change in our systems and human services are important.

### Documentation and Taking Notes

(Adaptation from Advocacy Training Manual. Wisconsin Coalition for Advocacy (1996), pp. 8, 18.)

Creating a paper trail means having in writing events and decisions which are important to your advocacy effort. Experience has shown that having a written record of what went on and when is crucial to building an agreement and substantiating your position. Paper trail skills include documentation and note taking.

### Documentation

Documentation is a critical component of good advocacy. Good documentation includes:

- Keeping notes of all conversations (phone and in-person) that you have regarding the situation beginning with the initial contact. Later in this section, we have developed a sample contact list and phone log that you can use to document and take notes of your activities.)

  The information you should have as part of the log or contact sheet is the following:
  - Date;
  - Time;
  - Full name of the person(s) you contacted;
  - Person's title;
  - Agency name;
  - Agency telephone number; and
  - A description of what was discussed.

  If there is a question about the accuracy of conversation, follow up with a letter to the party summarizing your understanding of the conversation. Keep a copy of the letter for your documentation.

  Keep all letters and copies of information you receive from agencies and individuals. Do not make any marks on copies received from other parties because those parties may claim the documents were tampered with.

  Keep copies of all letters and information that you send out regarding the situation.

  When you fax copies of documents, you should also mail a hard copy and make a note of this on your letter.

### Taking Notes

Note taking is a tool that provides a written record of what happened at a meeting or during a phone conversation. Note taking signifies to others that you are an active participant in what is occurring. When you are taking notes people around you are more likely to feel accountable. They become more productive and responsible and pay more attention to you. If you have never taken notes, it may at first seem like a lot of bother. But once you practice it becomes an effortless activity that you can easily do while fully participating with others in a group. If you have difficulty taking notes and participating in the meeting, bring someone with you to the meeting to take the notes for you. Take notes at every advocacy meeting and conference you attend as a record of all the information you receive. Also, keep a notebook by the phone so that you can keep a record of everyone you talk to and anything said which should be documented.

It is helpful to keep the following points in mind when taking notes:

1. At the beginning of your notes, list the names and role of those spoken to, and list the day, place and time of the conversation. State the primary purpose of the call or meeting in one or two sentences.

2. Use an outline format and modify it to meet the needs of each particular call or meeting.
3. Write key words and abbreviations rather than long sentences. The fewer words written, the more time is available for thinking and actively participating.
4. Leave space along the left-hand margin for filling in answers to questions and for clarifying points which are not initially understood. Ask the speaker to clarify what s/he is saying if you don't understand.
5. Use a colored felt tip pen to underline important terms and phrases. This is very helpful when you go back later to review your notes.
6. Before you end the communication, if possible, review your notes, be sure they are dated, and ask for any clarifications that are needed. It's sometimes a good idea to remind everyone that what they have said is documented. If you type your rough notes, be sure to save the originals in case of later misinterpretation.
7. File your notes in a home file.

The way in which you organize your home file is up to you. However, it is important for you to keep copies of every letter or other piece of correspondence which you write and receive regarding your case, copies of records and notes you take at meetings, or during telephone conversations.

### Advocacy on the Telephone

(Adaptation from Teacher's Guide, Freedom Self-Advocacy Curriculum, National Mental Health Consumers' Self-Help Clearinghouse (April 2000 Pilot Version), pp. 19-24.)

We all know how to use the telephone, but we can learn to use it more effectively as a tool for getting what we want. Many people - understandably - lose patience when dealing with large bureaucracies such as insurance companies or government agencies: more and more, callers must navigate automated menus before reaching a live person. Some people have feelings of fear or anxiety when making phone calls. However, we all can work to improve our telephone calls.

### Phone manners/managing anger

Resolving a problem by phone is oftentimes the quickest and most straightforward way to resolve a problem. However, the process still takes some time and causes some frustration. If you are able to control your anger at the delays and frustrations that you experience, then you'll be a much more effective advocate for yourself.

Using the telephone for self-advocacy is fairly common when dealing with managed care organizations (MCOs), insurance companies, hospitals, community mental health centers, and government agencies. With all of these different organizations, your first point of contact will often be those pre-recorded phone menus that ask you to press keys to be connected to the right department. When you finally do reach a live voice, it is often a front-line employee who might not have the authority to resolve your request.

Certainly, it is frustrating. Say for example, your MCO denies your request to see a certain doctor, or your benefit check is reduced without explanation. Your first inclination might be to scream at the first person you talk to - anger is natural. However, your ability to handle this anger might have an impact on how well (or poorly) the organization resolves your problem.

Of course, you should express your concern, but there's no need for name calling or shouting at the person on the other end. Also, the person will probably absorb the information better and be able to resolve the situation more efficiently if he or she doesn't feel under attack. Longtime advocate, Mary Ellen Copeland cautions, "Don't say anything attacking the other person's character." Instead, concentrate on explaining why you need the person to act.

Keep in mind that the person on the other end of the phone is just that - a person. He or she has good days and bad days just like you and looks forward to pleasant calls more than unpleasant ones. If it is the case that your problem was caused by an innocent mistake - a computer error for example - the employee might be much more helpful and make it a higher priority if you are pleasant on the phone.

By managing your anger, you can avoid developing a reputation as a "difficult caller." Most of the organizations that you deal with keep records that phone personnel access when you call them. By avoiding being labeled obnoxious or insulting, you are likely to get better service on future calls.

If you experience a problem that makes you very angry, how can you prevent the anger from boiling over into the phone conversation? The easiest way might be to take some time to cool off; Mary Ellen Copeland recommends that you do a relaxation exercise before making a stressful phone call. She also has a unique suggestion for managing your anger while you're on the telephone: "Have a friend with you when you make the call, that way you can make faces with your friend but remain calm on the phone."

Before making your call, you can also take time to plan what you are going to say, and gather the information that you might need. For example, it is common for someone to receive a hospital bill for services that were supposed to be covered by insurance; these situations are often caused by paperwork errors. If this happens to you, your first inclination might be to call the hospital or the insurance company and yell at someone.

Instead of doing so, take some time to calm down, gather the bill, your insurance policy, and the paperwork you received at the hospital. Then call your insurance company and find out why the bill wasn't paid. With this information, you are more likely to be able to calmly, but assertively, resolve the situation. Let's now look at how to use the phone assertively.

**Being assertive**

A big part of assertiveness when using the phone is being persistent enough to get in touch with someone who can help you. When calling large organizations, it's not always easy to reach people. If you have not heard back by the next day, call again and leave another message until you get a return call. If you're having trouble reaching someone, you should leave a message each time, including the dates and times that you are available to speak.

Your assertiveness must continue once you are speaking with a live person. Learning to be assertive without raising your voice or being rude is a skill to be learned, and one that will make you a much more effective advocate. We discuss assertiveness throughout the *Tool Kit*, but now let's look at specific ways to be assertive on the telephone.

- *Do your research.* If you are told that you cannot do something or qualify for certain benefits, you should know the standards. For example, you might say, "My insurance policy says that I have the right to appeal this decision, and I would like to appeal."
- *Set minimum standards.* Often, you will be dealing with low-level employees who do not have the power to compromise; therefore, if anyone compromises, it will have to be you. If a low-level employee cannot meet your minimum demands, ask to speak to his or her supervisor.
- *Recognize the other side of the argument.* If you demonstrate that you understand the other person's point of view, then he or she cannot dismiss you as being irrational. You might say, for example, "I can see why you don't normally authorize that medication because it is more expensive. But it's worked for me in the past, and it is cheaper than paying for my hospital bills."
- *Ask for clarification.* Don't let the other person confuse you with jargon or vague statements. Whenever the other person says something that you don't understand, ask for clarification. You can't win a dispute if you don't understand what the other person is saying.
- *Leave the door open.* State that you would like to reserve the right to submit additional information. If you become flustered on the phone, you can strengthen your case later.

The table below contains some more examples of assertive responses. These are just a few examples of the statements that you can make to assert yourself.

**Exercise:**
One effective way to work on your assertiveness is to role-play advocacy situations with a friend. Ask your friend to give you feedback about whether you were acting assertively.

**Assertive Responses**

| Statement | Assertive Response |
|---|---|
| *Insurance company customer service representative:* "I'm not the person who deals with this." | "Tell me the name and number of that person. I called the number listed in my policy, and if you can't help me, it's your responsibility to tell me who can." |
| *Social Security representative:* "I don't have all the information about your application, so I can't answer that question." | "When can I expect to hear back from you? I will call back if I don't hear from you by then." |
| *MCO executive assistant:* "I don't think that there are any openings on the advisory board right now." | "I was told that there are no consumers on the advisory board, and the law says that there must be consumer representation. Who is in charge of the selection?" |
| *MCO customer service representative:* "We can't pay for the treatment because it is not medically necessary." | "I would like you to send me an explanation of how you determine whether treatment is medically necessary." |

## Talking to the right person

As we mentioned in the previous section, when you're talking to someone on the phone, it is often someone who won't be able to resolve your situation for you due to lack of authority. Other times, the person on the other end of the line just happens to be a generally unhelpful person.

Author Brandon Toropov offers many helpful suggestions for resolving a problem by phone. His book, *The Complete Idiot's Guide to Getting along with Difficult People* (don't be put off by the sarcastic title), recommends that you seek a new contact person if the person with whom you've dealt:

- Is new to the job, based on what the person has said, or your best guess;
- Has not gotten in touch with you after you've left three messages;
- Has told you three times that he or she must appeal to a supervisor for information or authority, without results;
- Hesitates before answering important questions;
- Asks you to supply the same information or file the same forms more than once; or
- Is defensive, moody, or combative without being provoked by you.

When you're not getting anywhere by talking to lower-level employees, you might need to "go up the supervisory ladder." You should be aware that going to a supervisor too soon can backfire. Going to a supervisor before you've given someone a fair chance to resolve your problem can create bad feelings, and you can always go to a supervisor later.

If someone fails to resolve a problem to your satisfaction, then you should go up the supervisory ladder, one level at a time. In other words, always ask to speak with someone's immediate supervisor.

Some advocates recommend going straight to the top of the supervisory ladder, but there is an obvious advantage to moving one level at a time: you give more people the opportunity to give you what you want. If, on the other hand, you go straight to the top, and that person says "no," you probably won't get what you're after.

### Keeping records

With any form of self-advocacy, it is important to keep records, but it is especially important to keep accurate and complete records of your telephone conversations. Often, your records will be the best documentation of your attempts to resolve a situation or another party's suggested solutions.

You should keep an accurate record of every person with whom you spoke, as well as their titles and what they said. Sometimes, it will strengthen your position if you can demonstrate that the other party was unhelpful, and so you should also document every time that you couldn't get through to someone on the phone, as well as when you left messages for a person. Doing so will prevent someone from saying that your inactivity is the cause of the problem. You can use the Sample Phone Log as your guide.

### Following up

As with any form of advocacy, it is important to follow up when you are advocating by phone. The follow-up usually includes additional phone calls to ensure that agreed-upon actions will be taken, but might also include supplying written documentation or sending follow-up letters or faxes.

Following up on a phone conversation should begin during the conversation itself. For example, if the person with whom you are speaking cannot respond to your request immediately, you should ask when they will get back to you and the date on which you can expect action on what you've requested. If the person promises to take a specific action, then ask when that action will be taken. Be sure to record this information in your phone log.

Once you've established dates for responses and/or action, you should make sure that the person sticks to those dates. You can mark a calendar to keep track of the dates. If you haven't heard back or seen results by the agreed-upon date, you should call back.

Be polite but firm. Remind the person that he or she promised to respond or take action by a certain date and ask why this hasn't happened. You should persist until you get what you want, and if you don't see results, then you should proceed up the supervisory ladder one level at a time.

Usually people are handling multiple requests at a time, and one way to ensure that your request gets special attention is to follow a phone call with a fax. When speaking with someone, ask for the fax number where he or she can be reached.

After speaking with a person, send a fax summarizing the action requested and the agreed-upon follow-up dates.

If the person does not seem to be responding adequately, then a fax can be an especially effective tool. Obtain the name of the person's supervisor, and send the fax both to the person with whom you've spoken and his or her supervisor. At the bottom of the fax, write "cc:" followed by the supervisor's name so that the employee knows that the supervisor has also seen the fax. We'll examine written communication more closely in the next article, *Advocacy in Writing*. Before we explore advocacy through written communication, we have included two worksheets for you to use in documenting your contacts and telephone calls that you make.

## CONTACT LIST WORKSHEET

| Name & Organization | Telephone & Fax Numbers | Email |
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# TELEPHONE LOG WORKSHEET

| Outgoing Phone Log | Incoming Phone Log |
|---|---|
| Date: | Date: |
| Person called: | Person calling: |
| Telephone Number: | Telephone Number: |
| Referred by: | |
| Was call answered? | |
| Left message? | |
| Person spoken with: | |
| Title of person you spoke with: | Title of person you spoke with: |
| Fax number: | Fax number: |
| Summary of conversation: | Summary of conversation: |
| Action suggested: | Action suggested: |
| Action agreed upon? | Action agreed upon? |
| Deadline: | Deadline: |

## Advocacy in Writing

(Adaptation from Teacher's Guide, Freedom Self-Advocacy Curriculum, National Mental Health Consumers' Self-Help Clearinghouse (April 2000 Pilot Version), pp. 25-29.)

Being able to write a short, direct, and assertive letter will aid your advocacy efforts. Learning to write letters is a skill that must be learned, but fortunately it is easier to learn than almost any other style of writing. And the good news is that, as a general rule, the shorter your letter, the better. In this segment, we'll discuss how to write an effective letter, as well as provide some sample letters.

Keep in mind that every letter you write should become a part of your files on the matter in question. Keeping records of your letters is easier than keeping detailed records of phone conversations, but equally important, so be sure to keep a photocopy of each letter.

### The format of a business letter

When you write a letter for advocacy purposes, you should follow the standard format for business letters. Although there is some variation in the format used for business letters, *Sample Letters A and B* on pages 34 and 35 provide a good model to follow. Include your return address, the date, the other person's address, greeting, and signature in a manner similar to that in the sample letters.

Another feature to note is the "cc:" (copies circulated) line. The "cc" line is a way to record that you've sent a copy of the letter to someone else. So, if you see "cc: April Jackson," it means that you sent a copy of the letter to April Jackson. When sending a letter to someone, it can be good practice to also copy their boss or other person in authority because it can help to get your concern addressed sooner.

However, keep in mind that cc'ing someone's supervisor puts that person on the defensive. It can therefore be counter-productive to cc a person's supervisor before you've given the person a chance to resolve the problem.

Below the "cc" line is the "Encl." (enclosures) line. To show the recipient what you've sent, and to remind yourself when you look at a photocopy of the letter, use the "Encl." notation and a brief description of what you've sent.

Although the standard business letter is typewritten, it is acceptable to hand-write a letter if you cannot type your letter or find someone else to type it for you. Try to write as neatly as possible, and again, be sure to keep a photocopy.

### The content of the letter

The *Sample Letters* included here also provide an idea of what to include in your letter. When you write a letter, you should:

- *Open by explaining to the recipient why you are writing.* For example, in ***Sample Letter B***, the writer wants his insurance company to pay a hospital bill.
- *Include photocopies of relevant documents* or offer to provide whatever documentation is necessary. In ***Sample Letter A***, the writer offers to provide

documentation from her health care professional, and in ***Sample Letter B***, the writer includes a copy of the hospital bill.

- *Explain the reason why you are asking for action by the recipient.* The writer of ***Sample Letter A*** explains that the Fair Housing Amendments Act requires that landlords make "reasonable accommodations" for tenants with disabilities. In ***Sample Letter B***, the writer explains that he obtained a referral for the services; therefore, the insurer should pay for them.
- *If the action needed is urgent, explain why.* In ***Sample Letter B***, the writer is facing a negative credit report if the problem is not resolved swiftly.
- If applicable, *summarize steps that you have taken to resolve the problem.* In ***Sample Letter B***, the writer summarizes phone conversations and documents times that he tried to reach the insurance company.
- *If you are considering legal action or a formal complaint, note that you are considering it.* However, reserve this tactic for situations in which you feel that you have a valid case and could follow through; otherwise, the other party could call your bluff.
- In the closing paragraph, *give a time by which you expect the recipient to respond or take action.* This should be a reasonable amount of time in relationship to the urgency of the situation.
- Also in the closing paragraph, *thank the recipient*, or if the recipient has not proven helpful so far, then express your hope that they will resolve the matter as soon as possible.

### Other considerations

As you grow as a self-advocate, you will feel more comfortable writing letters, and you'll learn what works and what doesn't work. Here are some other things to think about when writing letters as part of your advocacy efforts:

- When writing your letter, *pay special attention to your tone*. Put yourself in the place of the writer of ***Sample Letter B:*** although he was probably angry at the insurance company's broken promise, he is not rude or insulting. He simply states why the recipient has done wrong and explains what the insurance company should do in order to rectify it. By not antagonizing or insulting the recipient of the letter, you reinforce that you are in the right and that your request should be granted.
- For a few extra dollars, you can send a letter via *certified mail*, return receipt requested. Not only will this make your letter stand out to the recipient, you'll know exactly when the letter arrived. Depending on the severity or urgency of the situation, you might also consider faxing your letter or using express delivery.
- You shouldn't hesitate to *ask friends for help in writing letters*. You can rely on friends to help with the writing and to check your letters for errors in spelling or grammar. They can also give you feedback on if the tone of the letter is polite.

## Sample Letter A

Elizabeth Martin
127 Maple St.
Apartment 105
Beloit, WI 53511

January 2, 2007

Mr. Edward Peters
Peters Property Management
13 E. Main St.
Beloit, WI 53511

Dear Mr. Peters:

I am a tenant in your building at 127 Maple Street. I am writing to request, as a reasonable accommodation required by the Fair Housing Amendments Act (FHAA), that I be allowed to keep a service dog in my apartment. The FHAA requires that landlords provide "reasonable accommodations" to tenants with disabilities.

I understand that the building has a "no pets" policy; however, health care professionals have recommended that I use a service animal for emotional support. I would be happy to provide written documentation of my disability and my provider's recommendations.

Please contact me within ten days to let me know whether my request has been granted because I need to proceed with finding a suitable service dog. You may reach me by telephone at (608) 555-2525. Thank you for your prompt consideration of my request.

Sincerely,

Elizabeth Martin

**Sample Letter B**

Steven Jones
14 Broad Street
Fond du Lac, WI 53945

January 2, 2007

Mr. Evan Brown
Claims Service Representative
Acme Insurance Company
2121 Lincoln Ave.
Milwaukee, WI 53201

Dear Mr. Brown:

I am writing to request the immediate payment of the enclosed hospital bill, for services provided on October 12, 2006. As you can see, the hospital is threatening to refer my account to a collection agency, and I am very upset that Acme Insurance has not paid this claim. I am considering referring this matter to the state insurance commissioner.

I had received a referral for the services in question. The referral number is BB 9854. Therefore, Acme should have paid this claim. When I spoke with you on the phone on November 20, 2005 you assured me that the bill would be paid within 10 days. After that time passed, I have been trying unsuccessfully to reach your department. I left messages on December 5, 10, 13, 15, and 19, 2006.

Please respond within five days of receipt of this letter. You can reach me by phone at (920) 555-2828. I am looking forward to the prompt resolution of this matter.

Sincerely,

Steven Jones

cc: April Jackson,
President, Acme Insurance

Encl: Hospital bill (photocopy)

## Advocacy in Person

(Adaptation from Teacher's Guide, Freedom Self-Advocacy Curriculum, National Mental Health Consumers' Self-Help Clearinghouse (April 2000 Pilot Version), pp. 30-35.)

For some forms of advocacy, such as participating in your own health care decisions, in-person advocacy is only natural. Mary Ellen Copeland says that meeting face-to-face with the person you're trying to influence is the most effective form of self-advocacy. By working to improve your in-person advocacy skills, you can help overcome the anxiety that many people experience when preparing for a meeting.

## Preparing for a meeting

Preparing in advance of a meeting not only helps to reduce anxiety, but preparation also helps you to become a much more effective self-advocate. Perhaps the first step in preparing for a meeting is writing down the appointment as soon as you've made it.

Although recording an appointment is a simple step, it is an extremely important one because it helps you keep the appointment. "Once you've scheduled a meeting, you have to write it down and keep it," says Howard Trachtman, a self-advocate and peer advocate from Massachusetts. "The person you're meeting with has other commitments," he continues, and if you don't keep your appointments, then the person "is going to spend more time with the people who are keeping their appointments and following through. That's just how it works."

If you absolutely cannot make a scheduled appointment, call in advance to cancel or reschedule it. Try to give the other person as much notice as possible; you shouldn't cancel a meeting on the same day unless it is a sudden, unanticipated emergency.

At the time you schedule your meeting, you should also ask for information that will help you prepare. Always ask if there is any type of documentation that you will need to bring to your meeting. Ask if you must meet certain qualifications in order to get what you're asking for. If the other party initiated the meeting, make sure that you understand the purpose of the meeting completely.

Another important step for planning a meeting at which you will advocate for yourself is to find a friend who can come with you. Although it helps to pick someone who knows something about advocacy, it's not necessary to do so. "Don't go in alone," says Brian Coopper, director of advocacy at the National Mental Health Association, "because the presence of another person will make the people you're meeting with behave."

Mary Ellen Copeland agrees, saying, "With doctors and professionals, you often have to take someone else with you. They act differently, even if your friend doesn't say anything. It's still self-advocacy because you're in control. It's a way to get around the system."

Another important part of preparing for a meeting is to think hard about what could happen at the meeting. Trachtman suggests that you ask yourself the following questions:

- What do I want to happen at the meeting?
- What do I want to learn at the meeting?
- What could happen as a result of the meeting?

By knowing what you want to happen, but preparing yourself for what could happen, you can better think through your strategy for the meeting. You should prepare an agenda for what you'd like to say, what you'd like to ask the other person, and how you would respond to the other party's suggestions of what they'd like to happen.

In addition to bringing your agenda with you, you should bring photocopies of all relevant documents (unless the other party says that you need to bring an original). Also, if you will be citing particular laws or regulations, you should bring photocopies of those as well. Says Alaska self-advocate Dan Roberts, "Don't just say, 'There's a law somewhere.' A photocopy gives people a chance to look at the law." By demonstrating that you know your rights, it makes it much more difficult for the other person to ignore your rights.

## Holding a successful meeting

An obvious but important first step in holding a successful meeting is to show up on time. Once you're there, you have many tactics that you can use to improve your chances of a successful outcome. Some of the tactics you'll find particularly helpful include body language, active listening, and negotiation skills. Although these skills require practice, once you learn them, you'll be a much more effective self-advocate. There is additional information on this topic in the Communication Skills section of this *Tool Kit*.

### Body language

In an ideal world, justice and fairness would govern everyone's actions. However, in the real world, image is important, and the way in which you present yourself at a meeting can have a major impact on its outcome. Using positive body language conveys confidence and assertiveness. Here are some examples of positive body language:

- *Dress and groom yourself appropriately for the meeting.* Poor grooming or sloppy dress can leave a negative impression regardless of the strength of your case. Brian Coopper explains, "Dress as nicely as you can. Not only does it show respect for people, but it reduces the power differential." If you dress nicely, people will - consciously or unconsciously - treat you with more respect.

- *Shake hands firmly.* When you introduce yourself at the beginning of the meeting, give the other person a firm handshake while you look the person in the eyes.

- *Do your best to maintain eye contact.* Although this can be difficult if you are shy or nervous, you will find that maintaining eye contact helps you maintain control over the meeting. Don't "stare down" the other person, but do look him or her in the eyes while either of you is talking.

- *Use good posture.* By sitting straight in your chair, you show respect for the other person and also convey confidence in what you are seeking.
- *Try not to fidget.* You should try to avoid some of the things people often do when they are nervous, such as wringing their hands or squirming in their chairs. Such actions convey your nervousness, making the other person feel more confident in his or her position.
- *Practice these skills.* Before an important meeting, you can practice your body language either with a friend or in front of a mirror. If positive body language does not come naturally to you, you should practice this skill. You can learn positive body language in the same way you learned to jump rope, hit a baseball, or play video games.

## Listening

When you are meeting with someone, active listening can mean the difference between being spoken to and being "spoken at." Active listening means that you take steps to find out the information that you need, rather than simply listening to what the other person says.

The simplest form of active listening is to ask for clarification if you don't understand something. For example, if the person uses jargon or an abbreviation that you don't understand, be sure to ask what it means. For example, if someone says, "well, we don't usually get involved in these types of situations until DDM has contacted us," you won't really know what to do next if you don't know what DDM stands for. Don't be afraid to ask for this information; if you try to find out after the meeting, you will miss important points during your discussion.

Active listening requires that you restate a person's position so that you both understand what the person is offering or requiring. In the above example, you might respond, "So what you're saying is that I should contact DDM and ask them to review my case." By restating the other person's position, you can make sure that you are both "on the same page" as you negotiate.

You should also ask for clarification if you don't understand someone's reaction to what you say. For example, if someone replies, "I see," it might mean that the person understands your position, but the person might mean, "I see that you are being difficult." When someone is vague, don't guess at his or her meaning; instead, ask.

Finally, to have a record of exactly what went on during the meetings, you should take careful notes of what was said. Be sure to write down:

- Any promises that the other person makes;
- Any actions that you must take;
- Any explanations that the person makes for granting or denying your requests; and
- Anything the person says that is supportive of your position.

Using a tape recorder allows you to keep an exact record of your meeting. Although some people might permit you to tape record a meeting others are put off by this suggestion.

## Negotiation

Learning to negotiate successfully is the centerpiece of self-advocacy. Negotiation is when tow groups who disagree work together to resolve a problem. All of our preparations feed into the negotiation process. As with other advocacy skills, negotiation is a skill that can be learned through study and practice. Here are some pointers for getting what you want through negotiation:

- *Lead with the strongest part of your argument.* For example, if you are dissatisfied with the treatment you have been receiving, you might start by pointing out that a doctor or staff person has violated your state's patients' bill of rights.
- *Keep your presentation short by focusing on relevant facts.* Often we want to tell our life story when we are trying to spur people to action. But by taking up too much of someone's time, you run the risk of alienating that person. Instead, focus on details that are the responsibility of that person. In other words, if you are experiencing problems with a certain program or service, focus on that program or service rather than other problems that you might be experiencing.
- *Focus on remedies, not complaints.* Unless your goal is simply to make someone feel sympathy for you, then you should have an action plan for what you want to happen. For example, rather than complaining about your housing, you should state that you want housing in a safer area.
- *Control your emotions.* No matter how much the other person upsets you, don't resort to yelling or name-calling. If you need to ask for a break to compose yourself, do so. You can go home and punch pillows after the meeting, but "blowing up" during the meeting reflects poorly on you, and people often use your behavior as an excuse for denying you what you want.
- *Have in mind a minimum that you are willing to accept.* To be a good negotiator, you should ask for more than what you really want, but keep in your own mind a minimum that you would be willing to accept.
- *Acknowledge the other person's position.* Demonstrate that you understand the limitations faced by the other person. This will help you keep your demand realistic and make the other person feel more comfortable in negotiating with you. For example, you might say, "I realize that the medication that I want is more expensive than other medications," or "I know that you have a limited amount of housing available."
- *Stick to your basic needs.* Just because you should acknowledge the other person's position doesn't mean that you should accept it. The best way to stick to your basic needs is to reiterate your position using "I" statements.

If you have tried other medications unsuccessfully, you can say, "I need a medication with fewer side effects." If you need a safer place to live, you can reiterate, "I need a safer place to live" in response to the other party's suggestion that he or she thinks your current arrangements are adequate.

- *Point out weaknesses or liabilities to the other person.* Give the other person a reason to want to help you. For example, you could say, "I have been trying for months to get safer housing. If something happens to me, your agency could face problems."
- *Ask for the chance to offer additional information.* Meetings sometimes put pressure on us, making it difficult to remember everything we have to say. You might wish to reserve the right to provide additional comments or support later.
- *Restate any actions decided upon.* If the other person makes any promises to you, restate them as you end your meeting. Equally important, if you make promises, restate these promises as well, so that you are sure of what you need to do.
- *Set a timeline for action.* A promise to "look into the problem" or "get to it as soon as we can" doesn't help you very much. By insisting on a timeline for action, you can contact the person if deadlines are not met.
- *Be prepared to walk out without resolving the negotiation.* Brian Coopper suggests, "If the meeting isn't going smoothly, don't agree to something just because of the urgency of the moment. Be prepared to get up and walk away - politely."
- *Practice negotiating with friends or support groups.* There are many books that provide negotiation exercises that you can practice with a group. (Additional information on negotiation is available later in this section.)

## Follow-up

As with any form of advocacy, following up is important after you meet with someone face-to-face. After your meeting, write a short letter thanking the person for his or her time. In your letter, you should also restate any agreements that were made in the meeting.

After your meeting, read over your notes and make sure that you understand them. While your memory is still fresh, you should also fill in any information that you might have forgotten to write down. Keep your meeting notes with other documentation, such as copies of letters and your phone log.

If the person with whom you met promises results by a certain time and these things do not happen, then you should contact the person. When you call or write to the person, be sure to refer to the date of your meeting and restate what you had agreed upon.

## More on Negotiation as a Tool for Change

(Adaptation from Taylor, Steven, Negotiation: A Tool for Change, DD Rights Center, Center of Human Policy, Syracuse, NY (1979), reprinted from the Advocacy Training Manual. Wisconsin Coalition for Advocacy (1996), pp. 27-30.)

Any time two groups with conflicting interests meet to discuss the issues between them, they are negotiating. Sometimes the negotiations are explicit; that is, the groups consciously draw on negotiating strategies. Usually they are not. Too often, those who advocate for change enter into negotiations with only a vague sense of what they hope to accomplish and how to accomplish it. This piece is designed to enable consumers, parents, and advocates to negotiate effectively.

### Short term -- Long Term

You can use negotiations to work for either short term or long term change. Short term change usually means helping one or a small number of people without radically altering the conditions that create the problems. Some examples of short term, limited change are gaining access to previously undisclosed information or records; obtaining entry to an institution; advocating for special ramps, toilet facilities, or prosthetic devices for a small group of persons with physical disabilities; or working for the establishment of a community residence for a small number of people. Each of these short term changes represents a challenge to the usual policies and practices of many service systems, but they do not represent broad sweeping reforms.

Long term change involves confronting systemic problems. Architectural barriers, institutional abuse, segregation -- all are symptomatic of underlying problems in societal attitudes and human services. In advocating for long term change, negotiations should be used together with a larger set of strategies mapped out beforehand. For instance, negotiating may be used along with media coverage, investigations, public forums, letter writing campaigns, and litigation (see Biklen, Douglas. (1974) *Let Our Children Go: An Organizing Manual for Advocates and Parents*. Syracuse, NY: Human Policy Press.).

### Approaches

Your approach should be determined by the intransigence, or willingness to change, of the opposite side. As Des Jardins (1971) notes, “If a bureaucrat gives you what you are entitled to, he is your friend. If he doesn’t, he is your enemy.” (Des Jardins, Charlotte. (1971) *How to Organize an Effective Parent Group and Move Bureaucracies*. Chicago, IL: Coordinating Council for Handicapped Children.)

You will sometimes need to take a “hard line” approach. When the opposing side actively resists change, you will have to be confrontational. Often a conciliatory approach will be most effective. For instance, when the opposition demonstrates willingness to change through its actions, you can afford to adopt a softer approach. But do not abandon your goals for the sake of getting along with bureaucrats and officials. As Saul Alinsky (1972) noted, “Reconciliation means when one side gets the power and the other side gets reconciled to it, then we have reconciliation." (Alinsky, Saul D. (1972) *Rules for Radicals.* New York, NY: Vintage.)

## Preparation

1. *Know when to negotiate.* Negotiations should be held prior to more dramatic or public actions, such as press conferences, demonstrations, or litigation, in order to provide agencies with an opportunity to meet your demands before you "go public." You should enter into negotiations when informal approaches fail; for example, when a parent's requests for services are denied.
2. *Obtain the backing of a group or a coalition of groups.* Make sure you identify yourself with consumer interests.
3. *Setting up the negotiation.* Request a meeting in writing. Your letter should establish your own credibility, explain the general purpose of the meeting, and specify which agency representatives should attend. Don't give too much information on your position beforehand. Save your demands and documentation for the negotiation session. Follow up the letter with a phone call to confirm the arrangements for the meeting. Be sure to find out which agency representatives will attend.
4. *Target.* You should only negotiate with persons who have the authority to make decisions. In most negotiations, you will want to meet with the head of the agency.
5. *What if they refuse to meet?* First, appeal to their superiors; for example, state officials when local agency representatives balk at meeting. Second, go public: hold a press conference; organize a sit-in or demonstration.
6. *Form a negotiating team.* Any negotiating team should include at least one consumer, a person well-versed in the law, and an "expert" in substantive issues (someone who can respond to clinical or professional issues).
7. *Prepare for the negotiation:*
    - Map out a set of strategies. What will you do if the negotiations do not meet with immediate success?
    - Hold planning sessions. Identify the issues, formulate your demands and fall-back positions, collect the facts, anticipate the opposition's responses.
    - Role-play the negotiation session.

## Strategies for Effective Negotiation

1. *Control the negotiation session.* You should define the issues and set the tone of the session.
    - Set the agenda. You might even come with a written list of agenda items.
    - Choose your seating carefully. Don't let an agency official hide behind a desk or sit at the head of a table. This gives control over the meeting.

- Refer to them as they refer to you. Titles carry authority. Don't let them call you by your first name if they refer to themselves by their titles (i.e., Mrs. Ms., Dr.).
- Bring your documents, such as letters, to the session.
- Chair the meeting. Review the circumstances or case leading to the meeting, the law, or other facts.
- Present your demands or positions clearly.

2. *Numbers*. Never negotiate when you are out-numbered. Leave if they try to overwhelm you with sheer numbers of people.

3. *Select a spokesperson*. While all members of the negotiating team should participate in the session, there should only be one person able to make compromises.
4. *Present a united front*. Make sure that members of the team do not contradict each other. The opposition will use this to resist change.
5. *Know and cite the facts*. Pay attention to officials' defenses or responses. Challenge them on the facts. Ask for specifics.
    - Know the agency and its services (budget, types of programs, etc.).
    - Know the law and legal precedents.
    - Be familiar with model programs elsewhere.
    - Know their philosophy. Point to discrepancies between philosophy and actual practices. Hold them to what they say.

6. *Know how people resist change* (see also Biklen, 1974). Anticipate "cool outs" and have your responses ready. Here are some of the more common "cool outs" used to resist change:
    - Double talk. "I agree with your philosophy, but . . ." (Challenge them to act on their beliefs.)
    - Passing the buck. "I agree with you, but I'm not in a position to make that decision." (Passing the buck is an age-old tactic used to maintain the status quo. Force them to accept responsibility.)
    - The money game. "We'd like to do what you ask, but we just don't have the money." (There usually is enough money; it's a matter of priorities. Further, a lack of money does not excuse violations of people's rights.)
    - Expert knows best. "Most doctors say that . . ." or "according to research . . ." (The fact of the matter is that research on these kinds of complex problems has failed to provide conclusive answers.)
    - Cover up. "We have one of the best programs in the country." (Know the facts about programs elsewhere.)

- Blaming the victim. “These people are too retarded to live in the community.” (Confront them on their backward attitudes. Don’t let them blame the client for the system’s failures.)
- Turning the tables. “You’re too emotional,” or “You just have to be patient.” (Don’t feel guilty about working for change. Why not feel emotional and impatient about people’s rights?)

7. *Be assertive, but don’t attack people personally.* Distinctions between “good” and “bad” or “friendly” and “unfriendly” officials or professionals are useless in a negotiating session. What is important is whether they yield to your demands. Don’t be afraid to challenge “nice” people. Don’t hesitate to be conciliatory with “unfriendly” bureaucrats who are forced to accept your position.
8. *Avoid being put on the defensive.* Don’t beg; services should be available as a matter of right, not charity. Don’t feel guilty; you are only asking for that to which people are entitled. Refuse to discuss your own past actions and other irrelevant issues (e.g., “That’s not the issue . . .”).
9. *Use your anger strategically.* Don’t express anger simply to vent your frustrations. Show anger to make a point or to break a deadlock.
10. *Create a record.* Take a tape recorder to the meeting so that you have a record of the proceedings. If you don’t have a tape recorder or if this is too threatening to the officials, one of the members of your group should act as a note taker. Don’t hesitate to ask a bureaucrat to repeat something “for the record.” This will put them on notice that you mean serious business.
11. *Latch on to any concessions.* Refer to any concession, however tentative, as a firm agreement on their part. Don’t let them back off. Chances are the opposition is not as organized as you are. Its members may not agree with each other. Treat the most conciliatory member as the spokesperson and his or her statements as binding.
12. *Establish firm timetables and standards of performance.* Don’t accept vague promises and empty statements. Ask them to be specific and to set firm deadlines.
13. *Don’t agree to do their work for them.* Don’t write their policy statements; if they aren’t committed enough to write them, they aren’t committed enough to implement them. Don’t agree to establish programs; that’s their job.
14. *Know what you will and will not accept.*
    - Prior to entering the negotiations, set maximum and minimum goals where the mini-mum is the very least with which you would be satisfied. Never compromise on the minimum.
    - Make high demands and few concessions (Manus, Roger. (n.d.) *Negotiation.* Chapel Hill: Developmental Disabilities Training Institute.).

- Never settle for less than 100% of your demands. But don't turn down less. Just don't settle for it. Keep the pressure up until you get the full 100% (Des Jardins, 1971).

- Never compromise without any thought of future consequences (Manus, n.d.).
- If you are not sure whether or not a proposed compromise is satisfactory, don't be forced into a premature agreement. Tell them you need time to think about it.

15. *What if the negotiation session deadlocks?*
    - Let them know you don't think you're getting anywhere.
    - Walk out. A carefully orchestrated "walk out" may break the deadlock and force concessions.
    - Threats. Don't hesitate to threaten other action, such as media coverage or litigation. "The threat is usually more terrifying than the thing itself (Alinsky, 1972)." Subtle threats are probably most effective since they allow an official to "save face;" for example, "Look, the press is really interested in these kinds of issues," or "We don't want to have to go to court to resolve this issue."

## Follow-Up

1. *Write a letter to the agency summarizing the major points discussed during the negotiating session.* The letter should highlight major agreements reached during the session, agreed upon timetables and standards for performance, and, if the session was unsuccessful, disagreements and glaring examples of agency unresponsiveness. Carbon copies of the letter should be sent to agency "higher-ups" as well as your own allies, whether consumer groups or attorneys. The letter should clearly state that if the official's recollection of the meeting differs from your record (based on carefully recorded notes or a tape recording), he or she should write you immediately. A certified letter carries an official and formal aura.
2. *Successful negotiations.* If you win your objective through negotiation, hold a press conference and send out an "action bulletin" to your constituency announcing a "major policy breakthrough." Your negotiations can serve as a precedent for other groups.
3. *Further negotiations.* Continue to negotiate only as long as you are making significant progress. Don't waste your time by negotiating with intransigent officials. When negotiations seem to drag on and on, with no end in sight, tell the officials that you want a firm decision within a specific time period.
4. *Buck-passing.* It is sometimes successful to negotiate around an issue with representatives of more than one agency. When you find officials continuing to

engage in passing the buck, call a meeting among all of the buck passers to locate responsibility for providing services.

5. *Unsuccessful negotiations.* Long-term change is seldom accomplished through negotiations alone. Do not be discouraged if negotiations do not result in immediate systemic victories. By increasing your understanding of the system and creating a record of attempts to resolve on a face-to-face basis, negotiating paves the way for other strategies: press coverage, lobbying, appeals to other authorities, litigation, public forums, and others.

### Bureaucratic Tactics of Avoidance

(Advocacy Training Manual. Wisconsin Coalition for Advocacy (1996), pp. 16-17.)

All of us, at one time or another, have experienced dealing with a bureaucracy. Whether we are dealing with an insurance company, our social service agency or the Social Security Administration, for example, each of these "systems" or bureaucracies can increase our frustration when we try to solve a problem or address a concern. The following piece describes some of the common obstacles or tactics that individuals who seek resolution to a problem might experience within a bureaucratic setting.

This article not only identifies these "bureaucratic tactics of avoidance," but also describes useful strategies that you can apply to seek resolution to your concern or problem. Bureaucratic tactics of avoidance are also very common when trying to change a system. Systems advocacy is trying to bring about change for groups of people, such as changing a policy or a law. To make such a change often involves influencing a bureaucracy. For this reason, both individual and systems advocacy examples are described below.

#### 1. Refuse to give out the information.

This tactic is a basic tool for any bureaucrat. By refusing to give you the facts, the bureaucrat hopes you will go away.

In order to reform the system or bring about a change, you need the facts. If you have the facts, the system is forced to deal with you more openly and on a more equal footing. Democracy depends on people having the facts. The refusal to give out the information may sound like this:

- We don't have that information.
- I'm sorry, but s/he is not in today, is on vacation, is out sick, has not authorized me to give out that information.
- Our computer is down.
- It's confidential.
- We can only give out a summary. (They decide what is included and excluded).
- I'm sorry, but we don't think you need that information.

Whenever you hear any of these statements, be on guard. Ask for a complete explanation of why the information can't be given. Ask when it will be available. Ask who it is available to. Then check with several other sources to find out if the information you have been given (or the excuse) is correct. If information is being withheld from you, use this as an issue to organize around. A lot of pressure can be brought on someone who is withholding information to which you have a right.

### 2. Give them a Red Herring to eat.

Whenever you are confronting the system, watch out for Red Herrings. When a bureaucrat tries to get the subject changed from what you are concerned about to what s/he wants you to focus on, s/he is trying to give you a Red Herring. You can tell a Red Herring because it doesn't smell right. The bureaucrat may sound like this: "Why are you interested in that issue; it's not very important. Why don't you start working on..." "Your issue is beside the point; it's extremist; you haven't done the research; that point isn't practical; etc." Suppose you ask your favorite bureaucrat to publish data by name, age, date, sex, types of problems, etc. S/he might answer you with the statement that such data would violate the right of individual privacy. Then s/he moves into a discussion of first amendment guarantees, U.S. civil rights, etc. In the heat of debate, she might hope that you a) get tired and go home, or b) forget the key issue.

When confronted with this tactic, immediately label it a Red Herring and don't get involved. Stick to the issue you want to discuss. You can always talk about the other person's issue at some later time.

### 3. Give the appearance of action without doing anything.

When faced with an obvious need for change, bureaucrats may try to give the appearance of action without actually doing anything. This tactic may sound like:

- "We have decided to appoint a committee to study the problem."
- "We would like to set up a commission to handle the problem and want members of your group to volunteer assistance because we don't have any money for staff."
- "We would like several members of your organization to join an advisory committee for this problem to help us work out solutions."
- "We plan to issue a policy statement of that problem next week so that everyone will know what to do in the future."

Don't accept these excuses. Set a reasonable amount of time for some real action, and then tell everyone that you expect action by that date. Don't join any study committees or advisory groups which have no real power to do anything.

### 4. Make it impossible for people to be involved.

A simple and common technique for the bureaucracy to maintain its control is to set things up so that others can't be involved. Some common examples are:

- Scheduling meetings during times when working people can't attend.

- Holding meetings in places which are difficult to reach or where people don't feel safe.
- Using language and terms which are difficult to understand, intimidating, highly technical, etc.
- Giving out guidelines or instructions which are too complicated to understand, or too long and detailed that others become frustrated in reading through them.

A key element in these tactics is to make it appear that the problem comes from consumers, not the system. The bureaucracy sets up an opportunity to participate and then points out that consumers are apathetic. When many consumers experience the same problem like meeting time and place, excessive guidelines, etc., then you have to put pressure on the system to find the solution. Make them responsible.

**Some general suggestions and guidelines**

Before you confront any bureaucracy, you should try to determine what kinds of tactics are likely to be used. As soon as a tactic has become apparent, LABEL IT. When you name the tactic publicly, it loses some of its power. When everyone involved recognizes the tactic, you can counter it with a minimum of wasted effort.

Hopefully this chapter helped to beef up your advocacy skills, and you feel more comfortable with the do's and don'ts of advocating for yourself. We leave you with a list of resources and a suggested reading on empowerment. We also wish you good fortune in your own journey and hope that this *Handbook* is helpful to you in your own healing and recovery.

## Wisconsin Advocacy and Disability Resources

### *ADAPT*

Website: http://www.adapt.org (national website)
Wisconsin ADAPT
Steve Verriden
(608) 249-4308
Email: adaptsteve@charter.net
Karla Smith
(608) 242-5690
Email: angel53717@yahoo.com

Southeast Wisconsin ADAPT
Tobie Tyler & Roxan Perez
(262) 792-1478
Fax: (262) 792-1484
Email ttobielaw@aol.com or travelroxy@aol.com

### *AIDS Network*

Website: http://www.aidsnetwork.org
Madison Office
600 Williamson St.
Madison, WI 53703
(608) 252-6540
Fax: (608) 252-6559
Janesville Office
101 E. Milwaukee, Suite 96
Janesville, WI 53545
(608) 756-2550
Fax: (608) 756-2545
Beloit Office
136 W. Grand Ave. Suite 202
Beloit, WI 53511
(608) 364-4027
Fax: (608) 364-0473

AIDS NETWORK'S SERVICE AREA: Adams, Columbia, Crawford, Dane, Dodge, Grant, Green, Iowa, Juneau, Lafayette, Richland, Rock, and Sauk Counties

### *AIDS Resource Center of Wisconsin*

The AIDS Resource Center of Wisconsin provides resources and advocates on behalf of all people living with HIV and AIDS in order to end the pandemic and the human suffering caused by HIV/AIDS.
820 Plankinton Ave.
Milwaukee, WI 53203
Website: http://www.arcw.org

(414) 273-1991
(800) 359-9272
Fax: (414) 273-2357
(Serving Milwaukee, Ozaukee, Washington, and Waukesha counties)

***Community Advocates Inc.***

Community Advocates was founded in 1976 to work with low income and destitute persons and families to gain and ensure access to programs and services that they need to meet their basic needs and to live in dignity.

4906 West Fond du Lac
Milwaukee, WI 53216
(414) 449-4777
Serves Milwaukee County

***DAWN (Disability Advocates: Wisconsin Network)***

A statewide grassroots cross-disability network of people who care about disability issues. DAWN supports legislative change in the programs and systems affecting people with all disabilities. The Wisconsin Council on Developmental Disabilities funds DAWN as part of the State Plan on Developmental Disabilities.

Website: http://www.dawninfo.org

***Disability Benefit Specialists***

Benefit Specialists provide confidential assistance at no charge to adults ages 18 to 59 with physical disabilities, developmental disabilities, mental illness and/or substance abuse disorders on benefits related questions. (Individuals age 60 and older can contact the Elderly Benefit Specialist Program in their county.) Currently, there are Disability Benefit Specialists in 21 counties throughout the state:

- Barron, Brown, Calumet, Fond du Lac, Forest, Green, Green Lake, Jackson, Kenosha, La Crosse, Manitowoc, Marathon, Marquette, Outagamie, Portage, Richland, Sheboygan, Trempealeau, Waupaca, Waushara, and Wood

Website: http://www.dhfs.state.wi.us/Disabilities/benspecs/program.htm
A map showing benefits counselors available in Wisconsin by county is available at:
Website: http://www.eri-wi.org/map/

***Disability Drug Benefit Helpline***

The Helpline helps anyone with disabilities under age 60 (or their friends or guardians) with questions about the new Prescription Drug Benefit under Medicare Part D.
1(800) 926-4862

***Disability Rights Wisconsin (DRW)***

The Disability Rights Wisconsin is the state's protection and advocacy agency for persons with developmental disabilities, serious mental illness, or physical/sensory disabilities.

Madison Office
131 W. Wilson St., Ste. 700
Website: http://www.disabilityrightswi.org
Madison, WI 53703
(608) 267-0214 voice/TTY
Toll-free (800) 928-8778 (Toll free: voice/TTY for consumers and family members only)
(608) 267-0368 (Fax)
(800) 926-4862 (Medicare Part D)

Milwaukee Office
Summit Place
6737 W. Washington Street, #3230
Milwaukee, WI 53214
(414) 773-4646 voice/TTY
Toll free (800) 708-3034 (Toll free: voice/TTY for consumers and family members only)
(414) 773-4647 (Fax)

Rice Lake Office
801 Hammond Ave.
Rice Lake, WI 54868
(715) 736-1232 voice/TTY
(877) 338-3724 (Toll free: voice/TTY for consumers and family members only)
(715) 736-1252 (Fax)

***Grassroots Empowerment Project***

The Grassroots Empowerment Project works to create opportunities for people with mental illnesses in order to exercise power in their lives. They provide systems advocacy, information and funding opportunities to consumer run organizations around the state.

P.O. Box 8683
Website: http://www.grassrootspower.org
Madison, WI 53708-8683
(800) 770-0588

### *Governor's Committee for People with Disabilities*

The Governor's Committee is dedicated to enhancing the health and general well being of disabled citizens in Wisconsin.
1 W. Wilson Street, Room 1150
Post Office Box 7851
Madison, Wisconsin 53707-7851
(608)266-7974
TTY: (608) 267-9880
Fax: (608) 266-3386
Website: http://www.dhfs.state.wi.us/Disabilities/Physical/gcpd.htm

### *Independent Living Council of Wisconsin (ILCW)*

201 W. Washington Ave. Ste. 110
Madison, WI 53703
(608) 256-9257
Toll Free: (866) 656-4010
TTY: (608) 256-9316 Toll Free: (866) 656-4011
Fax: (608) 256-9301
Email: http://www.ilcw@ilcw.org/

### *Medigap Helpline*

The Medigap Helpline (State Health Insurance Assistance Program) can help with questions about health insurance; primarily Medicare Supplements, Long Term Care Insurance, Medicare Advantage plans and other health care plans available to Medicare beneficiaries.
Toll Free: (800) 242-1060

### *Mental Health America* of Wisconsin

734 N. 4th Street
Milwaukee, WI 53203
(414) 246-3122
Toll Free (877) 642-4630
Fax (414) 276-3124
Email: info@mhamilw.org
Website: http://www.mhamilw.org

MHA of Wisconsin - Office of Public Policy

133 S. Butler Street, Room 330
(608) 250-4368
Fax (608) 442-7907

### *Mothers United for Moral Support (MUMS)*

MUMS is a National Parent to Parent Network whose mission is to help parents who have a child with any disorder, medical condition, mental or emotional disorder or rare diagnosis make connections with other parents whose children have the same or similar condition.
150 Custer Court
Website: http://www.netnet.net/mums/
Green Bay, Wisconsin 54301-1243
(920) 336-5333
(877) 336-5333 (Parents only please)

E-mail: mums@netnet.net

Fax: (920) 339-0995

***National Alliance on Mentally Illness (NAMI) of Wisconsin***

The National Alliance for the Mentally Ill of Wisconsin (NAMI-Wisconsin) provides support, education, advocacy and research on mental illness to consumers, families, and friends of people with severe mental illnesses, such as schizophrenia, major depression, bipolar disorder, obsessive-compulsive disorder, and anxiety disorders.

4233 W. Beltline Highway
Madison, WI 53711
Email: nami@namiwisconsin.org
Website: http://www.namiwisconsin.org
(608)268-6000
(800)236-2988 (in-state only)
Fax (608) 268-6004

***New Partnerships for Women***

The New Partnerships for Women project is a continuation of the Women and Mental Health Study Site of Dane County (WMHSS). The purpose of the project is to continue to build the capacity of the community to promote healing and recovery for women who have histories of trauma, mental health, and/or substance abuse problems, including women who are TANF eligible. The scope of the project includes: (1) training activities, (2) consumer involvement and empowerment activities, (3) the dissemination of information from the needs assessment of Dane County women who have used mental health and/or substance abuse services, and (4) advocacy activities on behalf of women who have experienced trauma, mental health, and/or substance abuse problems.

128 E. Olin Ave., Ste. 202
Madison, WI 53713
(608) 268-1042
Email: npw@choiceonemail.com

**The Prescription Drug Helpline** Toll Free: (866) 456-8211

The Prescription Drug Helpline is a service operated by the Elder Law Center of the Coalition of Wisconsin Aging Groups. Helpline counselors are available to provide assistance to Wisconsin Medicare beneficiaries age 60 and older regarding prescription drug benefits.

**Respite Care Association of Wisconsin, Inc.**

6320 Monona Drive, Suite 407
Madison, WI 53716
Website: http://www.respitecarewi.org/
Email: info@respitecarewi.org (608) 222-2033
Toll Free: (866) 702-RCAW (7229)
Fax: (608) 222-2034

**_Wisconsin Association on Alcohol and Other Drug Abuse_**
6601 Grand Teton Plaza, Suite A
Website: http://www.waaoda.org/
Madison, WI 53719
(608) 829-1032
Toll Free: (800) 787-9979
Fax: (608) 829-3473
Email: waaoda@tds.net
Toll Free: (866) 456-8211

**_Wisconsin Coalition Against Domestic Violence_**

The Wisconsin Coalition Against Domestic Violence (WCADV) is a statewide membership organization of domestic abuse programs, formerly battered women, and other individuals, that offers technical assistance and trainings geared towards ending domestic violence.

307 S. Paterson St., Ste 1
Madison, WI 53703
Website: http://www.wcadv.org
(608) 255-0539
(608) 255-3560 (Fax/TTY)

**_Wisconsin Coalition Against Sexual Assault_**

The Wisconsin Coalition Against Sexual Assault (WCASA) works to promote the social change necessary to end sexual violence in Wisconsin and to support a statewide network of concerned individuals and organizations as they work towards this goal.

600 Williamson St., Ste. N-2
Madison, WI 53703
Website: http://www.wcasa.org
Email: wcasa@wcasa.org
(608) 257-1516 (voice/TTY)
(608) 257-2150 (Fax)

**_Wisconsin Coalition of Independent Living Centers (WCILC)_**

Independent Living Centers (ILCs) are private, non-profit, consumer-directed, community- based organizations that provide services and advocacy by and for people with all types of disabilities. They provide an array of services including peer support, information, referrals, independent living skills training, advocacy, and community education. WCILC can refer you to one of the eight Independent Living Centers (ILCs) nearest you.

201 W. Washington St., Ste. 110
Madison, WI 53703
Website: http://www.wisilc.org
Email: ilcw@wisilc.org
(608) 251-9151
(608) 256-9316 (TTY)
(866) 656-4010 (Toll Free)
(866) 656-4011 (TTY Toll Free)

(608) 256-9301 (Fax)
Toll Free: (866) 456-8211

**Wisconsin Community Action Programs (WISCAP)**
1310 Mendota St., Ste 107 Madison, WI 53714
Website: http://www.wiscap.org/
Email: wiscap@wiscap.org
(608) 244-4422
Fax: (608) 244-4064

**Wisconsin Council on Children and Families**
A nonprofit, multi-issue child and family advocacy agency headquartered in Madison and Milwaukee. The Council's mission is to promote the well-being of children and families in Wisconsin by advocating for effective and efficient health, education, and human service delivery systems.
16 N. Carroll Street, Suite 600
Website: http://www.wccf.org
Madison, Wisconsin 53703
608.284.0580
Fax: 608.284.0583

***Wisconsin Council on Developmental Disabilities***
WCDD plans and advocates for adequate and appropriate supports for people with developmental disabilities in Wisconsin.
201 W. Washington Street, Ste. 110
Madison, WI 53703
Email: help@wcdd.org
Website: http://www.wcdd.org
(608) 266-7826
(608) 266-6660 TTY/TDD
(888) 332-1677 (Toll Free)
Fax: 608/267-3906
Disability Advocates Wisconsin Network (DAWN)
Advocacy website sponsored by the Wisconsin Council on Developmental Disabilities.
Website: http://www.dawninfo.org/

***Wisconsin Early Childhood Association***
744 Williamson Street, Suite 200
Madison, WI 53703
Website: http://www.wecanaeyc.org/ (608) 240-9880
Toll Free: (800) 783-9322
Fax: (608) 663-1091

**Wisconsin Early Childhood Association - Milwaukee Office**
1556 N. Farwell Avenue
Milwaukee, WI 53202
(414) 278-9322
Fax: (414) 278-9336

***Wisconsin FACETS***

Wisconsin Family Assistance Center for Education, Training and Support (Wisconsin FACETS) provides advocacy, resources, and training on education for children and adults with disabilities and their families.

2714 N. Dr. Martin Luther King Drive
Milwaukee, WI 53212
Website: http://www.wifacets.org/ (414) 374-4645
Toll Free: (877) 374-4677
Fax: (414) 374-4655
TDD: (414) 374-4635
Email: wifacets@wifacets.org

***Wisconsin Family Ties, Inc.***

Wisconsin Family Ties works with families that have children with severe emotional and behavioral disturbances and the professionals that work with these families.

16 N. Carroll St., Ste. 630
Madison, WI 53703
Website: http://www.wifamilyties.org
Email: info@wifamilyties.org
(608) 267-6888
(800) 422-7145
Fax: (608) 267-6801

***Wisconsin Front Door Housing***

The mission of wifrontdoorhousing.org is to assure every resident of Wisconsin is granted an opportunity to obtain affordable housing. They assist low to moderate income households with locating rental units by providing detailed and user-friendly information.

Website: http://www.wifrontdoorhousing.org/

***Wisconsin Head Start Association***

122 East Olin Avenue, #110
Madison, WI 53713
Website: http://www.whsaonline.org
(608) 442-6879
Fax: (608) 442-7672

**Wisconsin Economic Development and Housing Authority (WHEDA)**
201 W. Washington Ave., Ste. 700
Madison, WI 53703
Website: http://www.wheda.com/
Email: info@wheda.com
608-266-7884
TTY: 1-800-943-9430
Toll Free: 1-800-334-6873
Fax: 608-267-1099

**Wisconsin Independent Living Centers**
Access to Independence
2345 Atwood Ave.
Madison, WI 53704
Email: info@accesstoind.org
Website: http://www.accesstoind.org/
(608) 242-8484 (v)
TTY: (608) 242-8485
Fax: (608) 242-0383
Counties served: Columbia, Dane, Dodge, Green
Tribes served: Ho-Chunk Nation

## Government Resources in Wisconsin

***County Human Services***
Refer to the blue government pages in the telephone book for your county Human Services Agency.

***Office of the Governor***
115 East State Capitol
Madison, WI 53702
Website: http://www.wisgov.state.wi.us/
(608) 266-1212
TTY: (608) 267-6790
Fax: (608) 267-8983

***State of Wisconsin Board on Aging and Long Term Care***
1402 Pankratz Street, Suite 111
Madison, WI 53704-4001
Website: http://longtermcare.state.wi.us/home/
Medigap Helpline: 1-800-242-1060
Ombudsman Program: 1-800-815-0015
Fax: (608) 246-7001
Email: BOALTC@ltc.state.wi.us

***State of Wisconsin Department of Administration***
101 East Wilson Street
Madison, WI 53702
Website: http://doa.wi.gov/

***State of Wisconsin Department of Agriculture, Trade and Consumer Protection***
*A state agency that takes complaints regarding unfair business practices, the safety and quality of food, agricultural and commerce complaints, and other consumer protection issues.*
Division of Trade and Consumer Protection
PO Box 8911
Madison, WI 53708-8911
(608) 224-4949
Toll Free Consumer Protection Hotline: (800) 422-7128
Email: hotline@datcp.state.wi.us
Website: http://www.datcp.state.wi.us/

***State of Wisconsin*** ***Department of Corrections***
3099 East Washington Avenue
Post Office Box 7925
Madison, Wisconsin 53707-7925
Website: http://www.wi-doc.com/
Phone: 608-240-5000
Fax: 608-240-3300
Email: docweb@doc.state.wi.us

***State of Wisconsin*** ***Department of Health and Family Services***
The state agency responsible for programs related to the health of individuals and families in Wisconsin, with offices that specialize in developmental disabilities, physical disabilities, sensory disabilities, psychiatric disabilities and issues relating to the elderly.
1 W. Wilson St.
Madison, WI 53702
Website: http://www.dhfs.state.wi.us (608) 266-1865
(608) 267-7371 (TTY)

Directory of Department Services:
http://www.dhfs.state.wi.us/data/servicesearch.asp
Directory of Hotline Numbers: http://www.dhfs.state.wi.us/data/hotline.asp?ref=hp

***State of Wisconsin*** ***Department of Regulation and Licensing***
Regulates and monitors professionals that require a license or certificate. Credentialed health professionals monitored by the Department of Regulations and Licensing (DORL) include nurses, physicians, psychologists, social workers, ect. Each profession is regulated by the DORL is governed by a statute and administrative code, which are rules of professional conduct and ethical practice for the profession.
1400 E. Washington Ave., Rm 112
P.O. Box 8935
Madison, WI 53708-8935
E-mail: web@drl.state.wi.us
Website: http://www.drl.state.wi.us
(608) 266-2112

***State of Wisconsin*** ***Department of Workforce Development, Division of Vocational Rehabilitation***
A federal/state program designed to help find, retain, and improve the quality of employment for people with disabilities.
201 E. Washington Ave.
P.O. Box 7852
Madison, WI 53707-7852
Email: dwddvr@dwd.state.wi.us
Website: http://www.dwd.state.wi.us

(608) 261-0050 (voice)
(608) 243-5601 (TTY)
(800) 442-3477
(888) 877-5939 (TTY Toll Free)
Fax: (608)-266-1133

***Social Security Administration in Wisconsin***

| | |
|---|---|
| Toll-Free: | (800) 772-1213 |
| TDD: | (800) 325-0778 |
| Website: | http://www.ssa.gov |

***Wisconsin Medical Assistance Information***

Website: http://www.dhfs.state.wi.us/medicaid/index.htm

***Wisconsin SSI Supplemental Security Income Information***

Dept. of Health and Family Services
Website: http://www.dhfs.state.wi.us/ssi/
Division of Disability and Elder Services
1 W. Wilson St., Rm 450
PO Box 7851
Madison, WI 53703
(608) 266-6890

## Wisconsin Legal Advocacy and Legal Services Resources

### *Disability Rights Wisconsin (DRW)*

The Disability Rights Wisconsin is the state's protection and advocacy agency for persons with developmental disabilities, serious mental illness, or physical/sensory disabilities.

Madison Office:
131 W. Wilson St., Ste. 700
Website: http://www.disabilityrightswi.org
Madison, WI 53703
(608) 267-0214 voice/TTY
Toll-free (800) 928-8778 (Toll free: voice/TTY for consumers and family members only)
(608) 267-0368 (Fax)
(800) 926-4862 (Medicare Part D)

Milwaukee Office:
Summit Place
6737 W. Washington Street, #3230
Milwaukee, WI 53214
(414) 773-4646 voice/TTY
Toll free (800) 708-3034 (Toll free: voice/TTY for consumers and family members only)
(414) 773-4647 (Fax)

Rice Lake Office:
801 Hammond Ave.
Rice Lake, WI 54868
(715) 736-1232 voice/TTY
(877) 338-3724 (Toll free: voice/TTY for consumers and family members only)
(715) 736-1252 (Fax)

### *Elder Law Center of the Coalition of Wisconsin Aging Group*

A public interest legal services program serving persons aged 60 and over, operated under the umbrella of the Coalition of Wisconsin Aging Groups (CWAG). The Center engages in systems advocacy for issues affecting people over age 60, and provides initial and on-going training, legal support, and on-site supervision to a network of Benefit Specialists in 65 of Wisconsin's 72 counties.

2850 Dairy Drive, Ste. 100
Madison, WI 53718
(608) 224-0606
(800) 366-2990
(888) 758-6047 TTY/Textnet
Fax: (608) 224-0607

Email: cwag@cwag.org
Website: http://www.cwag.org

Altoona Office:
2427 N. Hillcrest Pkwy., Ste. 205
(715) 836-2287
Fax: (715) 836-5810
gmacinnes@cwag.org
E-mail: pgibson@cwag.org

Milwaukee Office:
2601 W. Howard Ave.
(414) 817-0030
E-mail:

### The Prescription Drug Helpline

The Prescription Drug Helpline is a service operated by the Elder Law Center of the Coalition of Wisconsin Aging Groups. Helpline counselors are available to provide assistance to Wisconsin Medicare beneficiaries age 60 and older regarding prescription drug benefits.
Toll Free: (866) 456-8211

### ***Lawyer Referral and Information Service of the State Bar of Wisconsin***

Provides free referral to an attorney, legal agency, or other legal service with the specialty needed.
(800) 362-9082
(608) 257-4666
Website: http://www.wisbar.org/bar/sblris.htm

### ***Legal Action of Wisconsin***

Provides civil legal services to low income people.
Website: www.badgerlaw.net

Milwaukee Office:
230 W. Wells St., Room 800
Milwaukee, WI 53203-1866
(414) 278-7722
(414) 278-7156 FAX
(888) 278-0633 Toll Free
Serving: Milwaukee and Waukesha counties

Madison Office:
31 S. Mills St.
Madison, WI 53715
(608) 256-3304
(608) 256-0510 FAX
(800) 362-3904 (outside Dane County)
Serving: Columbia, Dane, Dodge, Green, Iowa, Jefferson, Lafayette, Rock and Sauk counties

## National Resources

### ***American Association of People with Disabilities***

The largest national nonprofit cross-disability member organization in the United States, dedicated to ensuring economic self-sufficiency and political empowerment for the more than 56 million Americans with disabilities. AAPD works in coalition with other disability organizations for the full implementation and enforcement of disability nondiscrimination laws, particularly the Americans with Disabilities Act (ADA) of 1990 and the Rehabilitation Act of 1973.
Website: http://www.aapd-dc.org

***American Counseling Association***
5999 Stevenson Avenue
Alexandria, VA 22304-3300
Website: http://www.counseling.org
(703)823-9800
(703) 823-6862 TDD
(800) 347-6647 Toll Free
(800) 473-2329 FAX

***American Nursing Association***
8515 Georgia Ave., Ste. 400
Silver Spring, MD 20901
Website: http://www.nursingworld.org
(800)274-4262

***American Psychiatric Association***
1000 Wilson Blvd., Ste. 1825
Alexandria, VA 22209-3901
Website: http://www.psych.org
Email: apa@psych.org
(703) 907-7300

***American Psychological Association***
750 First Street, N.E.
Washington, DC 20002-0202
(800)374-2721 (202)336-5500
Website: http://www.apa.org
Fax: (202)336-5997

***Center for Mental Health Services***
CMHS leads Federal efforts to treat mental illnesses by promoting mental health and by preventing the development or worsening of mental illness when possible. CMHS is a component of the Substance Abuse & Mental Health Services Administration (SAMHSA), U.S. Department of Health and Human Services. Specific information for consumers/survivors also is available on the Center's website.
PO Box 42557
Website: www.mentalhealth.samhsa.gov
Washington, DC 20015
(800) 289-2647
(866) 889-2647 (TDD)
(240) 747-5470 (FAX)

***Center for Psychiatric Rehabilitation***
The Center for Psychiatric Rehabilitation is a research, training, and service organization dedicated to improving the lives of persons who have psychiatric disabilities by improving the effectiveness of people, programs, and service systems.
940 Commonwealth Ave. Website: http://www.bu.edu/cpr
(617) 353-3549
Boston, MA 02215

# Appendix 1
# Suggested Reading for Chapter 1: Introduction

# FORGING NEW PARTNERSHIPS WITH WOMEN: EXECUTIVE SUMMARY*

This project was funded by a grant from the Substance Abuse and Mental Health Services Administration (UD2 TI11376) to Joy P. Newmann and Dianne Greenley.

In 1998, the Substance Abuse and Mental Health Services Administration (SAMHSA) funded fourteen sites nationally for a two-year period to study and improve services for women with co-occurring mental health and substance use problems and histories of physical or sexual abuse. A key assumption that formed the backdrop for this national collaborative study is that women with these co-occurring problems, many of whom have children, are receiving fragmented and inadequate care in the specialty alcohol, drug, and mental health (ADM) treatment systems, even though they are among its heaviest users of services. Thus, the charge to the fourteen study sites was to work at the local level to develop an integrated and trauma-informed service system that might more effectively meet the needs of this group of women. In addition, sites were charged with the task of addressing the special service needs of women who are mothers of young children.

The Women and Mental Health Study Site of Dane County, one of the fourteen sites that were a part of this national collaborative study, undertook the charge with a special focus on economically disadvantaged women in Dane County, Wisconsin, specifically women who are dependent on publicly funded alcohol, drug, and mental health (ADM) services for their care. Employing a collaborative team of consumers, consumer advocates, Dane County system administrators and providers, and clinical and research faculty from Social Work, Nursing, Pharmacy, and Medicine at the University of Wisconsin-Madison, we designed an "action research" project that guided our system change efforts. In this report, we summarize findings from an important part of our research activities, namely interviews with 204 women who received two or more episodes of care in the ADM services system in Dane County in 1998. These interviews, which represent the first phase of our needs assessment, were designed to address three broad questions.

First, we wanted to determine *the scope of the problem*. That is, how many women receiving services in the public ADM system have histories of physical or sexual abuse and co-occurring mental health and substance use problems? Second, we wished to determine how these women, whom we subsequently refer to as women who meet target group criteria, *view the quality of their care* in comparison to other women receiving services in similar settings. In short, what evidence is there that women who meet target group criteria are falling through the cracks of our existing

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* Joy Perkins Newmann, Anne Ziege, and Jolanda Sallmann (August 1, 2001). *Forging New Partnerships for Women: Improving Services and Increasing Community Resources for Women with Histories of Trauma and Co-Occurring Mental Health and Substance Use Problems.* The Women and Mental Health Study Site of Dane County (WMHSS), School of Social Work, University of Wisconsin–Madison.

service delivery system versus getting high quality care? Finally, given our commitment to learning from women who are consumers of publicly funded services in Dane County, and to developing an integrated services model that is tied to women's perceptions of what they need to improve the quality of their lives, we wished to determine *what women who meet target group criteria define as their own recovery goals and needs*. That is, what do women view as important areas of their lives they want to change, how do they conceptualize their own recovery, and what services or resources do they feel they need to help them on the path to recovery? In the discussion that follows, we summarize findings related to these questions and discuss their implications for ongoing system change and service development efforts.

## The Scope of the Problem

Our findings show that the number of women who meet target group criteria is substantial. Forty-seven percent of the women interviewed were positive for a co-occurring mental health and substance related problem and a history of abuse. This included 61.9% of respondents who had had services from both a mental health and substance abuse service provider in 1998, 56.6% of respondents who had had services from a substance abuse service provider only, and 11.1% of respondents who had had services from a mental health service provider only. If we project these numbers to each of the three populations of women from which our samples were drawn, we conclude that almost a third of the women (30.3%) seen in the ADM system in 1998, or 648 women, would meet these criteria. Although the majority of women with co-occurring mental health and substance use problems and histories of abuse are seen in some segment of the substance use services system, significant numbers have treatment episodes in both systems.

Given the larger absolute number of women with two or more treatment episodes in the mental health services system in 1998 (1546) compared to the substance abuse services system (865), we estimate that approximately 337 women, or 1 out of every 5 women seen by a mental health service provider, would meet target group criteria. Another 465, or 1 out of every 2 women seen by a substance use service provider, would also meet target group criteria. These treatment episodes occurred in virtually every agency the county funds to provide services to women experiencing poverty in Dane County.

## Assessing Quality of Care

To assess women's perceptions of the quality of their care, we employed measures developed by the Consumer Outcomes Workgroup of Wisconsin, which were designed to assess three dimensions of quality care: (1) women's access to integrated, trauma-informed services; (2) women's perceptions of the quality of, and satisfaction with, those services, and (3) women's perceptions of the impact of services on important life outcomes. We also employed a number of other measures of women's functioning across an array of life domains. Since many of these measures are new and have no benchmarks, we compared women who meet target group criteria with other women who do not meet these criteria but who received services during the same period.

Findings show that significant numbers of women are very positive about the care they have received in the public ADM system in Dane County. This is particularly true with respect to women's perceptions of the caregiving climate and their relationship with their primary caregiver(s). For example, the vast majority of women interviewed--from 88% to 94% of the women, depending on the questions asked--perceived their caregivers as respectful and sensitive people who "are genuinely interested in me" and "care about my feelings." Moreover, close to 90% of the women feel that the place where they received care is "clean, inviting, and comfortable," as well as a place where they feel safe.

A majority of the women, in the aggregate, also view their services as well-coordinated, their caregivers as competent, and the caregiving relationship as "consumer oriented" in that women were actively involved in the development of their service plans, were given thorough assessments of their strengths as well as their problem areas, and received "recovery oriented" care that was focused on outcomes that mattered to them. Indeed, our summary measure of satisfaction with services shows that significant numbers of women--from three quarters to 87%, depending on the questions asked--are quite satisfied with the care they have received from providers and agencies that comprise the public ADM system in Dane County.

Moreover, contrary to the notion that women who meet target group criteria are more likely than other women to be receiving poor quality care, we find that the former group is significantly more positive than other women about their care along each of these dimensions. In fact, in all comparisons of the two groups along dimensions that the Wisconsin Governor's Blue Ribbon Commission on Mental Health (1997) has defined as benchmarks for high quality consumer-oriented care, women who meet target group criteria do not fare significantly worse than other women receiving services in the public ADM system. Thus, these findings afford some good news about the quality of care women are receiving in the public ADM system in Dane County.

However, other findings suggest that the news is not all good. A key and troubling finding is that women who meet target group criteria are significantly worse off than other women on virtually every outcome measure that Wisconsin has identified as critical for systems of care. They suffer from lower self-esteem, rate themselves significantly lower in daily functioning across a range of behaviors, are less satisfied with the quality of their daily lives, are more symptomatic across an array of measures, are more likely to be struggling with a substance use problem and its sequelae, and view their emotional problems as having a significantly greater adverse affect on their capacity to function in their daily lives, work, and social relationships compared to other women.

Moreover, although many women who meet target group criteria feel their services have helped them cope more effectively with their daily lives, particularly with the traumas in their lives and with their substance use problems, significant numbers do <u>not</u> feel their services have had much impact on other important aspects of their well-being and daily functioning. Notably, 40% of the women do not feel their symptoms have decreased as a result of services they have received, 37% are not doing any better in social situations, 36% are not doing better in their jobs or studies, and 28% do not feel their services have helped them feel more hopeful about the future. In short, even though many women who meet target group criteria like the services they have received in the publicly funded ADM services system, and are heavy users of services, those same services do not appear to be fueling a sense of hope for many woman, or helping them improve areas of life functioning that are important to them.

Although the cross-sectional nature of our data precludes estimating change in important life arenas over time, or linking such changes to the quality of care women have received in the public funded ADM system, three findings support the conclusion that many women, including disproportionate numbers of women who meet target group criteria, are indeed "falling through the cracks."

1) Women who meet target group criteria are <u>not</u> getting access to services needed to address their co-occurring problems.
2) Services that women are receiving do not consistently measure up to the standards for recovery-oriented care outlined in the Governor's Blue Ribbon Commission on Mental Health.
3) Women's own recovery goals call for a reconceptualization of public ADM services, as well as services that go beyond ADM treatment.

We discuss each of these findings and their implications for improving services below.

## Insufficient Access to Integrated, Trauma-informed Services

A major impetus behind the national collaborative study is the belief that women with histories of abuse and co-occurring mental health and substance use problems are not getting the kind of integrated and trauma-informed services needed to help move them toward recovery. Four critical services identified as part of the SAMHSA initiative are: (1) trauma-specific services; (2) mental health services; (3) substance abuse services, and (4) services related to the special needs of women who are mothers. Our findings show that many women are not getting access to these services despite considerable need. Moreover, integration of such services is lacking for some women.

(1) Among women who have experienced physical or sexual abuse (100% of the women who meet target group criteria and 83.3% of other women):

- 75% and 59.6%, respectively reported that it is moderately, considerably, or extremely important to "get help with these experiences now"

- Of these women, 39% of the former and 55% of the latter have not had any treatment for these experiences in the prior six months and are not currently in treatment
- 25% of women who meet target group criteria and 58% of other women have never had treatment that addressed the abuse experiences in their lives.

(2) Among women who report a current mental health problem, which includes 96% of women who meet target group criteria and 60% of other women:

- 31.5% of the former and 29.2% of the latter are not currently receiving mental health services
- Among those not receiving treatment, 79% of the former and 53% of the latter report that it is moderately, considerably, or extremely important to "get help with [their] mental health problems now"

(3) Among women who report a current substance use problem, which includes 43% of women who meet target group criteria and 4% of other women:

- 51% of the former and 50% of the latter are not currently receiving substance use services
- Among those not receiving treatment, 53% of the former and none of the latter report that it is moderately, considerably, or extremely important to "get help with [their substance use problems now"

(4) Among women who have had children, which includes 60% of women who meet target group criteria and 72% of other women:

- 38% of the former group and 47% of the latter have dependent children
- Among women who have dependent children, 36% of women who meet target group criteria and 32% of other women do not have those dependent children living with them
- Sixty-nine percent of the mothers who meet target group criteria have lost a child against their will compared to 40.3% of mothers who do not meet such criteria--an event ranked highest of all aversive events in terms of its continuing impact on women's lives
- Although the majority of women feel good about their parenting, a quarter to a third, depending on the question, neither feel good nor are confident about their parenting abilities
- Women who meet target group criteria are less confident about their parenting abilities than are other women
- 37% of women who meet target group criteria who have dependent children and 35% of other women who have dependent children feel they get little or no support from their mental health or substance use service providers with regard to their parenting roles and responsibilities

In sum, many women are not currently receiving services for major traumas in their lives, for their mental health and/or substance use problems, or for their problems related to children and parenting. Importantly, these are women who were very heavy users of services in the public ADM system in 1998, yet many continue to have major life problems with which they need help.

To better understand why many women with high need are not currently receiving care, we asked women a number of questions about their awareness of ADM services in the community, their perceived accessibility and convenience, as well as the sensitivity of providers to women's cultural and ethnic backgrounds. We also asked about specific barriers that may have deterred women from using services in the prior six months. Most women are aware of services and find them offered in a timely, convenient, and culturally competent manner. Moreover, women who meet target group criteria are somewhat more likely than other women to see services as accessible. Paradoxically, with few exceptions, women who meet target group criteria are also more likely than other women to report a number of barriers to receiving needed care:

- 46% (39% of other women) reported that they did not have the money to pay for needed services
- 31% (23% of other women) did not have adequate transportation to get to needed services.
- 30% (14% of other women) were deterred from seeking help because of a dislike of being labeled as "mentally ill"
- 19% (9% of other women) were deterred from seeking help because of a dislike of being labeled as an "alcoholic" or "drug abuser"
- 40% (35% of other women) agreed with the statement "I prefer to handle my problems on my own, rather than seek the help of professionals."

Women's reticence about seeking care is surprising, given that the majority of women who meet target group criteria view themselves as having major problems with which they need help. One explanation for this finding is that some women anticipate or fear adverse consequences from seeking help. For example, almost a quarter of the mothers who meet target group criteria and 11% of other mothers reported that they were reluctant to seek services because of a fear that their children will be taken away. In response to an open-ended query, other fears about unwanted treatment emerged including a fear of being sent back to prison, being hospitalized, or being forced to take medications, as well as the anticipation that desired services would simply not be available.

These findings suggest that significant numbers of women are "falling through the cracks," in the sense of not getting access to needed services. Support for this conclusion was further affirmed by women's response to the question: "If you were able to change one thing about the mental health and substance abuse services in

Dane County, what is the first thing you would do?" The most frequent response, endorsed by 50% of women who meet target group criteria and 42.6% of other women, was to recommend an increase in the availability and accessibility of affordable services. A second, and related theme is the need to reduce barriers that preclude a woman's ability to get the services she feels she needs. In some instances, these are limitations of insurance coverage; in others, ADM system-level or agency level policies that are often experienced as punitive and unreasonable. All, however, speak to women's economic adversity and the challenges of navigating a complex service delivery system with few material resources.

## Inconsistent Provision of Recovery-Oriented Care

Although many woman are satisfied with the care they have received in the publicly funded ADM system, and 10% state that they would not change anything with the existing mental health and substance abuse services in Dane County, a significant minority do not share these feelings. For example, almost a quarter of women, if given the choice, would choose to go elsewhere for their services, rather than continue with their current provider. Moreover, depending on the area of inquiry, we concluded that the quality of women's care is falling short of standards set by the Governor's Blue Ribbon Commission on Mental Health, as well as the Substance Abuse and Mental Health Services Administration. It is also falling short of many women's expectations. In response to the query: "If you were able to change one thing about the mental health or substance abuse services in Dane County, what is the first thing you would do?" almost a third of women proposed changes in the ADM system that were directed at "improving the quality of care." In the discussion that follows, we identify four themes that emerge from these findings.

### (1) Women want to have a greater voice in and control over services they receive, including medications.

The issue of having more voice in and control over one's services emerged repeatedly over the course of interviews with women. Thirty-six percent of women who meet target group criteria reported being "denied services I feel I need," and almost as many (33%) received services that they did <u>not</u> want. A critical area where women feel their voice is not heard and their choice compromised is in the area of medications. Three quarters of the women who meet target group criteria (74.1%) and over half of other women (56.1%) report they are currently taking a prescription medication for a mental health problem; 16.7% of the former and 1.9% of the latter also report taking medications for a substance use problem. When we asked women whether they had any choice in "picking medications that are right for me," 46% stated that they did not. Other queries about medication management suggest that significant numbers of women are not happy about this aspect of their treatment. Fully 30% of the women disagreed with the statement: "The medications I received were right for me." Further, almost 20% of the women felt their complaints about medication side effects were not taken seriously, and similar numbers reported that they had not been told what side effects to watch out for. Thus, one of the major areas of needed improvement in services is a system that is more responsive to women's perspectives on the use of medications.

### (2) Women want to be treated like "a whole person."

A second theme in women's suggestions to improve the quality of care in the ADM system coalesced around the notion of "wanting to be treated like a whole person." Often the experience of having a provider focus simply on medications, or the control of one's drinking, or even one's life traumas, in isolation from other aspects of a woman's life, undermines a sense of being treated like a whole person:

> *"Not assume everyone needs to take medication, or not assume every is depressed...tons of people who go into (agency), some are depressed but you can't just look at a person and say they need meds...like when you're sexually abused as a child, I might be depressed, but that is not the only thing, like sit down and talk to me, get to know me, before you say you're depressed and I'm going to give you some meds."*

### (3) Women want to be treated with greater respect.

Many women wanted to be able to tell their stories about their "journey in search of good services;" others have discontinued the journey because of experiences in the ADM system that were perceived as disrespectful, if not personally violating. In response to the question: If you were able to change one thing about the mental health or substance abuse services in Dane County, what is the first thing you would do?" one of the themes in women's responses was to improve the *humaneness of care*:

> *"Treat people like human beings, and not just assume everybody is the same, and be more open minded to other options...don't deny counseling or outpatient care constantly."*

> *"I would make the paramount priority respect for the patient. By respect, I mean to see the person."*

### (4) Many women want a different kind of care.

Finally, a fourth theme in women's suggestions about how they would change the existing ADM system is more radical, suggesting a need for a very different kind of care. For some women, a desire for more holistic care, as well as alternative healing modalities, is emphasized; for others, more consumer involvement in, and control over services, and for a handful, closing down existing services or sending all the providers back to school:

> *"To encourage other choices for therapy, such as more holistic, naturalistic, hypnotism. That are non-traditional...I'd like to know where some of them are."*

> *"Send all the doctors and therapist back to school to get more training on their people skills. And I would find people who love*

*their jobs--who are there because they love it. If they really wanted to be there we would be more comfortable and I would be feeling better about myself. After my experience with <agency>, I am afraid to seek help again."*

## Forging New Partnerships with Women

One of the strengths of Dane County's ADM services, particularly in the public arena, has been the effort of agencies to be increasingly responsive to the needs of cultural minorities, including people of color, as well as immigrant populations who are often not English speaking. We laud this effort and believe it should be strengthened in light of our findings regarding the diversity among women who enter the ADM system. However, we believe it must be also be expanded to include a greater sensitivity to gender, and to issues that are central concerns in the lives of women that cut across racial and ethnic boundaries.

For example, our findings show that women who receive services in the publicly funded ADM system are an extremely diverse group of women. They are diverse in their racial and ethnic make up--much more diverse than women in Dane County more generally--due largely to the overrepresentation of women of color, especially African American women and women who identify themselves as from "mixed ethnic and racial backgrounds." They are also diverse in age, in sexual orientation, in parental and marital status, and in their work circumstances. An appreciation of this diversity must be central in efforts to improve services for this population of women.

At the same time, women who receive services in the publicly funded ADM system share certain experiences that speak to their common oppression as women:

1) **They are predominantly economically disadvantaged women who struggle to make ends meet on a daily basis.** Close to 80% of the women interviewed reported having had serious money problems, including not enough money for a place to live or food at some point in their lives. Moreover, the issue of economic adversity looms large in these women's lives--both as a barrier to getting services they need and as a major aspect of their lives that they would like to change. Women are struggling with finding and keeping adequate housing, with transportation, with trying to find a job that is right for them, with trying to find childcare, with trying to lead 'normal' and productive lives. These are common struggles that are enormous in their scope and impact on women's lives and services must be guided by a fuller appreciation of the role that economic adversity plays in women's lives.

2) **Violence begins early for this group of women and, for many, continues into adulthood.** As our findings show, the vast majority of women--over 90% of the women we interviewed--report significant physical or sexual abuse in their lives and many continue to live in circumstances that feel unsafe to them. Moreover, over half of the women have had children removed from their care against their will, 69% have

been sent to jail or prison at some time in their lives, and a third have been "strip searched, forcibly restrained, or held against [their] will by a provider of mental health or substance abuse services" at some point in their lives. In short, women who enter the ADM system have been exposed to an epidemic of interpersonal violence that takes different forms across the life course, and that, for many women, is replicated in their experiences with the courts, the child welfare system, the jail and prison system, the welfare system, and within the ADM system itself. Improving services to women who enter the ADM system requires a greater sensitivity to the role of violence in the development and course of women's mental health and substance abuse problems, as well as a greater sensitivity to the ways in which women's experiences with violence may create a reluctance to seek care or to trust care providers.

3) **Women who receive publicly funded ADM services are more socially isolated and enjoy fewer family and social resources compared to other women in Dane County.** In the aggregate, women who received services in the ADM system are more likely to have never married; if they have married, few are presently in that status compared to other women in Dane County; moreover, they are more likely than other women in Dane County to either live alone or live with people who are not kin or family. Thus, women in the publicly funded ADM system are not only exposed to greater life adversity than most women in Dane County, they also enjoy fewer of the informal social supports and material resources that help to buffer one from the vagaries of such adversities.

**In a sense then, the starting point of our efforts to improve services for women should be a recognition of the multiple hardships that women face and the limited resources they have at hand to cope with those hardships.** In the language of SAMHSA and the national collaborative study, services for women must be "trauma informed," which means "trauma must be discussed, assessed, and addressed in all of the mental health and substance abuse services provided." We concur in this recommendation, although we believe that the concept of trauma must be expanded beyond histories of physical and/or sexual abuse to include other events, conditions, and experiences that are equally troubling to women.

## Listening to Women's Voices

Insight into what is most troubling to women is brought into bold relief in women's responses to the question: “In looking ahead to the next six months, what do you see as the areas of your life that you would most like to change?” A dominant theme in women's responses to this question is a desire to change their economic circumstances. Fully, 61% of the women in the aggregate identified changes in some aspect of their material circumstances as centrally important in fulfilling the most commonly mentioned recovery goal: leading a 'normal' and productive life. Moreover, close to 30% of the women in the aggregate mentioned additional material resources as the kind of help and support they need to make such changes. The latter included opportunities for more education, better jobs, better pay, better health insurance, a

Medicaid card, a windfall through winning the lottery--in short, a ticket out of poverty and into a world where one can purchase or secure the necessities of life.

Finally, when we ask women: "If you could wave a magic wand and get the kind of help and support you need to make those changes, what would that help be?", less than a third of women who meet target group criteria (30.2%), and less than a quarter of other women (22.2%) identify formal or professional services as an important source of help. In the aggregate, and in order of importance, the sources of help or support that women say they want and/or need are: (1) material resources (27.5%); formal services (26%); (3) informal supports and services (17.6%); (4) personal change (16.7%), and (5) a group of comments that were classified as "divine intervention (11.8%)." Thus, although many women view formal services as needed to help them address important aspects of their lives that they are most eager to change, other sources of help, including self-help, informal supports and services, and material resources, are also important.

## Improving the Lives of Women

Given these findings, an important question is: What can be done to improve the lives of women who meet target group criteria, as well as other women who enter the publicly funded ADM system? We offer a number of recommendations, which are highlighted below.

### Increase Women's Access to Integrated, Trauma-informed Care

Recommendation 1: Given that women who meet target group criteria show greater disability and greater need for care across a range of measures than do other women in the ADM system, and given that their needs closely approximate the needs that define the primary target group for the MH/AODA demonstrations, it is important that efforts be made ***to increase their access to integrated, trauma-informed care.***

Our recommendations for increasing women's access to integrated and trauma-informed care include several steps that build on our findings, as well as the recommendations of the Substance Abuse and Mental Health Services Administration:

- Consistent screening for co-occurring mental health and substance use problems, and histories of trauma at all portals of entry into the ADM system
- Referral of women who meet target group criteria to qualified ADM providers who can provide, or assemble and coordinate, needed services to address women's own recovery goals, including trauma-specific services as needed
- Adequate outreach and follow-along care for women who may relapse, or who may go to jail, to insure continuity of care
- Community education to:
    - Inform the public of the scope of the problems facing women in the ADM system

  - Inform the public of where to go to find services that are designed to address the special needs of women with these co-occurring problems
  - Reduce the stigma associated with seeking help for these problems
- Build capacity of existing ADM system to better serve women with these co-occurring problems:
  - Identify a network of care coordinators drawn from different agencies that comprise the ADM system in Dane County
  - Provide ongoing training of care coordinators in skills needed to provide services to women with co-occurring ADM disorders and histories of trauma
- Increase the integration of services across systems of care, agencies, and programs that are a part of the publicly funded ADM system:
  - Improve interagency networking through:
    - Cross-training activities among trauma, mental health, and substance abuse service providers
    - An integrated services problem-solving model developed at the system level to address problems as they arise in the work of care coordinators
  - Foster better structural integration of services at the county administrative level among the service systems that have significant contact with women who meet target group criteria and their children. These include mental health services, alcohol and other drug abuse services, trauma services, child welfare services, W2 services, the Dane County Jail, and the family court.

### Provide Consistent Gender-Sensitive, Recovery-Oriented Care

Recommendation 2: Efforts must be made to ***close the gap between existing care in the publicly funded ADM system and the vision for recovery-oriented care outlined in the report of the Governor's Blue Ribbon Commission on Mental Health.***

We offer three broad recommendations for improving the quality of women's care in the public ADM system, including care for women who do <u>not</u> meet target group criteria, as well as women who do:

- Expand the concept of "culturally competent care" to include a better understanding of, and greater sensitivity to, women's diversity, as well as women's common experiences with multiple forms of oppression
- Embrace the principles of a recovery-oriented system of service delivery, including:
  - A commitment to the notion that recovery is possible for every woman served

    - A commitment to the principle that consumers are welcomed as partners in their care, which means:
        - Women are treated with respect
        - Women assume a significant degree of control in the development of their treatment plans, and in determining the goals toward which they choose to work
        - Women are provided with sufficient information about treatment alternatives for their problems, which include and embrace a range of "non-traditional" services and supports
        - Women have more control over choosing services that are right for them
- Broaden the concept of ADM services to include a focus on outcomes that matter to women, in addition to their mental health and substance use problems:
    - Offer system wide screening for histories of trauma, including histories of severe and aversive life events and conditions, that may be contributing to women's mental health and substance use problems
    - Address immediate safety issues as a routine matter, including:
        - Safe housing and freedom from immediate threats of bodily danger from oneself as well as others
        - Other safety issues for children who may be in women's care
    - Address the economic adversity in women's lives, and women's related desire to lead 'normal' and productive lives, through providing services that:
        - Assist women with gaining access to benefits, such as Medicaid, economic assistance, housing, childcare, and transportation needs
        - Assist women with gaining access to education, job training, and other job preparation skills
        - Provide women with support around current employment
        - Make services available in evenings or weekends so working women can take advantage of them
    - Address women's social isolation and desire for improvements in the quality of intimate relationships, particularly with children, partners, family, and friends:
        - Assist women with opportunities to join with other women in problem solving groups
        - Assist women with parenting issues, including dealing with the loss and recovery of children

        - Offer greater access to "talk therapies" for women and their family members
    - Address women's desire for services related to their physical health problems and disabilities, and an improvement in the quality of women's daily lives:
        - Offer or help women secure access to diet and exercise classes
        - Offer or help women secure access to needed medical and dental care
        - Offer or help women secure access to services that are accessible to women with disabilities
    - Address women's desire for trauma-specific treatment as needed

## Build Infrastructure to Support and Reward Women-Sensitive Care

Recommendation 3: Strategies for bringing about the above services and system changes will require an ***additional investment of resources and time on the part of frontline workers, consumers, and systems administrators in the ADM system, as well as better preparation of the next generation of workers for these new tasks.*** We offer several recommendations to insure that these things happen.

- Empower staff: a key recovery principle:
    - Identify staff who are already doing exemplary work with women who have co-occurring ADM disorders and histories of trauma
    - Involve them as key caregivers for this population of women
    - Provide them with support and consultation, as well as opportunities to meet in cross-training exercises
    - Reward them for their good work in this area
- Develop consumer watchdog and advocacy groups to oversee the progress of the Dane County ADM system in addressing the recommendations of our study site:
    - Support for the development of an active and independent consumer advocacy voice in the publicly funded ADM system
    - Support for the development and provision of courses for consumers related to self-advocacy as well as advocacy on behalf of others
- Provide ongoing, independent evaluation of the quality of care provided in the publicly funded ADM system in Dane County:
    - Implementation of an ongoing, independent evaluation of services and their impacts on consumer outcomes over time
    - Development and implementation of quality improvements based on the findings from such outcome studies

- Improve the quality of training that ADM professionals receive at the UW-Madison and elsewhere:
    - Development of interdisciplinary training programs that addresses the intersection of women's trauma, mental health, and substance use problems, and the array of social and material deficits that are linked with such problems
    - Better preparation of professionals so that they are equipped to deal with the challenges and opportunities that will confront them when building programs to address the needs of special populations with multiple intersecting needs

### Build Community Resources and Supports for Women

Recommendation 4: Given that many women associate their recovery with reducing their dependence on the ADM system for their care, ***building community supports and services that foster independence within a supportive community environment is essential.***

- Develop and implement a training curriculum for consumers regarding the effects of trauma on one's life, symptom management, how to access basic needs resources, and how to advocate for oneself and for others
- Develop and provide cross training between mental health, substance abuse, and trauma service providers, as well as basic needs service providers, including the W-2 program
- Enhance consumer involvement and empowerment activities through the development of a plan for a warm line and consumer participation in ongoing capacity building efforts
- Promote the development of a Women's Healing Center where women could:
    - Gather to connect with other women who have had similar experiences, to participate in healing and health and wellness activities
    - Obtain information about other resources in the community
    - Spend some time in a quiet, safe environment
    - Continue learning about trauma, its impact on women, its meaning in different cultures, and alternative approaches to healing
    - Secure short-term respite in situations where one's currently living situation or environment feels unsafe
- Promote the development of services targeted at improving women's material resources

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We offer the above recommendations in the spirit of forging new partnerships with women, particularly women who enter the publicly funded ADM system in Dane County, Wisconsin. Many of these women have been our teachers, advisors, and collaborators over the past several years. It was, in fact, a consumer of such services who came up with the name, New Partnerships for Women, as an outgrowth of the collaborative work we have done together, and continue to do, to study and improve services for women with co-occurring ADM disorders and histories of trauma. We are encouraged by the new partnerships among women we have seen forming over these several years--partnerships among different service providers across systems of care, as well as partnerships between service providers and consumers. We are hopeful that the work of this project, and the many new partnerships that have developed, will ultimately contribute to women's collective goal of leading normal and productive lives that are free of substances and disabling symptoms and filled with peace and serenity for growing numbers of women.

# Appendix 2

# Suggested Readings for Chapter 2: The Nature and Scope of Trauma in Women's Lives

# WHAT IS PSYCHOLOGICAL TRAUMA?*

We all use the word "trauma" in every day language to mean a highly stressful event. But the key to understanding traumatic events is that it refers to extreme stress that overwhelms a person's ability to cope. There are no clear divisions between stress, trauma, and adaptation. Although I am writing about psychological trauma, it is also important to keep in mind that stress reactions are clearly physiological as well. Different experts in the field define psychological trauma in different ways. What I want to emphasize is that it is an individual's *subjective experience* that determines whether an event is or is not traumatic.

Psychological trauma is the unique individual experience of an event or enduring conditions, in which:

1. The individual's ability to integrate his/her emotional experience is overwhelmed, or
2. The individual experiences (subjectively) a threat to life, bodily integrity, or sanity. (Pearlman & Saakvitne, 1995, p. 60)

Thus, a traumatic event or situation creates psychological trauma when it overwhelms the individual's perceived ability to cope, and leaves that person fearing death, annihilation, mutilation, or psychosis. The individual feels emotionally, cognitively, and physically overwhelmed. The circumstances of the event commonly include abuse of power, betrayal of trust, entrapment, helplessness, pain, confusion, and/or loss.

This definition of trauma is fairly broad. It includes responses to powerful one-time incidents like accidents, natural disasters, crimes, surgeries, deaths, and other violent events. It also includes responses to chronic or repetitive experiences such as child abuse, neglect, combat, urban violence, concentration camps, battering relationships, and enduring deprivation. This definition intentionally does not allow us to determine whether a particular event is traumatic; that is up to each survivor. This definition provides a guideline for our understanding of a survivor's experience of the events and conditions of his/her life.

Jon Allen, a psychologist at the Menninger Clinic in Topeka, Kansas and author of Coping with Trauma: A Guide to Self-Understanding (1995) reminds us that there are two components to a traumatic experience: the objective and the subjective.

"It is the subjective experience of the objective events that constitutes the trauma...The more you believe you are endangered, the more traumatized you will

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* By Esther Giller, President and Director, The Sidran Foundation © 1995-2000. Reprinted with permission. Available at: http://www.sidran.org/whatistrauma.thml. The Sidran Institute, a leader in traumatic stress education and advocacy, is a nationally-focused nonprofit organization devoted to helping people who have experienced traumatic life events. For more information and resources, visit their web site at: www.sidran.org.

be...Psychologically, the bottom line of trauma is overwhelming emotion and a feeling of utter helplessness. There may or may not be bodily injury, but psychological trauma is coupled with physiological upheaval that plays a leading role in the long-range effects" (p.14).

In other words, trauma is defined by the experience of the survivor. Two people could undergo the same noxious event and one person might be traumatized while the other person remained relatively unscathed. It is not possible to make blanket generalizations such that "X is traumatic for all who go through it" or "event Y was not traumatic because no one was physically injured." In addition, the specific aspects of an event that are traumatic will be different from one individual to the next. You cannot assume that the details or meaning of an event, such as a violent assault or rape, that are most distressing for one person will be same for another person.

Trauma comes in many forms, and there are vast differences among people who experience trauma. But the similarities and patterns of response cut across the variety of stressors and victims, so it is very useful to think broadly about trauma.

## Single Blow vs. Repeated Trauma

Lenore Terr, in her studies of traumatized children, has made the distinction between single blow and repeated traumas. Single shocking events can certainly produce trauma reactions in some people:

- *Natural disasters* such as earthquakes, hurricanes, floods, volcanoes, etc.
- Closely related are *technological disasters* such as auto and plane crashes, chemical spills, nuclear failures, etc. Technological disasters are more socially divisive because there is always energy given towards finding fault and blaming.
- *Criminal violence* often involves single blow traumas such as robbery, rape and homicide, which not only have a great impact on the victims, but also on witnesses, loved ones of victims, etc. (Interestingly, there is often overlap between single blow and repeated trauma, because a substantial majority of victimized women have experienced more than one crime.) Unfortunately, traumatic effects are often cumulative.

As traumatic as single-blow traumas are, the traumatic experiences that result in the most serious mental health problems are prolonged and repeated, sometimes extending over years of a person's life.

## Natural vs. Human Made

Prolonged stressors, deliberately inflicted by people, are far harder to bear than accidents or natural disasters. Most people who seek mental health treatment for trauma have been victims of violently inflicted wounds dealt by a person. If this was done deliberately, in the context of an ongoing relationship, the problems are increased. The worst situation is when the injury is caused deliberately in a relationship with a person on whom the victim is dependent---most specifically a parent-child relationship.

## Varieties of Man-Made Violence

- *War/political violence* - Massive in scale, severe, repeated, prolonged and unpredictable. Also multiple: witnessing, life threatening, but also doing violence to others. Embracing the identity of a killer.
- *Human rights abuses* - kidnapping, torture, etc.
- *Criminal violence* - discussed above.
- *Rape* - The largest group of people with posttraumatic stress disorder in this country. A national survey of 4000 women found that 1 in 8 reported being the victim of a forcible rape. Nearly half had been raped more than once. Nearly 1/3 was younger than 11 and over 60% were under 18. Diana Russell's research showed that women with a history of incest were at significantly higher risk for rape in later life (68% incest history, 38% no incest).
- *Domestic Violence* - recent studies show that between 21% and 34% of women will be assaulted by an intimate male partner. Deborah Rose's study found that 20-30% of adults in the US, approved of hitting a spouse.
- *Child Abuse* - the scope of childhood trauma is staggering. Everyday children are beaten, burned, slapped, whipped, thrown, shaken, kicked and raped. According to Dr. Bruce Perry, a conservative estimate of children at risk for PTSD exceeds 15 million.
- *Sexual abuse* - According to Dr. Frank Putnam of NIMH, at least 40% of all psychiatric inpatients have histories of sexual abuse in childhood. Sexual abuse doesn't occur in a vacuum: is most often accompanied by other forms of stress and trauma—generally within a family.

We must be careful about generalizations about child sexual abuse: research shows that about 1/3 of sexually abused children have no symptoms, and a large proportion that do become symptomatic, are able to recover. Fewer than 1/5 of adults who were abused in childhood show serious psychological disturbance.

More disturbance is associated with more severe abuse: longer duration, forced penetration, helplessness, fear of injury or death, perpetration by a close relative or caregiver, coupled with lack of support or negative consequences from disclosure.

- *Physical abuse* often results in violence toward others, abuse of one's own children, substance abuse, self-injurious behavior, suicide attempts, and a variety of emotional problems.
- *Emotional/verbal abuse*
- *Witnessing*. Seeing anyone beaten is stressful; the greater your attachment to the victim, the greater the stress. Especially painful is watching violence directed towards a caregiver, leaving the child to fear losing the primary source of security in the family.
- *Sadistic abuse* - we generally think about interpersonal violence as an eruption of passions, but the severest forms are those inflicted deliberately. Calculated cruelty can be far more terrifying than impulsive violence. Coercive control is used in settings like concentration camps, prostitution and pornography rings, and in some families.

One of the best-documented research findings in the field of trauma is the DOSE-RESPONSE relationship --the higher the dose of trauma, the more potentially damaging the effects; the greater the stressor, the more likely the development of PTSD.

The most personally and clinically challenging clients are those who have experienced repeated intentional violence, abuse, and neglect from childhood onward. These clients have experienced tremendous loss, the absence of control, violations of safety, and betrayal of trust. The resulting emotions are overwhelming: grief, terror, horror, rage, and anguish.

Their whole experience of identity and of the world is based upon expectations of harm and abuse. When betrayal and damage is done by a loved one who says that what he or she is doing is good and is for the child's good, the seeds of lifelong mistrust and fear are planted. Thus, the survivor of repetitive childhood abuse and neglect expects to be harmed in any helping relationship and may interact with us as though we have already harmed him or her.

## Summary

Psychological effects are likely to be most severe if the trauma is:

1. Human caused
2. Repeated
3. Unpredictable
4. Multifaceted

5. Sadistic
6. Undergone in childhood
7. And perpetrated by a caregiver

## Who Are Trauma Survivors?

Because violence is everywhere in our culture and because the effects of violence and neglect are often dramatic and pervasive,

- *most clients/patients/recipients of services in the mental health system are trauma survivors.*

Because coping responses to abuse and neglect are varied and complex,

- *trauma survivors may carry any psychiatric diagnosis and frequently trauma survivors carry many diagnoses.*

And, because interpersonal trauma does not discriminate,

- *survivors are both genders, all ages, all races, all classes, all sizes, all sexual orientations, all religions, and all nationalities.* Although the larger number of our clients are female, many men and boys are survivors of childhood abuse and trauma. Under-recognition of male survivors, combined with cultural gender bias has made it especially difficult for these men to get help.

## What are the Lasting Effects of Trauma?

There is no one diagnosis that contains all abuse survivor clients; rather individuals carrying any diagnosis can be survivors. Often survivors carry *many* diagnoses.

Abuse survivors may meet criteria for diagnoses of:

- substance dependence and abuse,
- personality disorders (especially borderline personality disorder),
- depression,
- anxiety (including post traumatic stress disorder),
- dissociative disorders, and
- eating disorders, to name a few.

PTSD is the only diagnostic category in the DSM [Diagnostic and Statistical Manual of the American Psychiatric Assocation) that is based on etiology. In order for a person to be diagnosed with PTSD, there had to be a traumatic event. Because most diagnoses are descriptive and not explanatory, they focus on symptoms or behaviors without a context: they do not explain how or why a person may have developed those behaviors (e.g., to cope with traumatic stress).

For purposes of identifying trauma and its adaptive symptoms, it is much more useful to ask "What HAPPENED to this person" rather than "what is WRONG with this person."

## Symptoms as Adaptations

The traumatic event is over, but the person's reaction to it is not. The intrusion of the past into the present is one of the main problems confronting the trauma survivor. Often referred to as re-experiencing, this is the key to many of the psychological symptoms and psychiatric disorders that result from traumatic experiences. This intrusion may present as distressing intrusive memories, flashbacks, nightmares, or overwhelming emotional states.

## The Use of Maladaptive Coping Strategies

Survivors of repetitive early trauma are likely to instinctively continue to use the same self-protective coping strategies that they employed to shield themselves from psychic harm at the time of the traumatic experience. *Hypervigilance, dissociation, avoidance and numbing* are examples of coping strategies that may have been effective at some time, but later interfere with the person's ability to live the life s/he wants.

It is useful to think of all trauma "symptoms" as adaptations. Symptoms represent the client's attempt to cope *the best way they can* with overwhelming feelings. When we see "symptoms" in a trauma survivor, it is always significant to ask ourselves: what purpose does this behavior serve? Every symptom helped a survivor cope at some point in the past and is still in the present -- in some way. We humans are incredibly adaptive creatures. Often, if we help the survivor explore how behaviors are an adaptation, we can help them learn to substitute a less problematic behavior.

## Developmental Factors

Chronic early trauma -- starting when the individual's personality is forming -- shapes a child's (and later adult's) perceptions and beliefs about everything.

Severe trauma can have a major impact on the course of life. Childhood trauma can cause the disruption of basic developmental tasks. The developmental tasks being learned at the time the trauma happens can help determine what the impact will be. For example, survivors of childhood trauma can have mild to severe deficits in abilities such as:

1. self-soothing

2. seeing the world as a safe place
3. trusting others
4. organized thinking for decision-making
5. avoiding exploitation

Disruption of these tasks in childhood can result in adaptive behavior, which may be interpreted in the mental health system as "symptoms." For example, disruptions in:

1. self-soothing can be seen as ➔ agitation
2. seeing the world as a safe place ➔ paranoia
3. trusting others ➔ paranoia
4. organized thinking for decision-making ➔ psychosis
5. avoiding exploitation ➔ self-sabotage

## Physiologic Changes

The normal physiological responses to extreme stress lead to states of physiologic hyperarousal and anxiety. When our fight-or-flight instincts take over, the wash of cortisol and other hormones signal us to watch out! We humans are incredibly adaptive. When this happens repeatedly, our bodies learn to live in a constant state of "readiness for combat," with all the behaviors—scanning, distrust, aggression, sleeplessness, etc. that entails.

Cutting edge neurological research is beginning to show to what extent trauma effects us on a biological and hormonal basis as well as psychologically and behaviorally. Research suggests that in trauma, interruptions of childhood development and hypervigilance of our autonomic systems are compounded and reinforced by significant changes in the hard-wiring of the brain.

This may make it even more challenging (but not impossible) for survivors of childhood trauma to learn to do things differently. But it may also hold the promise of pharmaceutical interventions to address the biological/chemical effects of child abuse.

So, as scientists learn more about what trauma is, we are seeing see that it is truly a complex mixture of biological, psychological, and social phenomena.

This article originated as a workshop presentation at the Annual Conference of the Maryland Mental Hygiene Administration, "Passages to Prevention: Prevention across Life's Spectrum," May 1999.

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# Women and Trauma:
# Assessing the Scope of the Problem in the Publicly Funded Alcohol, Drug, and Mental Health (ADM) System

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## Introduction

Over the past two decades, there has been a growing interest in the link between histories of abuse and mental health and substance abuse problems among persons who enter the mental health and substance abuse service systems. This interest has grown out of two observations: (1) people who enter systems of care for a mental health or substance use problem typically have been exposed to more abuse than people in the general population, and (2) people with abuse histories often have more complex presenting problems and symptoms than people who do not have abuse histories. In 1998, the National Association of State Mental Health Program Directors (NASMHPD) developed a position statement on the importance of services and supports to trauma survivors, "given the serious negative consequences for an individual's mental health, self-esteem, use of substances and involvement with the criminal justice system" (NASMHPD, 1998). The position statement was later revised and updated in 2005 in recognition of the fact that "the psychological effects of violence and trauma in our society are pervasive, highly disabling, yet *largely ignored.*" The report concluded: "NASMHPD believes that responding to the behavioral health needs of women, men, and children who have experienced trauma is crucial to their treatment and recovery and should be a priority of state mental health programs" (NASMHPD, 2005).

Several national and state initiatives to address trauma in men and women's lives have focused, in particular, on women because of the assumption that trauma and abuse may be a more important treatment issue for women than for men. This conclusion comes from a handful of treated population studies, some of the abuse histories of those who enter the mental health services system and some of those who enter the substance abuse treatment system.

Within the mental health services literature, a number of studies have focused on rates of abuse among persons who have a diagnosis of serious mental illness (Newmann, Greenley, Sweeney, & Van Dien, 1998; Mueser et al., 2004). Studies of outpatient samples of this population show rates of childhood sexual abuse ranging from 25 to 45% of samples and childhood physical abuse ranging from 24 to 57% of samples. Rates of abuse among inpatient populations are even higher. In a recent survey of lifetime rates of abuse among men and women with severe mental illnesses, many of whom were hospitalized at the time of the study, Mueser and his colleagues (Mueser et al., 2004) concluded that 84% of the sample had experienced physical abuse in their lifetimes; 52% had experienced sexual abuse in their lifetimes. Although lifetime rates of physical abuse were comparable for men and women (86.1% and 82.1%), rates of sexual abuse were much higher for women than men (68.2% and 40.0%).

Other treated population studies that have compared the abuse experiences of men and women with serious mental disorders (Ross, Anderson & Clark, 1994; Lipschitz et al., 1996; Carmen, Ricker & Mill, 1984; Jacobson & Herald, 1990; Brown & Anderson, 1991) highlight three gender differences:

(1) reported rates of childhood abuse are generally higher for women with serious mental illnesses than for men, regardless of type of abuse, although the difference is greatest for sexual abuse experiences;

(2) women with serious mental illnesses are more likely than men to have experienced co-occurring physical and sexual abuse during childhood;

(3) women are also more likely than men to experience a pattern of revictimization during adulthood (Darves-Bornoz, Lemperiere, Degiovanni & Gaillard, 1995; Friedman & Harrison, 1984; Bryer et al., 1987; Lipschitz et al., 1996; Carmen et al., 1984).

Findings reported in the substance abuse literature suggest equally high, if not higher, rates of abuse in women's lives, particularly sexual abuse (Kovach, 1986; Yandow, 1989; Bollerud, 1990; Zweben, Clark & Smith, 1994; Teets, 1995). Yandow (1989) estimates that as many as 75% of women in treatment for alcoholism have a history of sexual abuse, which frequently starts in childhood. Similar findings are reported by Teets (1995) in her in-depth analysis of the link between women's histories of abuse and the onset and course of their substance abuse problems. Indeed, as Zweben et al. (1994) note, "The task of addressing traumatic experiences is emerging as one of the most important clinical challenges today, as more and more practitioners come to view this as a key element in improving outcome in addiction treatment settings" (p. 327).

Although these findings highlight the importance of attending to abuse in women's lives, the separation of these literatures implies that women who use mental health services and women who use substance abuse services are two separate populations. Moreover, because most of these studies are local in nature and do not focus on a comparison of women who use mental health versus substance abuse services, we have no way of knowing whether rates of abuse are, in fact, a more salient treatment issue for women who enter one or the other system. Nor do we know how many women use services in both systems of care.

In earlier analysis of data from the Women and Mental Health Study Site (WAMHSS), we found that significant numbers of women did use both systems of care over the course of a year (Newmann and Sallmann, 2004). In 1998, a total of 2,140 women, 18 years of age and older, had over 13,000 treatment episodes in the publicly funded ADM system. The majority of these women (1,274 or 59.5%) had two or more treatment episodes only in the mental health services system. Almost twenty eight percent (27.7%) or 592 women had two or more treatment episodes only in the substance abuse services system. However, 272 women--12.7% of the population--had had treatment episodes in both the mental health and the substance abuse services systems in 1998.

Our purpose in this paper, which we have written for the Consumer Curriculum, is to familiarize you, as a consumer of mental health or substance abuse services in Dane County, with the prevalence and impact of abuse in the lives of women who used mental health or substance abuse services in Dane County in 1998. Our findings are based on interviews with a subset of women who had two or more treatment episodes in Dane County in 1998 for a mental health or substance abuse problem in the publicly funded system of care. This system includes 20 different mental health service providers and 8 substance abuse service providers involving over 50 different individual programs in which women could enroll for services paid for by the county.

In 2000 and early 2001, we interviewed 204 women randomly selected from the 2,140 women who had had two or more episodes of care in the Dane Co. publicly funded system in 1998 to determine the scope of the problem of abuse in their lives and also to investigate its link with co-occurring mental health and substance use problems, and with a number of treatment outcomes. Our sample included 125 women who used mental health services only, 56 women who used substance abuse services only, and 23 women who used both mental health and substance abuse services.

In the 3 tables discussed below we present data on the scope of physical and sexual abuse in the lives of women who received services in one or both of these service sectors (Table 1). We also describe other adversities in the lives of these women, many of which are linked with abuse histories (Table 2). Finally, we share women's perceptions of how much each of these events has affected their lives in the past year—the year before their interview—and, for a subset of questions, show the average age of first occurrence of such events or experiences (Table 3).

## Discussion of Findings

We begin with Table 1, which reports rates of abuse for six questions we asked of women—three covering physical abuse experiences and three covering sexual abuse experiences. In the four columns in Table 1 to the right of the questions, we show the percent of women who responded yes to each of these questions for (1) women who received services in the mental health system only, (2) women who received services in the substance abuse service system only, and (3) women who received services in both systems. The fourth column of percents is for all women in the ADM system, which combines the numbers in the first three columns.

Let's begin by looking at the numbers in the far right column for all women in the ADM system in Dane County. You will see that there are little stars or asterisks by some of the numbers. Those tell us that there are statistically significant differences among the three groups of women in the per cent who endorse or say yes to a given question or set of questions. To find out which of the three groups differ significantly from each other, we ran another test—a post hoc Tukey analysis—and designate by a superscript letter (a, b, or c) these group differences as follows:

$^{a}$ indicates a statistically significant difference between women who use mental health and substance abuse services and women who use mental health services only;

$^{b}$ indicates a statistically significant difference between women who use mental health and substance abuse services and women who use substance abuse services only;

[c] indicates a statistically significant difference between women who use mental health services only and women who use substance abuse services only;

We first examine the percent of women who endorse one of the three questions we used to assess for physical abuse histories. One in four of the women we interviewed (24.6%) reported being physically neglected at some point in their lives as indicated by not being fed or properly clothed or left to take care of themselves when they were too young or too ill. One in six women (39.9%) reported having been robbed, mugged, or physically attacked by someone they did not know at some point in their lives. However, the most frequent physical abuse experience reported by 7 in 10 women (71.1%) was physical abuse at the hands of someone known to them, as evidenced by being hit, slapped, choked, burned, or beat up by someone they know, such as a parent, sibling, boyfriend, or girlfriend. Taken as a whole, these findings show that 8 in 10 women (83.3%) in the ADM system in Dane County have experienced at least one of the three forms of physical abuse in their lifetimes. Further, a little over half of these women, or 44.2%, reported physical abuse experiences that happened when they were children or adolescents—that is, before the age of 18.

Are patterns similar for sexual abuse? In general, fewer women report sexual abuse experiences than physical abuse experiences although the numbers are still quite high for two of the three sexual abuse items. Almost 6 in 10 women (56.8%) reported unwanted sexual touching at some point in their lives and 5 in 10 (49.5%) reported being forced to have sex orally, anally, or genitally when they did not want to and were threatened with harm if they did not comply. Finally, almost 1 in 4 women (23.9%) had sex when they did not want to in exchange for money, drugs, or other materials goods, such as shelter or housing—what some consider a form of forced prostitution. If we ask, what percent of women have experienced one of these forms of sexual abuse, we find that about two-thirds of the women (64.2%) have. About a third of these women (21.1%) reported that the sexual abuse experience first occurred during childhood or adolescence.

Finally, when we combine women who gave a yes response to one of the physical abuse or sexual abuse questions, we conclude that 88.3% of women who use ADM services in Dane County have experienced either physical or sexual abuse in their lifetimes—a number far larger than the 55% of women reported by the National Violence Against Women Survey. Moreover, the majority of women (59%) have experienced both forms of abuse at some point in their lifetimes. In short, histories of physical and/or sexual abuse are common in the lives of women who use publicly funded ADM services.

Are they equally common among women who use mental heath and substance abuse services? In general, we find that women who use services in *both* the mental health and substance abuse services sector report *more* abuse experiences than women who are exclusive users of mental health, or substance abuse, services. However, these differences are *not* statistically significant for any of the separate physical abuse inquiries, or for the two composite measures of physical abuse. In short, the experience of some form of physical abuse is very high among women who receive ADM services in Dane County, regardless of whether they use mental health or substance abuse services, or both.

The picture changes, however, when we consider rates of sexual abuse. Group differences are statistically significant for two of the three sexual abuse items and three of the composite scales. Again, we see the highest rates of each of the experiences for women who used both service systems. For example, 91.3% of women who had treatment episodes in both the mental health and substance abuse services systems reported histories of sexual abuse compared to 58.9% of women who used mental health services only and 64.9% of women who used substance abuse services only. However, our post hoc test of group differences showed that the contrast between women who used mental health services only and women who used both systems is statistically significant; the remaining contrast is not.

A similar pattern of differences across groups is seen for the childhood sexual abuse experiences—45.5% of the dual system users reported childhood sexual abuse experiences compared to 15.4% of women who used mental health services only and 24.1% of women who used substance abuse services only. Finally, the women who used both systems were more likely than women who used one system to report *both* physical and sexual abuse experiences and to report more of all forms of abuse combined. Eighty seven percent of women who used both systems reported having experienced both physical and sexual abuse in their lives compared to 52.0% of women who used only mental health services and 62.5% of women who used only substance abuse services. The average number of all abuse experiences was 3.6 for women who used both systems compared to 2.4 for women who used mental health services only and 2.7 who used substance abuse services only. Again, we find that significantly more women who use both systems report sexual abuse experiences than do women who use only mental health services, although the dual system users do not differ significantly from the women who use only substance abuse services.

Are there differences in sexual abuse experiences among women who are exclusive users of mental health or substance abuse services? In our post hoc analyses, we found that none of the rate differences between women who used mental health or substance abuse services exclusively are statistically significant. Nor are differences significant between women who used substance abuse services exclusively and women who used both substance abuse and mental health services. The significant differences were primarily for women who used mental health services exclusively and women who used mental health and substance abuse services. However, when we examine the proportion of women who report physical *or* sexual abuse in each group, we find no significant differences across the three groups. Almost 90% of women who used mental health services only reported one of these experiences compared to 82.5% of women who used substance abuse services only and 95.7% of women who used both service systems.

We conclude by asking: How do rates of abuse for women in each system compare to rates estimated in other treated population studies? If we consider rates of abuse for women who use mental health services, regardless of whether they have used substance abuse services—that is, if we combine women in columns 1 and 3--we would conclude that 84.5% of women have histories of physical abuse and 64% of women have histories of sexual abuse. Ninety one percent, or the vast majority of women who use mental health services, report having experienced either physical or sexual abuse in their lives. These rates are very comparable to lifetime rates of abuse reported for women with serious mental illnesses by Mueser et al. (2004). Estimating similar rates for women who use substance abuse services, regardless of their use of mental health services, we would conclude that 83.5% have histories of physical abuse and 72.5% have histories of sexual abuse; 87.3% report either physical or sexual abuse. Thus, these estimates, particularly for sexual abuse, are comparable to those reported by Yandow (1989) and Teets (1995).

In conclusion, these findings show that women who received publicly funded mental health and substance abuse services in Dane County have lifetime rates of physical and/or sexual abuse that are comparable across systems, although significantly higher than rates found among women in the general population. Moreover, women with the highest rates of abuse, particularly sexual abuse, but also childhood sexual and physical abuse, are active users of both systems of care.

We turn now to Table 2, which reports rates of other life adversities for women, again broken down by (1) mental health service users only, (2) substance abuse service users only, (3) mental health and substance abuse service users, and (4) all users combined. We have organized these adversities into three groups: (1) childhood traumas, (2) adult traumas related to children, and (3) other adult traumas. Again, turning first to the last column, which reports the percent of life adversities for all women in the two systems of care combined, we see that three quarters (74.4%) of all women report experiences of being emotionally abused or neglected, for example, being frequently shamed, embarrassed, ignored, or repeatedly told you were "no good." Sixty-eight percent reported witnessing family violence when they were growing up and 10.9% reported having been put in foster care or up for adoption.

Of the two child-related traumas, we find that over a third of women interviewed (36.2%) had been separated from a child against their will either through a loss of custody, or visitation, or kidnapping. Approximately 10% reported having had a baby with a serious mental or physical handicap.

Finally, we see that women who use publicly funded ADM services have faced other severe hardships and adversities as adults. Although it is not perhaps surprising that women who use publicly funded services are struggling with economic adversity, we were surprised and troubled to learn that 70% of women reported having had serious money problems, for example, not enough money for food or a place to live. Close to 60% (58.2%) have been sent to jail at some point, and almost half (48.3%) have experienced sexual harassment at the workplace or school. Finally, 30.4% report having been strip-searched, forcibly restrained, or held against their will by a provider of mental health or substance abuse services—a treatment experience that has been highly criticized because it is often experienced as a form of revictimization by trauma survivors (Jennings, 2004).

Do women who enter the mental health, substance abuse, or both systems of care differ in exposure to these life adversities? There are some similarities, and some significant differences, across the three groups. The percent of women who have been emotionally abused is equally high for the three groups, as is the experience of witnessing family violence while growing up and struggling with poverty. However, we find that, with only two exceptions, women who use both mental health and substance abuse services report more of all of these adversities than do women who use one or the other system of care exclusively. This is reflected in two of the composite measures at the bottom of the table. Women who use both systems report a significantly higher number of these life adversities (4.9) than do women who use only the mental health system (3.6), and a somewhat higher but non-significant number than women who use only the substance abuse service system (4.1). Second, women who use both systems report significantly more total life events, including physical and sexual abuse experiences (8.6), than do women who use only mental health (6.04) or substance abuse (6.8) services.

Two of the life adversities related to family ruptures are also significantly more common among women who use both vs. only one system of care. Twenty six percent of women who used both systems were put in foster care or up for adoption as children compared to only 7.3% of women who used mental health services only and 12.5% of women who used substance abuse services only. Again, only the contrast between dual system users and women who used mental health services is statistically significant. Interestingly, women who use both service systems are also significantly more likely to have been separated from a child against their will (64.3%) compared to women who used mental health services only (25.9%). Moreover, women who used substance abuse services only did not differ significantly from the former group in this experience, but did differ significantly from the latter. Almost half of the women who used substance abuse services only (48.7%) had also experienced the loss of a child through loss of custody, visitation, or kidnapping.

There are two exceptions to this overall pattern of differences across groups, both of which involve an experience of being physically restrained. Women who received substance abuse services only are significantly more likely than women who received mental health services only to have been sent to jail—77.8% versus 47.6%, respectively. Conversely, women who received mental health services, either exclusively or in combination with substance abuse services, are significantly more likely than women who received substance abuse services only to report that they had been "strip-searched, forcibly restrained, or held against their will by a provider of mental health or substance abuse services." Only 14% of the latter group reported this experience compared to 43.5% of women who used both systems and 35.2% of women who used mental health services only.

We conclude our analysis with an assessment of the impact of these adversities on women's lives, particularly in the past year. During the interview, women who said they had experienced a particular life adversity were asked: "How much has this experience affected your life in the past year?" The responses were coded: (1) not at all, (2) a little bit, (3) moderately, (4) quite a bit, and (5) extremely. For a subset of questions, we also asked: "How old were you when this first happened?"

Interestingly, there were no significant differences across the three service user groups in the perceived impact of these events, or the average age of first onset. Consequently, the results presented in Table 3 are pooled for all women in the ADM system.

We begin with a comparison of the average impact of subsets of events including (1) any physical abuse, (2) any sexual abuse, and (3) any other life adversities. A comparison of mean impact scores across the groups of items, which are presented at the bottom of the far right column in Table 3, shows that these life adversities, collectively, have very comparable impacts. That is, physical abuse, sexual abuse, and the other life adversities we assessed are viewed, on average, as having a moderate impact on women's lives in the past year. A statistical test of mean differences in the impact of these clusters of life events or adversities on women's lives shows that none of the comparisons differ in a statistically significant sense.

Do individual events stand out as particularly affecting for women in terms of their impact in the past year? To answer this question, we can examine and compare the impact scores for individual items. Interestingly, the event that has had the most impact on women's lives is the experience of having been separated from a child against one's will, either through a loss of custody, or visitation or kidnapping. The average impact rating of this experience, among women who responded yes, is 3.75 or "quite a bit" on the impact scale. Although this is likely to be a more recent experience in many women's lives than some of the abuse experiences that may have occurred years earlier, it is interesting to note that one of the traumas with the earliest age of onset—emotional abuse—is ranked as having an average impact of 3.59. This is also one of the most common abuse experiences that women report—having been emotionally abused or neglected, for example, being frequently shamed, embarrassed, ignored, or repeatedly told you were "no good." The average age of first occurrence of this event is 10.2 years and it continues, not surprisingly, to have a significant impact on women's lives. Moreover, 3 out of 4 women interviewed reported this experience.

Interestingly, the next highest ranked event is physical neglect, whose average age of first onset in women's lives is 12.1 years of age. Although this is a less common event than emotional abuse in that 1 in 4 women report it, its impact average is 3.4. Other events ranked at three or higher include in order of ranking: (1) having had sex when you did not want to in exchange for money, drugs, or other material goods such as shelter or housing (3.31); (2) having been touched or made to touch someone else in a sexual way because they forced you in some way or threatened to harm you if you didn't (3.20); (3) having been physically abused, hit, slapped, choked, burned or beat up by someone you knew, for example, a parent, sibling, boyfriend, or girlfriend (3.18); (4) having been forced to have sex orally, anally, or genitally when you didn't want to because someone forced you in some way or threatened to harm you if you didn't (3.17); (5) having had serious money problems, for example, not enough money for food or a place to live (3.04), and (6) having ever been sent to jail (3.02).

By way of summary, we have documented a range of adversities in the lives of women who use publicly funded mental health and substance abuse services in Dane County. We have also shown that these adversities come in clusters for women and have a considerable impact on their current lives. An important question is: Are women receiving treatment or services for these life adversities? We asked women this question and learned that 60% of women had received services or treatment at some point in their lives; 50% had received services or treatment in the past six months. Of the women who have received services, the vast majority (88%) had found the services to be moderately, considerably, or extremely helpful. Moreover, when asked: "How important is it for you to get help with these experiences now?", over 60% of the women reported that it was moderately, considerably, or extremely important to get help now. Women who used both mental health and substance abuse services were, in fact, significantly more likely than women who used mental health services only, or substance abuse services only, to feel a sense of urgency about getting help with these life adversities.

In subsequent reports, we will explore women's access to services and assess the quality of care they are receiving for their life problems, as well as investigate the impact of these life adversities on women in other ways. For now, we hope you will simply reflect on the scope of trauma in women's lives and consider how such experiences may be linked with mental health and substance abuse problems, as well as other difficulties—for women in general and for yourself in particular. You may, in fact, wish to complete the questionnaire we gave to women so you can reflect on your own experiences and reactions as you move through the curriculum. We have attached a copy of the questionnaire for you to fill out, should you wish to do so. We have also included a list of references to the articles we cite in the paper, along with other resources you may find useful.

We know that these are difficult issues to confront in one's own life. However, we believe that acknowledging these experiences, as well as sharing them with others, are important steps to take in one's personal recovery. They are also important steps to take if one is to engage in collective support and actions to address the personal assaults and indignities that women face on a daily basis. We wish you well in these efforts.

## *Table 1. Abuse Histories of Women by Location of Treatment Episodes*

| Questions[1] | Women with two or more treatment episodes in 1998 in | | | |
|---|---|---|---|---|
| | Mental Health Service System only | Substance Abuse Service System only | Mental Health and Substance Abuse Service Systems | Total ADM System |
| | Population size= 1274 | Population size = 592 | Population Size = 272 | Population size =2138[2] |
| | n = 125 | n = 56 | n = 23 | n = 204 |
| **Physical Abuse:** | | | | |
| 1. Have you ever been physically neglected, e.g. not fed, not properly clothed, or left to take care of yourself when you were too young or too ill? | 24.0 | 21.4 | 36.4 | 24.6 |
| 2. Have you ever been robbed, mugged, or physically attacked by someone you did not know? | 39.5 | 37.5 | 47.8 | 39.9 |
| 3. Were you ever physically abused, hit, slapped, choked, burned, or beat up by someone you knew, e.g. a parent, sibling, boyfriend, or girlfriend? | 66.4 | 75.0 | 87.0 | 71.1 |
| **Any physical abuse (% with yes response to 1,2,or 3):** | **83.1** | **80.4** | **91.7** | **83.3** |
| **Any childhood physical abuse:** | **45.8** | **33.9** | **60.9** | **44.2** |
| **Sexual Abuse:** | | | | |
| 4. Were you ever touched by or made to touch someone else in a *sexual way* because they forced you in some way or threatened to harm you if you didn't? | 51.2 | 58.9 | 81.8 | 56.8*[a] |
| 5. Did you ever have sex orally, anally, or genitally when you didn't want to because someone forced you in some way or threatened to harm you if you didn't? | 42.3 | 53.6 | 78.3 | 49.5**[a] |
| 6. Have you ever had sex when you did not want to in exchange for money, drugs, or other materials goods, such as shelter or clothing? | 19.7 | 28.6 | 34.8 | 23.9 |
| **Any sexual abuse (% with yes response to 4,5, or 6):** | **58.9** | **64.9** | **91.3** | **64.2**[a]** |
| **Any childhood sexual abuse:** | **15.4** | **24.1** | **45.5** | **21.1**[a]** |
| **Physical or sexual abuse:** | **89.6** | **82.5** | **95.7** | **88.3** |
| **Physical and sexual abuse:** | **52.0** | **62.5** | **87.0** | **58.8**[a]** |
| **Average number of physical and sexual abuse experiences:** | **2.41** | **2.74** | **3.63** | **2.64**[a]** |

[1] Percentages are given for women responding yes to each individual query adjusted for non-response and sample weights.

[2] Data were missing for two women.

*p≤ .05; ** p ≤ .01; *** p ≤.001.

[a] statistically significant differences between women who use mental health and substance abuse services and women who use mental health services only.

## *Table 2. Other Adversities in the Lives of Women by Location of Treatment Episodes*

| Questions[1] | Women with two or more treatment episodes in 1998 in | | | |
|---|---|---|---|---|
| | Mental Health Service System only | Substance Abuse Service System only | Both Systems | Total ADM System |
| | n= 1274<br>n = 125 | n = 592<br>n = 56 | n= 272<br>n = 23 | n=2138[2]<br>n = 204 |
| **Other Life Adversities:** | | | | |
| Childhood Traumas | | | | |
| 1. Have you ever been emotionally abused or neglected, for example, being frequently shamed, embarrassed, ignored, or repeatedly told you were "no good"? | 74.0 | 73.2 | 79.2 | 74.4 |
| 2. When you were young, that is, before age 16, did you ever see violence between family members, for example, hitting, kicking, slapping, or punching? | 64.0 | 71.4 | 78.3 | 67.6 |
| 3. Were you ever put in foster care or put up for adoption? | 7.3 | 12.5 | 26.1 | $10.9^{*a}$ |
| Adult Traumas—Child Related | | | | |
| 4. Has a baby or child of yours ever had a severe physical or mental handicap, for example, mental retardation, a birth defect, or an inability to hear, see or walk? (% of mothers) | 6.0 | 15.4 | 14.3 | 9.6 |
| 5. Have you ever been separated from your child against your will, for example through a loss of custody, or visitation or kidnapping? (% of mothers) | 25.9 | 48.7 | 64.3 | $36.2^{**a,c}$ |
| Other Adult Traumas | | | | |
| 6. Have you ever been bothered or harassed by sexual remarks, jokes, or demands for sexual favors by someone *at work or at school*, such as a co-worker, a boss, a customer, another student, or a teacher? | 44.8 | 50.0 | 63.6 | 48.3 |
| 7. Have you ever been strip-searched, forcibly restrained, or held against your will by a provider of mental health or substance abuse services? | 35.2 | 14.3 | 43.5 | $30.4^{**\,b,c}$ |
| 8. Have you ever been sent to jail? | 47.6 | 77.8 | 69.6 | $58.2^{**\,c}$ |
| 9. Have you ever had serious money problems, for example, not enough money for food or a place to live? | 70.2 | 66.7 | 78.3 | 70.1 |
| **Average number of other life adversities:** | **3.63** | **4.08** | **4.92** | **$3.90^{**\,a}$** |
| **Average number of total life adversities, including abuse experiences:** | **6.04** | **6.82** | **8.55** | **$6.54^{***\,a,b}$** |

[1] Percentages are given for women responding yes to each individual query adjusted for non-response and sample weights.

[2] Data were missing for two women. $^{*}$p≤ .05; ** p ≤ .01; *** p ≤.001.

[a] statistically significant differences between women who use mental health and substance abuse services and women who use mental health services only.

[b] statistically significant differences between women who use mental health and substance abuse services and women who use substance abuse services only.

[c] statistically significant differences between women who use substance abuse services only and women who use mental health services only.

*Table 3. Age of Onset and Impact of Abuse and Other Life Adversities on Women*

| **Abuse Histories and Other Life Adversities**[1] | Average Age of Onset[2] | How affected in past year[3] |
|---|---|---|
| Physical Abuse Experiences | | |
| 1. Have you ever been physically neglected, for example, not fed, not properly clothed, or left to take care of yourself when you were too young or ill? | 12.1 | 3.42 |
| 2. Have you ever been robbed, mugged, or physically attacked by someone you didn't know? | --- | 2.73 |
| 3. Were you ever physically abused, hit, slapped, choked, burned, or beat up by someone you knew, for example, a parent, sibling, boyfriend, or girlfriend? | 13.0 | 3.18 |
| Sexual Abuse Experiences | | |
| 4. Were you ever touched by or made to touch someone else in a *sexual way* because they forced you in some way or threatened to harm you if you didn't? | 12.7 | 3.20 |
| 5. Did you ever have sex orally, anally or genitally when you didn't want to because someone forced you in some way or threatened to harm you if you didn't? | 16.9 | 3.17 |
| 6. Have you ever had sex when you did not want to in exchange for money, drugs, or other material goods, such as shelter or clothing? | 23.3 | 3.31 |
| Other Childhood Traumas | | |
| 7. Have you ever been emotionally abused or neglected, for example, being frequently shamed, embarrassed, ignored, or repeatedly told you were "no good"? | 10.2 | 3.59 |
| 8. When you were young, that is, before age 16, did you ever see violence between family members, for example, hitting, kicking, slapping, or punching? | --- | 2.98 |
| 9. Were you ever put in foster care or put up for adoption? | --- | 2.42 |
| Adult Traumas--Child Related | | |
| 10. Has a baby or child of yours ever had a severe physical or mental handicap, for example, mental retardation, a birth defect, or an inability to hear, see or walk? (% of mothers) | --- | 2.90 |
| 11. Have you ever been separated from your child against your will, for example through a loss of custody, or visitation or kidnapping? (% of mothers) | --- | 3.75 |
| Adult Traumas--Other | | |
| 12. Have you ever been bothered or harassed by sexual remarks, jokes, or demands for sexual favors by someone *at work or at school*, such as a co-worker, a boss, a customer, another student, or a teacher? | --- | 2.39 |
| 13. Have you ever been strip-searched, forcibly restrained, or held against your will by a provider of mental health or substance abuse services? | 27.9 | 2.53 |
| 14. Have you ever been sent to jail? | --- | 3.02 |
| 15. Have you ever had serious money problems, for example, not enough money for food or a place to live? | --- | 3.04 |
| Physical Abuse Impact | | 2.99 |
| Sexual Abuse Impact | | 3.09 |
| Other Life Adversities Impact | | 2.94 |
| Total Life Adversities Impact | | 2.94 |

[1] All adversities are % yes responses.

[2] Average age of onset of was asked only for some of the queries.

[3] Average amount affected by event in past year 1 = not at all; 2 = a little bit; 3 = moderately; 4 = quite a bit; 5 = extremely.

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# Wisconsin Consumers Assess Their Services

# WISCATS II

## Stressful Life Events Questionnaire

Attached is the questionnaire that was developed for the Woman and Mental Health Study Site interviews with women. We have included it in the Consumer Curriculum so that you can administer it to yourself, if you would like.

## STRESSFUL LIFE EXPERIENCES MODULE

**Now I would like to ask you about some experiences that may be very upsetting or stressful to nearly anyone. Please think about your whole lifetime when answering the questions. If you need to take a break at any time, please do so. You should also feel free to skip any questions you prefer not to answer.**

**1. Have you ever experienced war as a soldier in direct combat, as a civilian or as a refugee?**

Yes .......................................................... 1
No .......................................................... 2 *[Go to 2]*

**A. How much has this experience affected your life in the past year?** *(circle a number)*

| | | | | | | |
|---|---|---|---|---|---|---|
| not at all | a little bit | moderately | quite a bit | extremely | DK | Refused |
| (1) | (2) | (3) | (4) | (5) | (8) | (9) |

**2. Were you ever put in foster care or put up for adoption?**

Yes.............................................................. 1
No.............................................................. 2 *[Go to 3]*

**A. How much has this experience affected your life in the past year?** *(circle a number)*

| | | | | | | |
|---|---|---|---|---|---|---|
| not at all | a little bit | moderately | quite a bit | extremely | DK | Refused |
| (1) | (2) | (3) | (4) | (5) | (8) | (9) |

**3. Have you ever been separated from your child against your will, for example through a loss of custody or visitation or kidnapping?**

Yes.......................................................... 1
No.......................................................... 2 *[Go to 4]*
*Have no children*.......................................... 8 *[Go to 4]*

**A. How much has this experience affected your life in the past year?** *(circle a number)*

| | | | | | | |
|---|---|---|---|---|---|---|
| not at all | a little bit | moderately | quite a bit | extremely | DK | Refused |
| (1) | (2) | (3) | (4) | (5) | (8) | (9) |

**4. Has a baby or child of yours ever had a severe physical or mental handicap. for example, mental retardation, a birth defect, or an inability to hear, see or walk?**

Yes.......................................................... 1
No.......................................................... 2 *[Go to 5]*
*Have no children*.......................................... 8 *[Go to 5]*

**A. How much has this experience affected your life in the past year?** *(circle a number)*

| not at all | a little bit | moderately | quite a bit | extremely | DK | Refused |
|---|---|---|---|---|---|---|
| (1) | (2) | (3) | (4) | (5) | (8) | (9) |

**5. Have you ever been sent to jail?**

Yes........................................................ 1
No......................................................... 2 *[Go to 6]*

**A. How much has this experience affected your life in the past year?** *(circle a number)*

| not at all | a little bit | moderately | quite a bit | extremely | DK | Refused |
|---|---|---|---|---|---|---|
| (1) | (2) | (3) | (4) | (5) | (8) | (9) |

**6. Have you ever had serious money problems, for example, not enough money for food or a place to live?**

Yes........................................................ 1
No......................................................... 2 *[Go to 7]*

**A. How much has this experience affected your life in the past year?** *(circle a number)*

| not at all | a little bit | moderately | quite a bit | extremely | DK | Refused |
|---|---|---|---|---|---|---|
| (1) | (2) | (3) | (4) | (5) | (8) | (9) |

**7. Have you ever been robbed, mugged, or physically attacked by someone you did not know?**

Yes........................................................ 1
No......................................................... 2 *[Go to 8]*

**A. How much has this experience affected your life in the past year?** *(circle a number)*

| not at all | a little bit | moderately | quite a bit | extremely | DK | Refused |
|---|---|---|---|---|---|---|
| (1) | (2) | (3) | (4) | (5) | (8) | (9) |

**8. Have you ever been bothered or harassed by sexual remarks, jokes, or demands for sexual favors by someone *at work or school*, such as a co-worker, a boss, a customer, another student or a teacher?**

Yes........................................................ 1
No......................................................... 2 *[Go to 9]*

**A. How much has this experience affected your life in the past year?** *(circle a number)*

|  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|
| not at all<br>(1) | a little bit<br>(2) | moderately<br>(3) | quite a bit<br>(4) | extremely<br>(5) | DK<br>(8) | Refused<br>(9) |

**9. When you were young, that is, before age 16, did you ever see violence between family members for example, hitting, kicking, slapping, punching?**

Yes........................................................ 1
No........................................................ 2 *[Go to 10]*

**A. How much has this experience affected your life in the past year?** *(circle a number)*

|  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|
| not at all<br>(1) | a little bit<br>(2) | moderately<br>(3) | quite a bit<br>(4) | extremely<br>(5) | DK<br>(8) | Refused<br>(9) |

**10. Have you ever been emotionally abused or neglected, for example, being frequently shamed, embarrassed, ignored, or repeatedly told that you were "no good"?**

Yes........................................................ 1
No........................................................ 2 *[Go to 11]*

A. How old were you when this first happened? ____________
Age

B. Over a period of how many months or years did it last? _____ months _____ Years

**C. How much has this experience affected your life in the past year?** *(circle a number)*

|  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|
| not at all<br>(1) | a little bit<br>(2) | moderately<br>(3) | quite a bit<br>(4) | extremely<br>(5) | DK<br>(8) | Refused<br>(9) |

**11. Have you ever been physically neglected, for example, not fed, not properly clothed, or left to take care of yourself when you were too young or ill?**

Yes........................................................ 1
No........................................................ 2 *[Go to 12]*

A. How old were you when this first happened? ____________
Age

B. Over a period of how many months or years did it last? _____ months _____ Years

**C. How much has this experience affected your life in the past year?** *(circle a number)*

|  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|
| not at all<br>(1) | a little bit<br>(2) | moderately<br>(3) | quite a bit<br>(4) | extremely<br>(5) | DK<br>(8) | Refused<br>(9) |

**12. Were you ever physically abused, hit, slapped, choked, burned, or beat up by someone you knew, for example, a parent, sibling, boyfriend or girlfriend?**

Yes........................................................ 1
No.......................................................... 2 *[Go to 13]*

A. How old were you when this first happened? ____________
Age

B. Over a period of how many months or years did it last? ______ months ______ Years

**C. How much has this experience affected your life in the past year?** *(circle a number)*

| | | | | | | |
|---|---|---|---|---|---|---|
| not at all | a little bit | moderately | quite a bit | extremely | DK | Refused |
| (1) | (2) | (3) | (4) | (5) | (8) | (9) |

**13. Were you ever <u>touched by</u> or made to <u>touch someone else</u> in a *sexual way* because they forced you in some way or threatened to harm you if you didn't?**

Yes........................................................ 1
No.......................................................... 2 *[Go to 14]*

A. How old were you when this first happened? ____________
Age

B. Over a period of how many months or years did it last? ______ months ______ Years

**C. How much has this experience affected your life in the past year?** *(circle a number)*

| | | | | | | |
|---|---|---|---|---|---|---|
| not at all | a little bit | moderately | quite a bit | extremely | DK | Refused |
| (1) | (2) | (3) | (4) | (5) | (8) | (9) |

**14. Did you ever have sex orally, anally or genitally when you didn't want to because someone forced you in some way or threatened to harm you if you didn't?**

Yes........................................................ 1
No.......................................................... 2 *[Go to 15]*

A. How old were you when this first happened? ____________
Age

B. Over a period of how many months or years did it last? ______ months ______ Years

**C. How much has this experience affected your life in the past year?** *(circle a number)*

| | | | | | | |
|---|---|---|---|---|---|---|
| not at all | a little bit | moderately | quite a bit | extremely | DK | Refused |
| (1) | (2) | (3) | (4) | (5) | (8) | (9) |

**15. Have you ever had sex when you did not want to in exchange for money, drugs, or other material goods such as shelter or clothing?**

Yes ........................................................ 1
No ........................................................ 2 *[Go to 16]*

A. How old were you when this first happened? ______________
Age

B. Over a period of how many months or years did it last? ______ months ______ Years

**C. How much has this experience affected your life in the past year?** *(circle a number)*

| not at all | a little bit | moderately | quite a bit | extremely | DK | Refused |
|---|---|---|---|---|---|---|
| (1) | (2) | (3) | (4) | (5) | (8) | (9) |

**16. Have you ever been strip searched, forcibly restrained, or held against your will by a provider of mental health or substance abuse services?**

Yes ........................................................ 1
No ........................................................ 2 *[Go to 17]*

A. How old were you when this first happened? ______________
Age

B. Over a period of how many months or years did it last? ______ months ______ Years

**C. How much has this experience affected your life in the past year?** *(circle a number)*

| not at all | a little bit | moderately | quite a bit | extremely | DK | Refused |
|---|---|---|---|---|---|---|
| (1) | (2) | (3) | (4) | (5) | (8) | (9) |

**17. Are there any other major life events we did not include that you would like to mention?**

Yes........................................................ 1
No........................................................ 2 *[Go to 18]*

**A. What was the event?**

A. How old were you when this first happened? ______________
Age

B. Over a period of how many months or years did it last? ______ months ______ Years

**C. How much has this experience affected your life in the past year?** *(circle a number)*

|  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|
| not at all<br>(1) | a little bit<br>(2) | moderately<br>(3) | quite a bit<br>(4) | extremely<br>(5) | DK<br>(8) | Refused<br>(9) |

**If you answered yes to any of the above life experiences, please answer the next few questions.**

**18. Have you ever received treatment or services for any of these experiences?**

|  |  |
|---|---|
| Yes……………………………………………… | 1 |
| No……………………………………………… | 2 *[Go to 20]* |

**19. Have you received treatment or services for any of these experiences in the <u>past 6 months</u> ?**

|  |  |
|---|---|
| Yes……………………………………………… | 1 |
| No……………………………………………… | 2 *[Go to 20]* |

**19a. Where?** ________________________________

**19b. Which of your experiences was a focus of your treatment?** ____________________

________________________________________________________

**20. How helpful did you find this treatment or service? Would you say *not at all, slightly, moderately, considerably, or extremely helpful*?** (please circle one number below)

|  |  |
|---|---|
| Not at all……………………… | 1 |
| Slightly……………………… | 2 |
| Moderately……………………… | 3 |
| Considerably……………………… | 4 |
| Extremely……………………… | 5 |
| Don't Know……………………… | 8 |
| Refused……………………… | 9 |

**21. How important is it for you to get help with these experiences now? (please circle one number below)**

|  |  |
|---|---|
| Not at all……………………… | 1 |
| Slightly……………………… | 2 |
| Moderately……………………… | 3 |
| Considerably……………………… | 4 |
| Extremely……………………… | 5 |
| Don't Know……………………… | 8 |
| Refused……………………… | 9 |

# Appendix 3

# Suggested Reading for Chapter 3: The Effects of Trauma in Women's Lives

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# UNDERSTANDING TRAUMA[*]

In this topic you will learn about trauma and the feelings associated with it, and how you have learned to cope with trauma in your life. This is difficult work, and may bring up some strong emotions for you. You may not want to complete the whole chapter all at once. To help ease you into (and out of) this work, we'd like to first introduce you to a simple ritual. Each time you begin and end your work, use this ritual to keep yourself focused in the present and to remind yourself of the positive aspects of your life.

## Beginning and Ending Ritual

Use this simple activity any time you are working on difficult issues. Some women like to complete this activity just prior to talking with a counselor, writing in a journal, visiting with a family member, doing some artwork related to trauma, or repeating an exercise from this book. First, write down four good things that happened to you in the last two days. They don't have to be big things-just things that made an impression on you and that were enjoyable. For instance, my list for the last two days is:

1. I saw a cute baby and she smiled at me.
2. I had a nice visit with an old friend.
3. I finished reading a heartwarming novel.
4. The sweater I put on this morning felt warm and cozy.

At the end of the session, write down two things you are looking forward to. One that is within the next few days and one in the more distant future. For example, my list would be:

1. Coming right up: buying a new kind of bread I really like at the grocery store.
2. In the future: spring-warm weather, flowers, and birds.

The purpose of this ritual is to help you stay connected with the good things in your life while you are doing this work and also to put a frame around your work so it becomes a small part of your life with a beginning and an end, not your whole life.

To begin work on this topic, write four good things that happened to you in the last two days:

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## Categorizing Your Traumas

Everyone experiences minor trauma-things that are temporarily upsetting and that may make us anxious and upset. Such things include:

- not getting an anticipated check on time,
- the car breaking down,
- missing an appointment,
- a friend being rude to you, or
- getting a cold.

Most of the time you probably get over these small traumas quickly. Below, list some minor traumas that you have experienced recently:

From time to time everyone experiences trauma that is harder to deal with and more upsetting: seeing a beloved pet hit by a car, losing a friend to a devastating illness, having your house broken into, getting divorced, or being a victim of a robbery. These experiences may cause an increase in anxiety and fears, insomnia, depression, nightmares, and flashbacks. As time goes on, the impact of these traumas tends to decrease until finally, while the person may still think of such traumas from time to time, day-to-day activities are not significantly affected.

List any of these kinds of trauma you have experienced in your life.

Unfortunately, people also experience trauma that is so horrific that it may seem almost impossible to overcome-trauma that is so awful that the symptoms persist and often overwhelm the person's life. Examples of these kinds of trauma include child abuse, sexual abuse, physical abuse, emotional abuse, being a victim of a violent crime, losing one or several close family members, or living through a war. Sometimes right after the trauma occurs, and sometimes much later, people who experience these kinds of trauma develop severe and persistent symptoms such as depression, anxiety, rage, nightmares, flashbacks, and feeling out of touch with reality. They may turn to alcohol, illegal drugs, promiscuous sex, or self-harming behaviors to try to ease the pain.

Little notice was taken of the effects of trauma, or the relationship between traumatic experiences and these kinds of symptoms, until after World War II and, more recently, the Vietnam War. In fact, people who experienced severe war trauma were (and still are) often told that they had a mental illness. After World War II, some soldiers and survivors of the Nazi concentration camps displayed serious and persistent symptoms that demanded attention. Similarly, during the Vietnam War, veterans returned from the battlefield with symptoms so serious and so obviously related to their war experiences that the effects of trauma could not be ignored. In recent years, the effects of other kinds of horrific trauma have also been recognized-yet much of the literature about trauma still reflects what we learned from soldiers, especially prisoners of war, and holocaust survivors.

We know that relieving the effects of trauma on a person's life takes very specialized treatment along with lots of persistence and courage. Activities such as the ones in this book can help you regain a sense of your power, validate your experiences, help you regain your sense of self so you can enjoy life, and relearn how to connect with others in meaningful ways.

What kinds of severe trauma have you experienced?

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## Factors That Affect Recovery and Healing

Every person responds to trauma in his or her life differently. There is no set period of time for recovery. The factors that seem to affect how long it takes to get over the effects of trauma in one's life—or at least reduce these effects so they are not controlling the person's life—include:

- personality type;
- the environment you grew up in—was it hectic and chaotic, or calm and peaceful;
- your current living circumstances;
- your general health;
- substance abuse or addictions;
- the length of your exposure to the trauma;
- the number of traumas you have experienced—even minor traumas; and
- the severity of the trauma.

No one else can determine how a trauma could or should affect someone else; do not feel that your trauma was "too small" to have had such a powerful impact.

One woman told us that she grew up in a hectic and chaotic household—small traumas were happening all the time, such as burned dinners, people yelling at each other, lots of people moving in and out. Some traumas that were harder to deal with were also happening simultaneously—she lost her favorite pet and she was involved in a serious car accident. These factors all combined to make it harder for her to deal with a serious sexual assault when she was a teen.

What factors in your life do you feel affect your healing journey?

## Sharing Feelings and Experiences

List five words that you often use to describe how you feel.

For many people, talking about the trauma helps—it's part of the healing process. You may be uncomfortable or not used to talking about it, but the inability to talk about feelings and the hard things that happen to us in our lives can make the healing process more difficult. In many families, people don't talk about trauma at all. There are a couple of reasons for this. First, family members may feel it is best to forget the bad things that have happened.

When Charlene was a little girl, her friend was killed in a very bad accident while she was playing with Charlene. Charlene's family felt it was best for her not to talk about the accident and they tried to get her to focus her attention on other things so she would forget. Charlene never forgot. As an adult she spent many years in counseling to relieve the effects of this trauma.

Many schools now offer children special programs and services when there has been a tragedy in the community to give students the opportunity to talk about the trauma and begin to heal.

A second reason for silence in families is that the family members don't want other people to find out about bad things that are happening, especially if it involves abuse. It becomes a family secret—a secret that protects the abuser and allows the abuse to go on. Family members may even be threatened to keep them from telling others what is happening, or there may be an unspoken rule in the family not to talk to anyone about certain things.

How did your family talk about feelings and other experiences?

It helps to think about the words associated with these experiences so you can think more clearly about them, write about them, and tell supportive people what happened to you.

In this exercise, you will write some words that could be used to describe feelings related to trauma. To help you think more clearly about the feelings associated with the word, think of a color that matches that feeling you are describing. (You can use the same color over and over if that feels right to you.) For example, "angry-bright red," "isolated-dark gray."

________________________________________________

________________________________________________

________________________________________________

Now make a list of ten "feeling" words that describe the trauma you experienced.

________________________________________________

________________________________________________

________________________________________________

________________________________________________

How did it feel to write and think about these words?

________________________________________________

________________________________________________

________________________________________________

________________________________________________

________________________________________________

## Coping with Trauma

When you were traumatized, especially if you were traumatized repeatedly, you figured out some ways to cope with the trauma so you could get by and still go to school, do your homework, find some peace and quiet for yourself, play, and so on without feeling the pain so much. This took a lot of strength and creativity.

One woman found some special places in the woods near her home. She called these places "camps" and spent a lot of time there reading books, playing with her dolls, day-dreaming, and watching the clouds through the treetops. She felt safe and comfortable there because nobody could find her.

Describe some ways that you learned to cope with abuse in your life.

Repeat several times, out loud if possible, "I am a strong and creative person. I used these attributes to help me get through the hard times in my life."

## Ending Ritual

Describe something you are looking forward to that will happen soon.

Describe something you are looking forward to that is happening in the more distant future.

## Optional Activities

1. Glance at the headlines in your local paper. How do you think the people in these stories might have been affected by what happened to them? Do you think these things will be easy or hard for them to "get over"?
2. Begin talking about trauma. Briefly talk to someone you trust about your trauma—a sentence or two would be fine.

   How did that feel?

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## Things to Remember Every Day

- I can talk about feelings related to trauma if I wish. Talking to others about bad things that have happened to me helps me heal.
- I am a strong and creative person—I was able to develop some ways to cope with trauma that helped me at that time. I am proud of my strength and creativity.

# THE BODY REMEMBERS WHAT THE MIND FORGETS*

## Beginning Ritual:

To begin work on this topic, write four good things that happened to you in the last two days:

________________________________________

________________________________________

________________________________________

________________________________________

## Body Memories

Usually, when we are asked about a memory most of us assume that we must search for a story of some sort. We might try to conjure up a visual image of something that happened or a place where we spent time. Thoughts, words, and images do constitute our memories, but not entirely. We also remember things in other ways, such as through sound, smell, and taste. Sometimes the smell will be all we remember—the context is lost but the smell remains.

Our bodies also have memories. A feeling, an ache, an itch—these are physical sensations, but they can also be memories. Just as our intellects remember in words, our bodies' memories are stored in sensations. That pain in your back may be because you got too much exercise, or it may be a memory of something that happened a long time ago. In some cases, there will be other memories that accompany the pain, but in other cases the pain itself will be the only memory you have.

When you were traumatized, your body responded to this severe stress by trying to protect itself. It secreted hormones and other substances that may have given you some of the strength it took to endure what you went through. But with severe and repeated trauma, the body forgets how to shut this release off. You may feel tense, irritable, anxious, and nervous all or most of the time. When this goes on for a long period of time, you develop chronic tension and pain in various parts of your body—sometimes in the part of your body that was most affected by the trauma.

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You may have so much pain that you try to ignore it. You may feel that you are really out of touch with your body and how it feels, or perhaps the discomfort and pain is so persistent that it keeps you from doing the things you want to do. With consistent use of some of the relaxation and stress-reduction exercises in this topic, you will notice that your body starts feeling better and better.

Patsy, a thirty-year-old stockbroker, felt that her body was always very tense and tight. She assumed this was normal. However, when she started getting aches and pains in her neck, shoulders, and lower back, she sought help. She began getting massages from a physical therapist, and noticed that each time she received one, her body felt more loose, flexible, and comfortable. The physical therapist explained to her the connection between the tension in her body and the trauma she experienced as a child. She now uses stress-reduction exercises she learned from the physical therapist to continue to release the tension she has held in her body for so many years.

This topic contains several exercises that, if used regularly, will gradually help you relieve the tension in your body. Most people notice they feel much better each time they do a relaxation and stress-reduction exercise. Occasionally people report that while engaging in a relaxation exercise they suddenly feel overwhelmed by very uncomfortable feelings in their bodies. If this happens to you, open your eyes right away and stare at something that you really like to look at (a book, a plate, a pet, and so on) for several moments until the uncomfortable feelings go away. If this happens to you often, you could keep your collection near or in the place where you do these exercises so you can look at them when these feelings come up, and when you feel better you can either return to the exercise or leave the work until another time. (Don't forget to do your closing ritual before leaving your work for the day!)

Repeat the exercises in this chapter that feel good to you as often as possible—make them an important part of your life.

## Body Scan

Read this exercise before you do it and then do it from memory—trying to read it as you are doing it will be too distracting.

Relax comfortably in a chair or lie down—whichever feels better to you. Loosen any tight clothing. Take three deep breaths. Notice how your body feels in the space it is in. Notice how your body feels as it comes in contact with the chair, or the floor or ground. Notice how your clothes feel on your body. Now pretend you have a searchlight. Use that searchlight to search inside your body to find places that feel relaxed. Spend a few moments focusing on each of these places. Next, use the searchlight to find places where your body feels tense or uncomfortable. Spend a few moments focusing on each of these places.

Where in your body did you feel comfortable and relaxed?

________________________________________________

______________________________________________

______________________________________________

Where did you feel tense?

______________________________________________

______________________________________________

______________________________________________

Why do you think you feel tense and uncomfortable in this part of your body? Do you feel it has to do with something that is going on now, such as stress at work or carrying a heavy object, or do you think it has to do with something that happened in your past?

______________________________________________

______________________________________________

______________________________________________

You may have had this tension or discomfort in your body for many years. It may have affected the way you sit, stand, and walk.

One woman noticed that she had a lot of tension in the upper part of her chest. Sometimes the pain became quite sharp and debilitating and she actually needed to hunch over to relieve it. Medical testing didn't show any problem. She remembered that the pain in her chest began when she was very young, when she felt afraid of the older boy in her neighborhood who frightened and hurt her.

You may not know why these places in your body feel the way they do. Fortunately, it is not necessary to know where the tension came from in order to release it.

Now that you have identified the places in your body that need help, try the exercises that follow. With practice, your body will begin to change the way it responds to the things that happen (and happened) to you.

## Tension Releasing

Again, read the exercise before you begin, then put the book aside. This should take about five minutes. Play soft music in the background if you wish.

Choose one of the problem areas of your body to focus on. Explore that part of your body in detail with your mind. Ask yourself, "What are the sensations in this part of my body? How does it move?" Let this part of your body relax completely. Using your mind, imagine softness and warm light flowing into this part of your body.

How did you feel before you did this exercise?

____________________________________________________________

____________________________________________________________

How did you feel after you did this exercise?

____________________________________________________________

____________________________________________________________

Repeat this exercise as often as possible, focusing one at a time on each part of your body that is tense and uncomfortable. Do this exercise whenever you have a few free moments—before you go to sleep at night, if you awaken and have a hard time getting back to sleep, when you are taking a short break from your work.

## Progressive Relaxation

Through teaching you to systematically tense and then relax muscle groups of your body, this exercise will help you learn to relax various parts of your body and help you understand how relaxation feels. Again, read the exercise before you begin, then put the book aside and do it from recall. Or, you might want to make a tape recording of this exercise—reading it into the microphone with soft music in the background. Be sure you leave yourself plenty of time on the tape to tense and relax your muscles. You could also have a good friend or counselor read it to you.

Always do this exercise in a quiet space where you will not be disturbed. You can do it either lying on your back or sitting in a chair, as long as you are comfortable.

Close your eyes. Clench your right fist as tightly as you can. Be aware of the tension as you do so. Keep it clenched for a moment. Now relax. Feel the looseness in your right hand and compare it to the tension you felt previously. Tense your right fist again, then relax it. Again, notice the difference.

Now clench your left fist as tightly as you can. Be aware of the tension as you do so. Keep it clenched for a moment. Now relax. Feel the looseness in your left hand and compare it to the tension you felt previously. Tense your left fist again, relax it, and again notice the difference.

Bend your elbows and tense your biceps as hard as you can. Notice the feeling of tightness. Relax and straighten out your arms. Let the relaxation flow through your arms and compare it to the tightness you felt previously. Tense and relax your biceps again.

Wrinkle your forehead as tightly as you can. Now relax it and let it smooth out. Feel your forehead and scalp becoming relaxed. Now frown and notice the tension spreading through your forehead again. Relax and allow your forehead to become smooth.

Close your eyes now and squint them very tightly. Feel the tension. Now relax your eyes. Tense and relax your eyes again. Now let them remain gently closed.

Now clench your jaw. Bite hard and feel the tension through your jaw. Now relax your jaw. Your lips will be slightly parted. Notice the difference. Clench and relax again.

Press your tongue against the roof of your mouth. Now relax. Do this again.

Press and purse your lips together. Now relax them. Repeat this.

Feel the relaxation throughout your forehead, scalp, eyes, jaw, tongue, and lips.

Hold your head back as far as it can comfortably go and observe the tightness in your neck. Roll it to the right and notice how the tension moves and changes. Roll your head to the left and notice how the tension moves and changes. Now straighten your head and bring it forward, pressing your chin against your chest. Notice the tension in your throat and the back of your neck. Now relax and allow your shoulders to return to a comfortable position. Allow yourself to feel more and more relaxed. Now shrug your shoulders and hunch your head down between your shoulders. Relax your shoulders. Allow them to drop back and feel the relaxation moving through your neck, throat, and shoulders; feel the lovely, very deep relaxation.

Give your whole body a chance to relax. Feel how comfortable and heavy it is.

Now breathe in and fill your lungs completely. Hold your breath and notice the tension. Now let your breath out and let your chest become loose. Continue relaxing, breathing gently in and out. Repeat this breathing several times and notice the tension draining out of your body.

Tighten your stomach and hold the tightness. Feel the tension. Now relax your stomach. Now place your hand on your stomach. Breathe deeply in your stomach, pushing your hand up. Hold for a moment and then relax. Now arch your back without straining, keeping the rest of your body as relaxed as possible. Notice the tension in your lower back. Now relax deeper and deeper.

Tighten your buttocks and thighs. Flex your thighs by pressing your heels down as hard as you can. Now relax and notice the difference. Do this again. Now curl your toes down, making your calves tense. Notice the tension. Now relax. Bend your toes toward your face, creating tension in your shins. Relax and notice the difference.

Feel the heaviness throughout your lower body as the relaxation gets deeper and deeper. Relax your feet, ankles, calves, shins, knees, thighs, and buttocks. Now let the relaxation spread to your stomach, lower back, and chest. Let go more and more. Experience deeper and deeper relaxation in your shoulders, arms, and hands, deeper and deeper. Notice the feeling of looseness and relaxation in your neck, jaws, and all your facial muscles. Now just relax and be aware of how your whole body feels before you return to your work in this book.

How did you feel before you did this exercise?

____________________________________________________

____________________________________________________

How did you feel after you did this exercise?

____________________________________________________

____________________________________________________

Here are some other ways that will help you release feelings and relax your body or specific parts of your body.

- If you can afford it, have a regular massage with a certified massage therapist.
- Take a warm bath as often as possible. If you wish, scent the water with lavender oil or some other scent that you find calming and relaxing.
- Gently rub parts of your body. If it feels comfortable, ask a friend or your partner to do this for you.
- Learn yoga. There are many good books that will teach you how to stretch and relax your body.
- Drink a cup of soothing herbal tea such as chamomile.
- Eat dairy foods, turkey, and leafy green and yellow vegetables—they contain calcium and will help you relax.
- Avoid foods that contain caffeine—coffee, black tea, soda, and chocolate—as they will make you feel more anxious.
- Avoid using alcohol or drugs to help you feel more relaxed and comfortable. While it may help briefly, it will make things much worse in the long run.

## Dealing with Unusual Feelings, Sensations, and Responses

You also may have noticed that you have unusual feelings, sensations, and responses to certain events. For instance, if you see a car of a certain make and color, you may feel a sense of fear and dread. If a person you love speaks to you in a certain way, you may recoil in horror though what they said was perfectly acceptable. This is another example of the body remembering what the mind has forgotten. Your body is responding to situations, circumstances, and events that happened in the past. It is responding in ways that are no longer necessary and that interfere with your life, sometimes making you and others feel bad.

Describe some times when you have noticed unusual feelings, sensations, and responses to certain everyday events.

________________________________________________________________

________________________________________________________________

________________________________________________________________

________________________________________________________________

As you become aware of these situations, you can respond in ways that will help you feel better quickly and help you respond appropriately to the actions of others. Try getting in the habit of responding to these feelings in one or more of the following ways.

- Stop what you are doing. Breathe in slowly and deeply, paying close attention to your breath. Let the breath out very slowly, again paying close attention. Do this three or four more times. Notice the feeling of relaxation in your body after you do this.
- Do a reality check. Ask yourself the following questions:
    1. What is really going on here? Is this response helping or is it making the situation worse?
    2. Are my feelings or is my response really appropriate to the situation, or is it based on something I learned in the past that is no longer applicable?
- Count to ten, or even a hundred.
- Take time out and do something you really enjoy—read a chapter in a good book, play with your dog, listen to a musical piece you like, or draw a picture.
- Talk to a friend about what happened.

List other ways you have discovered to respond to unusual feelings, sensations, and certain events.

________________________________________________________________

________________________________________________________________

## Ending Ritual

Describe something you are looking forward to that is happening soon.

Describe something you are looking forward to that will happen in the more distant future.

## Optional Activity

Get a book on relaxation and stress-reduction techniques. Practice the exercises that are described, and make tape recordings of these that you find to be particularly helpful. For three titles that we especially like, see the Relaxation and Stress Reduction section of the Resources list at the back of this book.[1]

## Things to Remember Every Day

- I can teach my body new ways of responding to feelings, sensations, and events in my life.
- I am in charge of my responses.

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[1] This is referring to the Copeland & Harris book, not the *NPW Consumer Curriculum*.

# WHAT IS POST-TRAUMATIC STRESS DISORDER (PTSD)?*

## Introduction

There is a growing awareness among healthcare providers that traumatic experiences are widespread and that it is common for people who have been traumatized to develop medical and psychological symptoms associated with the experience.

Recent studies have shown that childhood abuse (particularly sexual abuse) is a strong predictor of the lifetime likelihood of developing PTSD. Although many people still equate PTSD with combat trauma, the experience most likely to produce PTSD is rape. PTSD is associated with an extremely high rate of medical and mental health service use, and possibly the highest per-capita cost of any psychological condition.

But there is help and there is hope.

PTSD is a long-term problem for many people. Studies show that 33-47 percent of people being treated for PTSD were still experiencing symptoms more than a year after the traumatic event. Without treatment many people continue to have PTSD symptoms up to ten years after the traumatic event.

## What are the symptoms of PTSD?

PTSD symptoms are divided into three categories. People who have been exposed to traumatic experiences may notice any number of symptoms in almost any combination. However, the diagnosis of PTSD means that someone has met very specific criteria. The symptoms for PTSD are listed below.

***Intrusive Re-experiencing.*** People with PTSD frequently feel as if the trauma is happening again. This is sometimes called a flashback, reliving experience or abreaction. The person may have intrusive pictures in his/her head about the trauma, have recurrent nightmares or may even experience hallucinations about the trauma. Intrusive symptoms sometimes cause people to lose touch with the "here and now" and react in ways that they did when the trauma originally occurred. For example, many years later a victim of child abuse may hide trembling in a closet when feeling threatened, even if the perceived threat is not abuse-related.

***Avoidance.*** People with PTSD work hard to avoid anything that might remind them of the traumatic experience. They may try to avoid people, places or things that are reminders, as well as numbing out emotions to avoid painful, overwhelming feelings. Numbing of thoughts and feelings in response to trauma is known as

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"dissociation" and is a hallmark of PTSD. Frequently, people with PTSD use drugs or alcohol to avoid trauma-related feelings and memories.

***Arousal.*** Symptoms of psychological and physiological arousal are very distinctive in people with PTSD. They may be very jumpy, easily startled, irritable and may have sleep disturbances like insomnia or nightmares. They may seem constantly on guard and may find it difficult to concentrate. Sometimes persons with PTSD will have panic attacks accompanied by shortness of breath and chest pain.

## Who gets PTSD?

PTSD can affect anyone at any age who has been exposed to a traumatic event where he/she experienced terror, threat (or perceived threat) to life, limb or sanity and his/her ability to cope was overwhelmed. Conservative estimates show that nine-ten percent of the general population has PTSD. Among people who were victims of specific traumatic experiences (rape, child abuse, violent assaults, etc.), the rate of PTSD is 60-80 percent.

## Diagnosis

Unfortunately, it is common for those with PTSD to avoid treatment. Also, it is common for those who do seek treatment to be misdiagnosed. Because PTSD often occurs at the same time as other physiological and mental health disorders, PTSD symptoms may be masked or difficult to identify. Examples of common co-occurring conditions are depression, substance use/dependence and bipolar disorder. Trauma survivors may also experience headaches, chest pain, digestive or gynecological problems as well. However, there is a growing number of clinicians who are skilled at recognizing PTSD and still others who are specializing in treatment of traumatic stress disorders. If you think you might have PTSD you should seek professional help for a thorough physical and mental health assessment.

## Can PTSD be treated?

Yes. A person who has survived a traumatic event will probably never feel as if the event didn't happen, but the disruptive, distressing effects of PTSD are completely treatable. Depending on the source of the trauma (manmade vs. natural), the nature of the trauma (accidental vs. purposeful), and the age of the victim at the time of the trauma, treatment strategies may vary. Treatment involves both managing symptoms and working through the traumatic event. Most experts agree that psychotherapy is an important part of recovery. Medications can help reduce some symptoms allowing psychotherapy to be more effective.

## Where can I get more information?

Sidran Institute for Traumatic Stress Education and Advocacy is the only national nonprofit, charitable organization specifically devoted to providing mental health information and referral services, technical assistance, resources, publications, and education to survivors of psychological trauma, their supportive family members and mental health care service providers. Our mission is to support trauma survivors through advocacy, education and research.

The Sidran Press publishes books and educational materials on traumatic stress and dissociative conditions. New in 2002, *The Essence of Being Real: Relational Peer Support for Men and Women who Have Experienced Trauma* gives survivors a framework for developing peer support groups that facilitate hope and the power of relationships. *Growing Beyond Survival: A Self-help Toolkit for Managing Traumatic Stress* is a symptom management workbook for trauma survivors. Recent titles include the *Risking Connection* trauma training curriculum for mental health providers and workbooks *Managing Traumatic Stress through Art* and *The Way of the Journal*.

The Sidran Bookshelf on Trauma and Dissociation is an annotated mail order catalog of the best in clinical, educational, and survivor-supportive literature on post-traumatic stress and dissociative conditions and related subjects. The catalog is available online.

Sidran Education and Training Services provide professional and survivor training on many trauma-related topics, including Trauma Symptom Management. We will be glad to customize presentations for the specific needs of your agency. Sidran has also developed educational workshops on the psychological effects of severe trauma for a variety of audiences.

# WHAT ARE TRAUMATIC MEMORIES?*

## Introduction

Recent debates between differing schools of scientific thought, fueled by the media and by lay organizations with varied political agendas, have left the public confused and misinformed regarding the nature of traumatic memories. This confusion is causing great distress to many people who are survivors of child abuse and those who care about them.

The purpose of this brochure is to reach beyond the hype of popular media and the rhetoric of single-purpose organizations to clarify the issues and to discuss the body of knowledge agreed upon by most mental health professionals about traumatic memories and their retrieval.

There is strong documentation to prove the high incidence of child abuse in the general population. Sexual abuse of children and adolescents is known to cause severe psychological and emotional consequences. Adults who were sexually abused in childhood are at higher risk for developing a variety of psychiatric disorders, including dissociative disorders (such as dissociative identity disorder/multiple personality disorder), anxiety disorders (panic attacks, etc.), personality disorders (borderline personality disorder, etc.), mood disorders (such as depression), PTSD, and addictions.

In order to understand the essential issues about traumatic memory, one must first understand the human mind's response to a traumatic event.

## What is trauma, and how do people cope with it?

Psychological "trauma" is defined by the American Psychiatric Association as "an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others." Examples include military combat, violent personal attack, natural or manmade disasters, and torture. For children, sexually traumatic events may include age inappropriate sexual experiences without violence or injury (DSM IV, p. 424).

Like adults who experience trauma, children and adolescents who have been abused cope by using a variety of psychological mechanisms. One of the most effective ways people cope with overwhelming trauma is called "dissociation." Dissociation is a complex mental process during which there is a change in a person's consciousness which disturbs the normally connected functions of

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identity, memory, thoughts, feelings and experiences (daydreaming during a boring lecture is a good example).

## How does trauma affect memory?

People may use their natural ability to dissociate to avoid conscious awareness of a traumatic experience while the trauma is occurring, and for an indefinite time following it. For some people, conscious thoughts and feelings, or "memories," about the overwhelming traumatic circumstance may emerge at a later date. This delayed retrieval of traumatic memories has been written about for nearly 100 years in clinical literature on military veterans who have survived combat.

In fact, in Post Traumatic Stress Disorder (PTSD), a psychiatric diagnosis common among people who have survived horrific events, the defining diagnostic features are memory distortions. People with PTSD inevitably experience extremes of recall regarding traumatic circumstances: intrusive memories of the event (hypernesia) or avoidance of thoughts and feelings about the event (amnesia).

> Some people say they are "haunted" by memories of traumatic experiences which intrude on and disrupt their daily lives. They often can't get the "pictures" of the trauma out of their heads. They may have recurring nightmares, "flashbacks," or they may even relive the trauma as if it was happening in present time.

It is also common for traumatized people to make deliberate efforts to avoid thoughts or feelings about the traumatic event and to avoid activities or situations which may remind them of the event. In some severe cases, avoidance of reminders of the trauma may cause a person to have "dissociative amnesia," or memory blanks for important aspects of the trauma.

## *Why do some people undergoing extreme stress have continuous memory and others have amnesia for all or part of their experience?*

There are several factors which influence whether a traumatic experience is remembered or dissociated. The nature and frequency of the traumatic events and the age of the victim seem to be the most important. Single-event traumas (assault, rape, witnessing a murder, etc.) are more likely to be remembered, but repetitive traumas (repeated domestic violence or incest, political torture, prolonged front-line combat, etc.) often result in memory disturbance. The extremely stressful experiences caused by natural or accidental disasters (earthquakes, plane crashes, violent weather, etc.) are more likely to be remembered than traumatic events deliberately caused by humans (i.e. incest, torture, war crimes). People who are adults when they experience traumatic events are less likely to dissociate conscious memories of the events than children who experience trauma. Research shows that the younger the child is at a time of the trauma, the less likely the event will be remembered.

Case studies show that traumatic events in which there is pressure towards secrecy are more likely to induce forgetting as a dissociative defense. For example, a woman who is brutally attacked by a stranger but who receives sympathy, family support, and many opportunities to tell her story, may suffer from PTSD, but is unlikely to develop amnesia for the event. However, a young girl who endures repeated incest with her father and has been sworn to secrecy will more likely have memory impairment for the abuse.

| **Factors Influencing Continuous Memory** | **Factors Influencing Dissociation/Amnesia** |
|---|---|
| *Single traumatic event* | *Multi-event (repetitive)* |
| *Natural or accidental cause* | *Deliberate human cause* |
| *Adult victim* | *Child victim* |
| *Validation and support* | *Denial and secrecy* |

Clinical evidence indicates that the population most likely to develop amnesia for traumatic experiences consists of child victims coerced into silence about repetitive, deliberately caused trauma such as incest or extra-familial physical, emotional, or sexual abuse. Another factor that contributes to memory disturbances is the double-bind felt by children trying to make sense of living in abusive relationships on which they depend for nurturance. Doctors or therapists can have an indication of dissociative amnesia if there are gaps or blank periods in a person's autobiographical memories.

## What is known about how memories work?

Human memory is a complex operation. Although there is still much to learn about how memories work, scientists generally understand and accept that there are four stages of memory: intake, storage (encoding), rehearsal, and retrieval. Each of these processes can be influenced by many factors such as developmental stage, setting, expectation, post-event questioning, etc. Even the conditions at the time of the telling of a memory can change the form of the memory, influencing its content and belief in the truth of the memory in the future.

Most scientists also agree that there are two identified forms of memory: explicit and implicit. Explicit memory, also called declarative or narrative memory, is the ability to consciously recall facts or events. This is the form of memory used, for example, when a person recounts the events of his or her day at work or school. Implicit memory, also called procedural or sensorimotor memory, refers to behavioral knowledge of an experience without conscious recall. A person who demonstrates proficiency at reading but who cannot remember how he or she learned the skill is an example of implicit memories in the absence of explicit memories.

## Why are traumatic memories controversial?

There are differing schools of thought, grounded in solid research and clinical experience, about the reliability of memory. The details of this scientific debate are often obscure, and the subtleties can be confusing to the public.

Some researchers have proven in the laboratory that ordinary or slightly stressful memories are easily distorted. These scientists are concerned that therapists may be unintentionally distorting the memories of people who report histories of traumatic abuse. This is of particular concern to scientists studying the effects of hypnosis on eyewitness testimony because there is laboratory evidence that setting and expectation can "contaminate" a person's memories.

However, this laboratory research on ordinary memory may be irrelevant in regard to memories of traumatic experiences. Scientists argue that traumatic memories are different from ordinary clinical memories in the way they are encoded on the brain. There is evidence that trauma is stored in the part of the brain called the limbic system, which processes emotions and sensations, but not language or speech. For this reason, people who have been traumatized may live with implicit memories of the terror, anger, and sadness generated by the trauma, but with few or no explicit memories to explain the feelings. Trauma clinicians believe that implicit memories are not easily distorted. It would, of course be unethical to create in a laboratory setting the traumatic experiences necessary to study traumatic memories and their ease of contamination or distortion. For this reason, our knowledge of traumatic memories must come from clinical experience. Clinical data since 1919 has shown a direct correlation between trauma and amnesia or other memory disturbance (van der Kolk, 1994).

## What about memory retrieval long after the trauma?

Sometimes a current event or experience may trigger long-forgotten memories of earlier trauma. Often when this happens, the person may be "flooded" with implicit sensorimotor memory: he or she may have just the picture, the feeling, the physiological panic aroused by the memory of the traumatic event without the facts that would explain the meaning of the sensations. Initially, the person may not even be aware of what has triggered the memory, or how the pictures and feelings relate to his or her life.

There is often intense psychological distress when a person is exposed to events which in some way resemble or symbolize the past trauma. These "triggers" may be any sound, smell, or other stimulus such as hot, humid weather which may remind a veteran of his service in southeast Asia, or the smell of a particular cologne which was worn by an abuser.

## Can I believe my memories?

At this time, there is no completely accurate way of determining the validity of abuse reports without external corroboration, and that kind of corroboration is often impossible. Many things -- questioning (especially of young children), suggestion by a trusted person, even the recounting of a traumatic experience in therapy -- may influence the accuracy of abuse memories. Even people who have documented corroboration about their abuse may have inconsistent elements in their stories.

Nevertheless, trauma specialists such as Harvard's Dr. Bessel van der Kolk believe that "the body cannot lie." If a person spontaneously sees a flashback and feels terrified, the feeling can be trusted, especially before an implicit memory has been discussed and possibly contaminated. If the person has the symptoms of PTSD, or a dissociative disorder that is known to be associated with a traumatic history, then it is likely that there are real traumatic experiences in the person's background. Unless one is preparing for a criminal investigation, the exact authenticity of a specific memory may not be important.

It is the job of the individual to figure out his or her own life history. Many people with post-traumatic stress or dissociative disorders have found it helpful to gather information from siblings or other family members to help them understand their memories.

## What can I expect from therapy?

A therapist can help by showing a person how to put these memories in the context of other psychological symptoms, and guide them in the process of getting on with their lives. A good therapy situation is a collaborative effort in which the client can feel comfortable taking the lead; a competent therapist may inquire about but generally does not suggest an abuse history. Uncovering memories is only one step in the process of healing from trauma. Other therapy goals may include learning to live with feelings, handling anger, dealing with cognitive distortions, ending a cycle of repeated victimization, etc.

A client should feel comfortable about the relationship with a therapist, and feel free to make decisions about the direction and pacing of treatment. A good therapist is willing to be flexible. Ultimately, the decision about whether or not specific memories are valid is the responsibility of the client.

If you have been diagnosed with a dissociative disorder or PTSD, it would be most helpful to see a therapist with a specialty in these areas. Names of therapists who have experience treating trauma survivors are available through the Sidran Foundation. To practice their specialty, therapists should have a license from the state in which they work. If you have doubts about the progress of your therapy, seek a second opinion from a well-credentialed expert.

## What about hypnosis?

The use of hypnosis in trauma therapy is quite common and careful use of hypnotherapy can be helpful but it also can be problematic if used imprudently. Many people think that memories recovered while under hypnosis are more valid than memories retrieved under other circumstances. However, research has shown that hypnotically-retrieved memories may be more prone to distortion.

One of the best uses of hypnosis in trauma therapy is for stabilization: to help a person focus on tasks of daily functioning, and to manage the pain of traumatic memories. People with dissociative disorders often find hypnotherapy helpful in fostering cooperation between dissociated parts or alters.

The uncovering of forgotten memories needs to occur in the larger context of treatment for psychiatric distress or disability. For some people, hypnosis may not be necessary at all. It is, however, generally not appropriate to use hypnotherapy as a "digging tool" to find out if a person has been traumatized.

Any client whose therapist suggests the use of hypnosis should be an informed consumer and ask about the purposes of this type of therapy. A good therapist will get informed consent (preferably in writing) from a client before beginning any course of treatment, including hypnotherapy. This means that before hypnosis is used, the client will be informed of the purposes, benefits, and risks of, and alternatives to this type of treatment, and will (without coercion) agree to its use.

## What do I do if I can't remember?

Not all abuse or trauma survivors can clearly remember their traumatic experience/s. Some individuals have only a vague recollection of "something" happening; others can't recall anything traumatic occurring in their lives at all. Traumatic stress symptoms can be extremely distressing for people who have no concrete trauma memories to explain what they are feeling. Common thoughts may include:

- "I can't feel this way for no reason."
- "No one will believe how I feel if I can't explain what happened to me."
- "I am afraid I will never remember."

Even before you begin to tackle the issue of traumatic memories, the first critical aspect of your therapeutic work will be to stabilize your current functioning. Memory loss related to traumatic experiences may serve as a protective function, which should be respected. "Digging up" the past will not alleviate your current difficulties. There is no such thing as a "quick fix" or "skipping steps" when it comes to healing from trauma. Without first establishing the necessary framework for a healthy lifestyle and level of functioning in the present, the challenges of coping with and integrating memories of past trauma may further add to your current difficulties and symptoms.

Therefore, it is highly valuable to first work on your present life issues, the problems that you can more readily identify and address. This will provide you with a solid foundation for further therapeutic work dealing with possible traumatic memories.

If you are struggling with memory disturbances related to trauma or abuse, it is important for you to know you are not alone in this experience and you are not "going crazy." Here are some helpful things to keep in mind:

- Recognize that there *is* a reason for your current difficulties; your "symptoms" are meaningful. They did not come from "nowhere."
- Trust in your own process and timing.
- Find a treatment provider with whom you can establish a safe and trusting therapeutic relationship.
- Acknowledge the idea that symptoms of traumatic stress (such as nightmares or "flashbacks") should not be used to determine the exact nature of the trauma that may be causing your memory disturbances. Beware of drawing conclusions based on the types of symptoms you are presenting. This precaution in no way diminishes the value of your past and present story but is intended to strengthen the authenticity of your symptoms and experiences.

Just as it takes time to build strong foundations of trust and deep roots of connection in relationships with others, so too must you establish these elements internally to strengthen an inner connection within yourself. This will greatly support the work you do both therapeutically and individually.

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# SCHIZOPHRENIA, TRAUMA AND RECOVERY*

A lot of people including many professionals believe that a person who has the diagnosis of Schizophrenia primarily just needs treatment with psychotropic medication to stabilize. But there is a growing body of knowledge to the affect that many symptoms of schizophrenia; hallucinations, paranoia, self-destructive delusional systems, and bizarre behavior may have roots in traumatic experience. We are learning that trauma can cause chemical changes in the brain and a wide range of mental health symptoms. And we need to recognize the value of trauma counseling and educational services for people who are diagnosed Schizophrenic.

Let me share the story of B. He carried the diagnosis of Schizophrenia when I met him. His symptoms included hearing voices, visual hallucinations, frequent catatonic periods, and violent behavior such as brandishing a knife at caregivers while in a trance state, a history of suicide attempts, and long-term psychiatric hospitalization. Soon after engaging in supportive counseling B began to share a complex delusional system, which incorporated the voice and presence of a dominating person. Additionally, the story of many years of childhood sexual and physical abuse by multiple perpetrators began to unfold as well as multiple sexual abuse experiences suffered while an in-patient in psychiatric hospitals. As the therapy progressed the delusional dominator began to be less intrusive and was eventually integrated as part of my client's personality. Through eight years of therapy my client's diagnosis changed from Schizophrenia to Post Traumatic Stress Disorder (PTSD) and finally to Adjustment Disorder - (adjusting to being healthy and independent). This client, while meeting diagnostic criteria of Schizophrenia, would have been able to receive more appropriate therapy had someone explored his trauma issues years earlier and used a PTSD diagnosis instead.

Even those who have correctly been diagnosed with Schizophrenia, because of their vulnerability socially, often have layers of trauma and abuse to cope with. That is why it is time to move to a recovery model of mental health treatment. With the support and appropriate counseling many seriously mentally ill people are recovering to greater extents than was ever thought possible.

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*Ellen Magee, MSW (2002). Written for the *New Partnerships for Women Consumer Curriculum.* The author grants permission to reprint this article. Citation of the source is appreciated.

# SIV: ROOTS AND REASONS*

This editorial of THE CUTTING EDGE explores the reasons Self-Inflicted Violence (SIV) exists in the lives of many women, and identifies some of the most common "triggers" experienced for self-injury. Many of your shared thoughts and experiences have clarified both the complexity as well as the simplicity of SIV. SIV, in the simplest perspective, is a method of managing extreme discomfort. The discomfort takes many forms and, therefore; the specific triggers for SIV are varied and sometimes convoluted. It may take some time for one person's reasons for SIV to be made clear. The primary thought that SIV is a tool for managing intense difficulties, however, remains as the basis for its existence.

One of the most commonly given purposes for SIV is the relief it provides from intense and very uncomfortable emotions. The most public figure to discuss SIV, the late Princess Diana of Wales, said that she cut herself "because I was in so much pain." Feelings of terror, rage, despair and grief may be experienced as psychically insurvivable and are, therefore, experienced as threatening to survival. Indeed, people who suicide often state that unbearable emotions precipitated their deaths. SIV provides a short-circuit to these emotional states—the self-injury brings about a shift in focus and the experience of diminished emotional intensity. A preferable feeling of numbness is oftentimes the result of SIV when it is used to cope with emotional pain. Indeed, it is not unusual to learn that many women living with SIV feel strongly that using SIV as means of coping with such profound internal turmoil has kept them from committing suicide. This is a very different perspective from the one held by some mental health professionals that SIV is a form of "mini-suicide" or a "suicidal gesture."

Managing anger, fury, or rage can be difficult for many women living with SIV. SIV disperses those feelings by directing them at oneself rather than an external person. Oftentimes people fear their own natural and very human potential for violence when they have feelings of great anger. For those who fear their own potential, SIV may be an ethically preferred means of dispersing the emotion. This is by no means an insinuation that women living with SIV are prone to violence. Rather, very few women living with SIV are violent. However, many of us are fearful of the emotions that precede violence in others and utilize the SIV to manage emotions that even hint at violence.

Self-hatred is also, unfortunately, not an uncommon experience for women living with SIV, and self-injury may serve as a means of expressing it. An unrealistic self-image and self-expectations may predispose someone to perfectionist standards that they cannot possibly meet. When expectations are not met, self-hatred can be triggered. That self-hatred can then serve as a trigger for SIV. For example, anger at oneself for a mistake can feel resolved by a punch to the head. The tension of the mistake triggers the self-hatred and shame, the SIV resolves the difficult emotions, and the person can then go on. This self-hatred is also often triggered by feelings of

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* Ruta Mazelis, Fall, 1998. The Cutting Edge, 9, 3(35): 1-8. For more information email rutamaz@eohio.net.

profound shame and guilt, whether realistic or not. Shame is perhaps the most painful human emotion and can easily trigger SIV when it is experienced.

Increasing stress, the feeling of internalized pressure, is also diminishable with SIV. Because of trauma and its resultant need for safety, a survivor scrutinizes her environment diligently and frequently. On a daily basis this results in a high stress level, and is common among women living with SIV. As such, one is susceptible to triggers from the past accompanied by a consistent feeling of tension in the present. Alertness in the abuse survivor, once necessary for safety in the past, becomes overwhelming and stressful when carried into the present. SIV serves to diminish the stressful buildup.

Whereas SIV is used as a coping mechanism to manage excruciating emotional states, it can also serve to alter feelings of profound numbness or deadness. Clinically known as dissociation, many women living with SIV experience a sense of strong detachment from themselves. They may feel disconnected from their physical bodies, and turn to SIV to "reattach" to them. A woman who cuts herself to the point of drawing blood uses the reality of the blood to recognize her physical self, to know that the body she has cut is truly her own. This process can seem oppositional to the one occurring when SIV is used to ameliorate feelings. SIV seems to be an effective tool for managing dissociation in both directions—to facilitate it when emotions are overwhelming, as well as to diminish it when one feels too disconnected from oneself and the world.

SIV can also be one of the ways a woman attempts to communicate her internal pain to the outside world when she is unable to express herself verbally. As Janice McLane has written, SIV can serve as "a voice on the skin." This is very different from the perspective traditionally held by the mental health community that SIV is a simple "attention-seeking" behavior. In reality, most women who live with self-injury are extremely secretive about it, and fearful and ashamed of its existence. This is far different from the perception of us as wild bleeding women who are desperate for attention whatever form it may take. Actually, the "attention" often given to those living with SIV is usually harmful and often brutal. Exposing one's life as including SIV puts woman at risk of being forcibly hospitalized, restrained, secluded, and/or medicated. This is not the form of attention people desire. Rather it is punishment for a behavior seen to be both superficial and horrific at the same time. Communicating via SIV may be the only avenue a woman has. Self-injury can let us, and those we choose to tell about it, know that we are suffering and are having a very difficult time expressing or externalizing that suffering.

Trauma itself can be communicated via SIV, particularly the trauma of abuse. Those consciously unaware of previous abuse in their lives may find it surfacing later on, when they are emotionally safer, in the form of re-enactments. For example, a woman who was beaten by her father for expressing anger towards him may find herself punching herself in the face when she feels anger towards a man in an authoritarian position. She may not be aware of the connection between the past and the SIV in the present. Many women living in with SIV fear for their sanity until they become aware of the connection between SIV in the present and trauma in the past.

Survivors of rape and other forms of sexual abuse, including sexual harassment, may self-injure the parts of their bodies that they hold "accountable" for the abuse, or that feel "dirty" as a result of it. It is common for women to turn on themselves, as, especially when sexual abuse occurs at a young age, their perpetrators tell them the abuse is their fault. If a girl is told that she was raped because she "looked sexy," then it is understandable that she may later hold those parts of her body accountable for the abuse. Some women then either punish their bodies, especially their breasts and vagina, or re-enact the abuse in an attempt to better manage the complex emotions resulting from it.

Abuse survivors commonly experience flashbacks of their abuse experiences. These are often unwanted global or fragmented memories of the traumatic events, and are very uncomfortable to experience. SIV may be part of the flashback itself, or may be utilized to stop the flashback process if it gets overwhelming. SIV is also a means of depicting previous abuse without having to resort to using words to "tell." Many survivors of abuse have been warned not to "say a word" about it, and have been threatened with harm to themselves or others if they dared to tell. This warning can invoke fear and silence even decades later. SIV may be the first form of expression a person has to begin disclosing the secrets of the past.

SIV can occur in the context of relationships, as it is in relationships that painful feelings can be experienced. Trauma itself impacts one's connection with oneself, others, and the world at large. SIV is connected to intimacy, as it is a tool of connection and expression when other means are not possible as a result of traumatic wounds. Sexual intimacy is often problematic for abuse survivors, and SIV serves the function of managing some of the difficulties that arise with sexuality. Human beings crave many forms of intimacy, yet not all of us are able to know or express our needs. SIV has often been correlated with feelings of abandonment, some of which may be triggered by experiences of neglect in the past as well as the present. A woman who has been neglected in childhood, and who uses SIV as a coping tool, may further feel abandoned and neglected when others in her life demean her for needing the SIV.

Women living with SIV might have confusion regarding personal boundaries, whether psychological, emotional, or physical ones. Some of us experience ourselves as having rigid, protective walls, while others feel overly vulnerable and without barriers to the world and others in it. Many of us experience both at various times. SIV serves as a boundary check for some of us. If confused about one's own physical boundaries, SIV can make one's body objective and real because, for example, a cut can show you where your body starts and that it is substantive. People who struggle to experience boundaries may often be triggered into SIV when they feel invaded and unable to physically or psychically set limits with others.

For those of us whose bodies host a group of personalities (diagnosed as Multiple Personality Disorder, now revised to Dissociative Identity Disorder), SIV can serve a multitude of purposes. Basically, every reason a woman who is not multiple, and who lives with SIV, has for her SIV may be applicable to the woman who is multiple. Different personalities may have different reasons for the SIV. Not all may be aware of each other, and some can experience great fear and confusion about SIV they are not cognizant of. SIV can be a powerful tool of communication amongst personalities, and can serve as a warning by some to others. Every personality in the system has a purpose and was created from a need for survival. Some are considered protective of the others and may communicate via SIV to them if they feel that the system as a whole is unsafe. This is not an uncommon occurrence when one personality begins to talk about the past abuses out of which the necessity for multiplicity arose. SIV while appearing as anger or punitiveness, is in actuality a caring warning that there is danger in disclosure.

Ritual abuse survivors commonly turn to SIV for a vast variety of reasons. However, one particular aspect of SIV for survivors of sadistic cults is programmed self-injury, which can occur when the victim attempts to disclose the abuse or leave the group. Also, SIV for ritual abuse survivors may occur on anniversary dates of the events experienced earlier, and may include specific representations of ritual symbols.

Some people, but not most women living with SIV, see the problem as purely biological, a defect in the brain chemistry. Others determine it to be an addiction. Psychiatric researchers theorize that the stimulus of SIV results in the production of certain brain chemicals known as endogenous opiods (specifically the endorphins) which produce a type of "high" resembling morphine. It is this narcotic feeling that the person is supposedly addicted to. Interestingly, not one researcher has yet explained why this "drug effect" only occurs with SIV and not accidental injury. If this were a true addiction we would all be at risk of developing it as a result of accidental injury. These theories overlook the one profoundly consistent factor that correlates to SIV—a history of trauma. It could never be (honestly) stated that SIV is simply an addiction because it targets a very specific population. While endorphin release may or may not be associated with SIV, it is also associated with activities such as eating chocolate, exercising, and meditation. And while brain chemistry changes certainly occur with life experiences, the narrowness of the pharmaceutical and psychiatric industries' interests limits the knowledge of brain chemistry changes to what drugs can be created and prescribed to alter those changes. Drug companies that spend a great deal of money influencing physicians and paying for research usually disregard the biochemical effects of therapy and other methods of healing. The business of psychiatry is focused on stopping the symptom of SIV while ignoring the healing of the person living with it.

It is therefore crucial that we not end a discussion of the reasons that SIV exists without exploring the source of the triggers for the SIV. Perhaps a way to conceptualize this is the diagram on the following page.

The various triggers for SIV, such as deeply uncomfortable emotional states, dissociation (both inducing a dissociative state as well as diminishing it), flashbacks and memories, self-image and identity (the trigger of self-hate), boundaries (physical, psychological, emotional), the ability to manage stress, the experience of multiple personalities, and difficulties with intimacy (social relationships, friendships, sexuality), rest on a base of a history of trauma. Traumatic experiences have many consequences and aftereffects. These aftereffects are affected by the nature and duration of the trauma, the age and experience of the victim, support available at the time, and many other factors, including the individuality of the person surviving the trauma. One of the most consistent experiences inherent in trauma, in my opinion, is the experience of helplessness. Helplessness itself may be the most consistent factor in triggering SIV. A woman living with SIV is using SIV to manage many of the repercussions of trauma. SIV is a survival tool. Just as other tools can be used to help with a variety of circumstances, so too can SIV be a means of managing a range of problems. SIV is powerful—it brings immediate change to situations that have represented powerlessness for a very long time.

In discussing trauma, I imply a wide range of experiences that can have the repercussions mentioned. By far the most common form of trauma linked with SIV is childhood abuse, however; other forms of trauma have certainly been described in the origins of SIV. For example, women who experienced repetitive, invasive (and necessary) medical procedures in their childhoods have turned to SIV to manage some of the repercussions of those experiences. Women who have been raped and people who have been at war may also find a need for SIV. Self-injury is rampant amongst people who have been institutionalized in prisons and psychiatric hospitals as these facilities are traumatic by nature. People who have survived natural disasters, but have lost their loved ones, and others who experience profound grief and despair, may find a temporary soothing and means of expression in SIV as well.

In discussing the traumatic nature of childhood abuse, it is important to understand the range of experiences this involves. The most recent absolute focus on the link between sexual abuse (primarily incest) and SIV is important, yet it is as important to identify the impact of physical and emotional abuses, and neglect as well. These are more common experiences, and often don't receive much-needed acknowledgement. To separate out SIV from its context is to alienate the voice of SIV itself. SIV is a language born of helplessness and pain. Its existence speaks to a life of struggle and survival, of limitations. SIV arises from traumatic roots. It is imperative that we recognize that trauma, in whatever context it is identified, is the ultimate trigger of self-injury. With that understanding we are well on our way to a compassionate and realistic perspective on the lives of women living with SIV.

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# WOMEN AND SELF-INJURY*

## What is self-injury?

"Self-injury" is any sort of self-harm which involves inflicting injuries or pain on one's own body. It can take many forms.

The most common form of self-injury is probably cutting, usually superficially, but sometimes deeply. Women may also burn themselves, punch themselves or hit their bodies against something. Some people pick their skin or pull out hair.

## How common is self-injury?

Self-injury is far more widespread than is generally realized. All sorts of people self-injure. Often they carry on successful careers or look after families and there is little outward sign that there is anything wrong. Self-injury seems to be more common among women, partly because men are more likely to express strong feelings such as anger outwardly.

Many women who self-injure believe they are the only person that hurts themselves in this way. Fear and shame may force women to keep self-injury secret for many years. This means that the true extent of the problem is unknown. Our experience shows that where it is acceptable to talk about, many women reveal that they have self-injured at some time.

## Why do women self-injure?

There are always powerful reasons why a woman hurts herself. For most women it as a way of surviving great emotional pain.

Many people cope with difficulties in their lives in ways which are risky and harmful to themselves. Some drink or eat too much, smoke, drive too fast, gamble or make themselves ill through overwork or worry. They might do this to numb or distract themselves from problems or feelings they cannot bear to face. (Like "drowning your sorrows.")

Self-injury, though more shocking, bears many similarities to these "ordinary" forms of self-harm. Like drink or drugs, hurting herself may help a woman block out painful feelings. Like taking risks or gambling, it may provide danger and distraction.

Often women say that self-injury helps them to release unbearable tension, which may arise from anxiety, grief or anger. It puts their pain outside, where it feels easier to cope with. For others it relieves feelings of guilt of shame. Sometimes a woman's self-injury is a "cry for help"; a way of showing (even to herself) that she has suffered and is in pain. Perhaps hurting herself is a way of

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* Modified from a brochure by the same name from the Bristol Crisis Service for Women, available at: http://www.selfinjury.freeserve.co.uk/women.html. For more information, please visit their web site at: http://www.users.zetnew.co.uk/bcsw, write: PO Box 654, Bristol BS99 1XH, or telephone 0117 925 1119.

feeling "real" and alive, or having control over something in her life. What lies behind women's distress may be painful experiences in childhood or adulthood. A woman may have suffered neglect or abuse, or may have always been criticized or silenced, rather than supported and allowed to express her needs and feelings. Some women who self-injure lost parents early, or came from chaotic or violent families. For others, adult experiences of emotional or physical cruelty have led to their desperation.

## Myths about self-injury

**Self-injury is a failed suicide attempt.** Self-injury is a way of carrying on with life, not of dying. Injuries are seldom life-threatening. It is important to distinguish self-injury from a suicide attempt, so that its true meanings can be understood.

**Self-injury is "just attention seeking."** Self-injury is primarily about helping oneself cope with great pain. For some, it is a desperate attempt to show that something is really wrong, and attention should be paid to their distress.

**Self-injury is a sign of madness.** Self-injury is a sign of distress, not madness; a sign of someone trying to cope with her life as best she can.

**A person who self-injures is a danger to others.** Someone who self-injures is directing her hurt and anger at herself, not at others. Most would be appalled at the idea of hurting someone else.

## What can help?

Self-injury causes great distress, and can seem a difficult problem to overcome. But it is possible for a woman to stop hurting herself, if she can understand and resolve the problems behind what she does.

**If you are someone who self-injures.** Think about what your self-injury is "saying" about your feelings and your life. This will give you clues about problems you need to work on. You might find it helpful to talk about your self-injury and what lies behind it with friends or a counselor.[2]

**If you want to help someone who self-injures.** Naturally you may feel upset, shocked or angry when someone you care about hurts herself. Try to keep seeing the person in pain behind the injuries. The most precious thing you can offer are acceptance and support. Let your friend know you understand that self-injury is helping her to cope at the moment. She is not "bad" or "mad" for doing it. You could invite her to talk about her feelings, or to call you if she is having a difficult time. But only offer as much as you can cope with, and don't try to take responsibility for stopping her from hurting herself.

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[2] For women who are interested in finding a counselor, Ruta Mazelis, editor of *The Cutting Edge*, has recommended the following book: Robin E. Connors (2000). *Self-Injury: Psychotherapy with People Who Engage in Self-Inflicted Violence.* Northvale, NJ: Jason Aronson Inc. This was not suggested in the original Bristol Crisis Service for Women brochure, but is rather an NPW adaptation.

# IN HARM'S WAY: SUICIDE IN AMERICA*

Suicide is a tragic and potentially preventable public health problem. In 1997, suicide was the 8th leading cause of death in the U.S.[1] Specifically, 10.6 out of every 100,000 persons died by suicide. The total number of suicides was approximately 31,000, or 1.3 percent of all deaths. Approximately 500,000 people received emergency room treatment as a result of attempted suicide in 1996.[2] Taken together, the numbers of suicide deaths and attempts show the need for carefully designed prevention efforts.

Suicidal behavior is complex. Some risk factors vary with age, gender and ethnic group and may even change over time. The risk factors for suicide frequently occur in combination. Research has shown that more than 90 percent of people who kill themselves have depression or another diagnosable mental or substance abuse disorder.[3] In addition, research indicates that alterations in neurotransmitters such as serotonin are associated with the risk for suicide.[4] Diminished levels of this brain chemical have been found in patients with depression, impulsive disorders, a history of violent suicide attempts, and also in postmortem brains of suicide victims.

Adverse life events in combination with other risk factors such as depression may lead to suicide. However, suicide and suicidal behavior are not normal responses to stress. Many people have one or more risk factors and are not suicidal. Other risk factors include: prior suicide attempt; family history of mental disorder or substance abuse; family history of suicide; family violence, including physical or sexual abuse; firearms in the home; incarceration; and exposure to the suicidal behavior of others, including family members, peers, and even in the media.[5]

## Gender Differences

More than 4 times as many men than women die by suicide;[1] however, women report attempting suicide about 2 to 3 times as often as men.[6] Suicide by firearm is the most common method for both men and women, accounting for 58 percent of all suicides in 1997. Seventy-two percent of all suicides were committed by white men, and 79 percent of all firearm suicides were committed by white men. The highest suicide rate was for white men over 85 years of age—65 per 100,000 persons.

## Children, Adolescents, and Young Adults

Over the last several decades, the suicide rate in young people has increased dramatically.[7] In 1997, suicide was the 3rd leading cause of death in 15 to 24 year olds—11.4 of every 100,000 persons—following unintentional injuries and homicide.[1] Suicide also was the 3rd leading cause in 10 to 14 year olds, with 303 deaths among

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19,097,000 children in this age group. For adolescents aged 15 to 19, there were 1,802 suicide deaths among 19,146,000 adolescents. The gender ratio in this age group was about 4:1 (males: females). Among young people 20 to 24 years of age, there were 2,384 suicide deaths among 17,488,000 people in this age group. The gender ratio in this age range was about 6:1 (males: females).[8]

## Attempted Suicides

There may be as many as 8 attempted suicides to 1 completion;[9] the ratio is higher in women and youth and lower in men and the elderly. Risk factors for attempted suicide in adults include depression, alcohol abuse, cocaine use, and separation or divorce.[10,11] Risk factors for attempted suicide in youth include depression, alcohol or other drug use disorder, physical or sexual abuse, and aggressive or disruptive behaviors.[12-14] The majority of suicide attempts are expressions of extreme distress and not just harmless bids for attention. A suicidal person should not be left alone and needs immediate mental health treatment.

## Prevention

All suicide prevention programs need to be scientifically evaluated to demonstrate whether or not they work. Preventive interventions for suicide must also be complex and intensive if they are to have lasting effects. Most school-based, information-only, prevention programs focused solely on suicide have not been evaluated to see if they are effective, and research suggests that such programs may actually increase distress in the young people who are most vulnerable.[15] School and community prevention programs designed to address suicide and suicidal behavior as part of a broader focus on mental health, coping skills in response to stress, substance abuse, aggressive behaviors, etc., are more likely to be successful in the long run.

Recognition and appropriate treatment of mental and substance abuse disorders also hold great suicide prevention value. For example, because most elderly suicide victims—70 percent—have visited their primary care physician in the month prior to their suicides,[16] improving the recognition and treatment of depression in medical settings is a promising way to prevent suicide in older adults. Toward this goal, NIMH-funded researchers are currently investigating the effectiveness of a depression education intervention delivered to primary care physicians and their elderly patients.

If someone is suicidal, he or she must not be left alone. You may need to take emergency steps to get help, such as calling 911. It is also important to limit the person's access to firearms, large amounts of medication, or other lethal means of committing suicide.

For More Information

American Association of Suicidology
Phone: (202) 237-2280
Web site: http://www.suicidology.org

American Foundation for Suicide Prevention
Phone: (212) 363-3500
Web site: http://www.afsp.org

Suicide Prevention Advocacy Network
Phone: (770) 998-8819
Web site: http://www.spanusa.org

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# THE INSIDIOUS RELATIONSHIP OF TRAUMA AND ADDICTION*

Everyone wants to numb some kind of pain at some point in her life. Survivors of trauma have a lot of stuff to numb out. Emotional numbing is one of the main responses to trauma, and there is a continuum of intensity with which one numbs herself. There are many ways to achieve this state of numbing. Dissociated identities and amnesia are two extremes. Over-eating or obsessive exercising are two common ones.

> Another quite popular and rather successful way to numb is with alcohol and drugs. Just like dissociation, getting wasted is merciful. It blocks tremendous amounts of pain, horrendous memories, and makes life seem livable-at least for that moment.

The problem with alcohol and drugs is that they are *addictive!* What was used to soothe away the effects of hell actually kidnaps the brain. Using is not the problem. Using alcohol and drugs is just one more creative coping mechanism used to manage the negative effects of trauma. It is the *addiction* that becomes the problem.

> There is a lot of good brain research that has identified the process of addiction. We know what parts of the brain are effected and the result. We know there is a genetic predisposition, but that is not the only factor. The frequency and intensity of use also has an effect.

The important thing to know is that addiction is a brain process. Thoughts of alcohol and drugs, seeing old using buddies, or driving past a bar trigger a part of the brain that activates the craving process, which is a very real, physical sensation. It is similar to a flashback in that one does not have control over the brain's response and subsequent physiological effects. Both are chemical processes that are adaptations to the presence of certain chemicals in the brain. The big difference is that trauma was not a choice, and alcohol and drug use usually is.

As a therapist I saw my clients getting the shit kicked out of them by drugs and alcohol. Some would come in with cuts and bruises. Sometimes they lost things, got raped, or lost all judgment and did things they regretted. They suffered tremendous loss because of alcohol and drugs. When I would say, "drugs are abusing you," they would stare at me for a few moments. I would say, "It is not you who abuses alcohol and drugs. You use them to feel good. That is not the problem. The problem is that the alcohol and drugs take over and kicks the shit out of you, but you can't feel it until the next day!" This twist on the theme of abuse offers great relief to many. They had been labeled an addict for so long that the identity took on a life of its own; a self-fulfilling prophecy. This new definition gives back dignity.

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* By Carin Mizera (2002). Written for the *New Partnerships for Women Consumer Curriculum*. Please contact the author at carin@chorus.net for permission to reprint.

## Trauma Bonds

Another definition I share with many of my clients is that of a trauma bond, especially those in abusive relationships. A trauma bond is something that had been first observed in victims of extreme torture, usually prisoners of war. It is known that this same psychological process takes place between victims of physical and sexual violence and their perpetrator. The victim comes to believe that the abuser can take her life at any moment. When this doesn't happen, she experiences the abuser as merciful. That perception becomes a bond and a drive. One begins to try to figure out what it is that will make the abuser happy and not kill her, or not hurt so much. And each time death is not the outcome, the bond becomes stronger. Even if actual death is not a real threat, the brain doesn't differentiate this. It only experiences intense fear.

Understand that this is not a conscious process. It comes out of our innate drive to survive and to believe that we have control over what happens to us. It is through this process that a victim becomes psychologically trauma-bonded to her abuser! This gratitude begins to feel a lot like love. If the abuse is sexual and the body responds as it is designed to, the confusion is even greater. Again, physiologically the relationship that develops feels like love.

The relationship and bond to alcohol and drugs is even more insidious. Even as it is abusing, it is numbing the pain. Sober we may never be at a party and have sex with strangers. But drunk we do, and we don't even have to feel it. Isn't that drug merciful?

I define this relationship with alcohol and drugs as a trauma bond in its own right. It is more dangerous than a loved one telling us we are being beaten for our own good, because he loves us, because we deserved it, then giving us flowers and telling us how much he loves and needs us. It is worse because it numbs the pain before we feel it. It is worse because we are held responsible with no empathy. It is worse because we initiated the process ourselves, adding another false positive to our sense of worthlessness.

## Perpetrator of Our Own Abuse

Let's go back to the point about the alcohol and drugs being the abuser. Though the drug takes over and abuses the person, it is the person herself who used the drug in the first place. The choice to use alcohol and drugs did not include abusing oneself, but that was the outcome. (I won't go into the shame felt about what one might do to others while intoxicated, but that also plays a major role.) How many times have we said to ourselves "how could I have done that? I am such a bad person!"

> What began as a choice to just feel good for awhile has now become a complex, confused jumble of psychological and physiological effects. Which brings us back to the beginning of this vicious circle: We are in pain. It is so intense that we seek relief. The alcohol and drugs do a great job of relieving

pain. We use, we're relieved, the drug abuses us, we become physically addicted and psychologically trauma-bonded, and we go spinning into that cycle of shame, denial, desperation, and emotional pain. And at some point it all starts again because the pain becomes too great.

But wait! There's more!

## Inability to Feel Good

Alcohol and drugs and trauma affect the brain. We know this. But we are only recently beginning to understand how exactly the brain is effected. One of the most critical effects of alcohol and drugs is that they trigger the "pleasure center" of the brain *instantly*. That's why it feels so good to get off.

For trauma survivors, enjoyment is often a difficult state to achieve. We are often wallowing in depression, hostage to hyper vigilance, or numbed to all emotion. For most people enjoyment is a normal everyday thing, taken for granted. A beautiful sunrise, a good joke, or a puppy can make a day worth living. This doesn't happen for trauma survivors.

Alcohol and drugs do it instantly for you. So once again, mercy *and* a little fun! Unfortunately, the brain eventually becomes incapable of experiencing pleasure without the drug! This is the addiction part that makes it so dangerous. This is one reason why recovery is so difficult! A therapist may suggest we find new activities to build a new life. Whether it is trauma or AODA therapy, the recovery process is much the same. Problem is, the brain is just not up to finding pleasure in anything.

The good news is that the human brain is a miraculous machine and can heal itself given the right conditions. We *can* reprogram our ability to experience happiness and fun. One of the traditional AA phrases, "fake it 'till you make it," is full of intuitive genius. But we know that is not the whole picture.

## Healing with La Loba

Healing takes time; we all know that. It is a long journey for many of us. But it is possible. I know this. I am doing it. I know others who are doing it, who are happy, healthy, productive, content, and satisfied people.

This is a fable about *La Loba, The Wolf Woman.*

> *La Loba is said to live in the dessert gathering bones. She does so quietly, rarely speaking, but often making animal sounds. She gathers all bones, but she specializes in wolf.*
>
> *When she has collected all the bones she assembles them into a complete skeleton. She gazes at her creation and chooses the song she will sing for this emerging creature. She begins to sing, and as she does the creature begins to flesh out, to grow fur, to tremble with life. La Loba continues her song. The wolf continues to grow.*

> *From the depths of her soul La Loba sings the final notes, and the wolf springs to life and runs free into the wilderness!*
>
> *As she runs, whether it be a ray from the sun or moon shining in her eye, a splash of water from the river on her fur, or the song of a bird in her ear, the wolf suddenly becomes a laughing woman full of life and love.*

We are each of us *La Loba*. La Loba of our own lives, creating our own *wolf-into-woman*. Each day we collect the bones of our experiences and we assemble them in new and creative ways. Maybe we each have a pack of wolves to be reclaimed, and many, many bones to collect. But each bone we collect is usable. And each note of our song we sing grows more flesh on our bones.

Each action we take for our healing is not wasted. We may have come to believe that it is our negative past that rules us and will never go away. Or that our addiction will never leave us at peace.

> But this is not true. We have many tools to use to dismantle the effects of trauma and addictions; exercise and good nutrition, support groups and psychotherapy. We work hard to get rid of the pain. It is the shedding of this weight that allows us to use our strength to carry all the good around.

It is known that once we love, even if only a little, that love never goes away; especially love for our own self. It exists in perpetuity. It exists in our mind and our soul, if only we learn to access it and keep that love energy flowing. And this is true for every success, every act of self-love, and no matter how small or short. For every day you did not drink, *that is one more day you did not drink!* No one can take that away from you. No one.

Only our selves will ever know the full extent of our own pain, all the injustices we've suffered. Only our selves will ever know the truth about all the drugs we did and what we remember while using. And now you and I are *La Loba*. Let's give our selves the compassion that we would give our sister if she told us all those stories. Let's begin to gather our bones.

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# MENTAL ILLNESS IS A COPING MECHANISM*

Mental illness is a coping mechanism. We know for sure that victims of horrendous childhood sexual abuse, most often by a family member from whom they can't escape, use such coping mechanisms as dissociation (going away in your mind) when they cannot escape physically from the torture. And further down that continuum is multiple personality and amnesia. These are all ingenious and remarkable ways that children learn to survive situations that are intolerable. And many people—without the label of mental illness—use coping mechanisms to survive the stress of everyday life. We use alcohol, drugs, sex, work, exercise, shopping, smoking, eating, gambling—some to excess and some, just enough to take the edge off—but we do use them. In moderation these coping mechanisms are considered socially acceptable; however, going "manic" or becoming "psychotic" is not.

After three years of listening to people call the 800 line at the National Empowerment Center, I must say I have drawn some very strong conclusions. First and foremost, the one thing that is clear to me is that no one calling the National Empowerment Center comes from the "Beaver Cleaver" family. Be it parents, consumers/survivors, siblings, lovers, spouses, or friends, there is always some trauma involved when the story is told: poverty, death of a parent at an early age, abandonment, divorce, incest, alcoholism, drug addiction, neglect, etc. And then the story continues the same. Some time later on in life, always a stressful time in life—off to college, wrestling with sexuality in the teen years, the birth of a child, the death of a parent, a divorce or broken love relationship—it happens. Mania, psychosis, panic attacks, depression, obsessive-compulsive behavior, and agoraphobia—these all of a sudden appear in those who have never known such things. Why? Well think about it logically. Trauma may not cause mental illness, but we all have our breaking points. And I think those of us who are not lucky enough or able to find a socially acceptable way of handling our stress, a way that does not too drastically interfere with our day-to-day lives, may end up becoming manic or going psychotic. What better way to leave behind a reality that is too cumulatively painful than to create one of our own...as in psychosis? What better way to feel like we can accomplish and do anything when we are feeling insecure and overwhelmed than becoming manic...where we can do anything and everything? And what better coping mechanism can we find than to wash our hands fifty times a day when we are feeling so unsafe? And if the world has been a cruel and unforgiving place, where but in the safety of your own bedroom, as in agoraphobia, could there be a safer place to be?

Some would say that mental illness runs in families—that it is genetic. When I was growing up, alcohol was the way in which my Irish Catholic family coped. I watched it all my life. So when I ran into trouble in my early twenties, alcohol was the way in which I self-medicated and tried hard to make the pain go away. My girlfriend down the street grew up in an Italian Catholic family. Food was the drug of choice in her home. Whenever anything emotional happened—a death, a birth, a

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wedding—food was what was used to stuff the feeling. So when my friend's husband left her with two small babies when she was 18, she started eating and did not stop until she had gained 50 pounds. And the same is true with so-called mental illness. If you grow up with depression, suicide, mania and psychosis as role models for coping mechanisms, the more likely you may use these as ways to cope when the need arises.

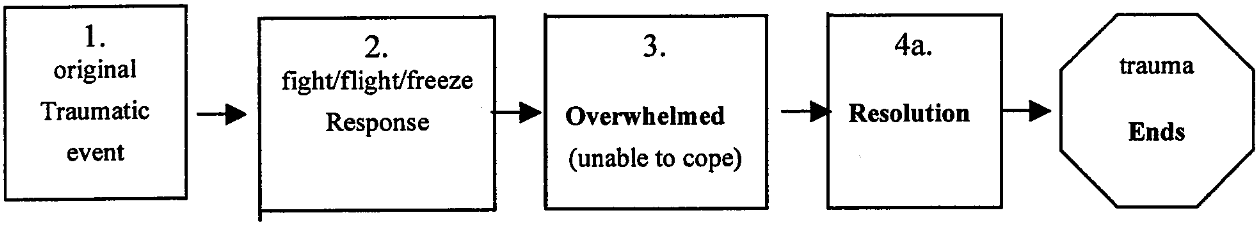
It is not a coincidence that most of the staff at the NEC are trauma survivors—later to be diagnosed with mental illness. But it is also not a coincidence that we have all recovered. We share common ideals and principles that have allowed us to find new coping mechanisms that work in our lives. Drugs, in and of themselves, were not the answer. Electroshock was not the answer. The answer was making it safe for us to come back, and finding a new way to cope with the stress when we did return. You know, if you had a nervous stomach and you went to your doctor, he or she might give you Maalox and Tagamet and tell you to reduce the stress in your life. Well, you could take all the medicine, but if you went home to the car that would not start, the dog who just died, the lover who is cheating on you and the job you hate, you can be pretty sure that your stomach would kick up again—no matter what you take—until you find a new way to cope and deal with the stress in your life.

Mental illness is a coping mechanism, not a disease. And those who know this know that drugs will only fend off the pain for so long and then it comes back again. And it seems to me, the difference between those who recover and those who go on to become chronic, lifelong mental patients are those who are aware of this, those of us who know that a second, third or fourth drug added to our repertoire will not ease the pain. In fact it only increases the pain—when we feel hopeless and helpless. Create a safe space. Find a new way to cope. And I believe you too can recover from your so-called mental illness.

# “MAY THE CIRCLE BECOME BROKEN”[*]

Carin Mizera of New Partnerships for Women has developed an “Effects of Trauma” diagram that wonderfully explains what happens when 1. a trauma event is resolved versus unresolved, 2. the repeat pattern of cyclical symptoms, and 3. how that PTSD cycle can be broken to bring an end to the trauma.

### 1a. Trauma Resolution Pattern



Where there is resolution to a traumatic event, even though one still has memories of the event and emotions to those memories, the event is not relived and the person is able to go on with their life without being overwhelmed or obsessed with the past trauma. Example -

> *When I was nine years old, I cut across the parking lot behind a drug store at dusk to get home from a friend’s house before dark on a school night. An old man standing behind a dumpster called out to me and asked if I wanted to see something. I squinted at what he was holding and thought it was a vinyl, school-supplies holder in the shape of a pencil I’d been wanting. When I got closer though, I saw it was his penis [trauma] and I stopped, frozen with fear [F/F/F] and remembering a second-grade girl in nearby Racine, WI who’d been raped, then strangled and later found in a thrown-out refrigerator the winter before [overwhelmed]. He asked me if I’d ever seen one before and I nodded yes (to save on the water bill, my mom used to toss several of us pre-school age kids into the tub together on Saturday bath night.)*

*Then he asked me if I wanted to earn some money and I shook my head no, saying, “I gotta get home before it gets dark or my mom’ll be mad.”*

*I carefully backed away and as soon as I hit the Main St. sidewalk, I took off running across the bridge and home faster than I’ve ever run [flight]. Where I chose to not tell of the incident because (taking in account my nine-year old logic whose only knowledge of the law was what I saw on TV) I didn’t think I could pick him out of a line-up since he looked liked your average drunk, old white man.*

*Even though I vividly remember the event, it never drags me into an obsessed, depressed state because I took care of myself. He wanted to do something to me but I got myself out of the situation untouched and intact [resolution]. So when I*

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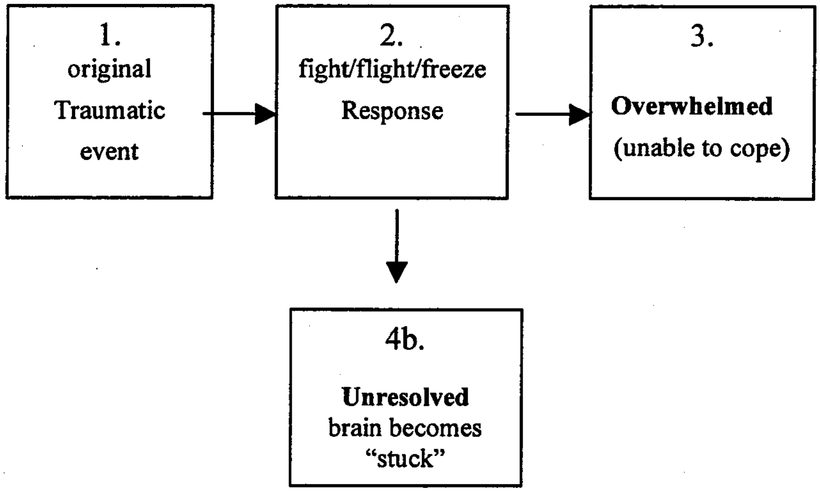
*remember this, I feel pride for that nine-year old girl who defended herself. Thus, the trauma ended shortly after it began.*

### 1b. Unresolved Trauma Pattern



However, when there is not resolution to a traumatic event, the brain can become stuck repeating the original event over-and-over in conscious or unconscious memory. Example from my past where the trauma still has not ended though the abuse stopped over twenty years ago -

> *On Easter Eve when I was fourteen and a freshman in high school, I was raped by my best friend's father. A periodic molestation that went on for 2½ years before it stopped with him dead on an operating table my senior year. **[trauma]** Whenever he did something, I would freeze and silently stand there, feeling ashamed, scared, embarrassed, and confused. **[freeze response]** His sexual abuse the first time made me so physically ill I stayed in bed all day Easter Sunday and missed school for the first time for an actual sickness since having the measles in second grade. Two days later I got my period and went back to school, wondering how I could face my best friend without saying anything and losing her friendship. **[overwhelmed]** I stayed away for nine months **[flight]** until her birthday in December, and finally went over when she began wondering out loud that maybe we weren't best friends since I never came to visit or spend the night anymore. He didn't do anything that visit, so I figured it was a one time thing. Then the next visit, while kneeling on her bedroom floor gluing together a Santa pom pom ornament, there he was at me again. And I gave up. **[overwhelmed]***

The trauma went unresolved while it was happening for several reasons: One, because there was no one in my family I could confide in or trust. I was the classic "lost child" growing up in a dysfunctional family. My father was an alcoholic who preferred the two children from his second marriage to us seven kids from the first family, usually only coming to visit when he was drunk and dangerous. My mother had given birth eight times in twelve years and only had so much emotional support to go around after getting stuck raising all of us on her own before the last one was even born (my dad ditched us for the last time when my mom was seventh months pregnant). As the third oldest and a naturally quiet person, I learned by my teen years to rely only on myself to solve my problems, living by the ACOA creed - "don't talk, don't trust, don't feel".

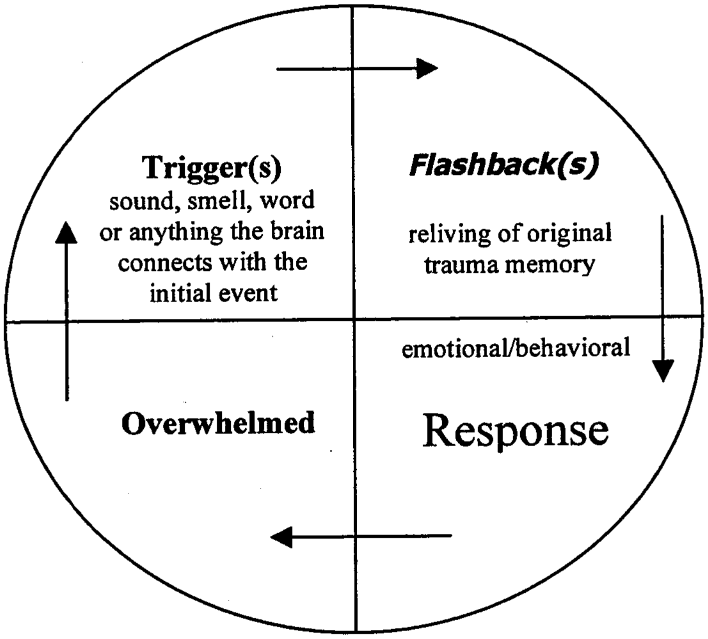
Two, because I was growing up in a very prejudiced, narrow-minded town, I didn't believe that if I told he'd be arrested and imprisoned for the actual crime of raping an underage girl. Another friend of mine was molested by a white high school janitor while working for CETA (an employment program for teens from low-income families). At the trial, it was brought up that he was a deacon of the church while she was called a slut (she didn't even go out on her first date until her senior year!). Needless to say, he was acquitted even though other CETA girls came forward and confessed that he'd made sexual advances at them, too. My family was regarded poorly by the town for being poor. My best friend's father was not white. With all the racism and classism in that small town (which happens in every state in this country, not just the southern ones), I don't believe then-or-now that a fair trial would have occurred. I believe he would have been found guilty based on his ethnic background and that if he'd been white, he probably would have been acquitted because I was from a family on welfare.

Third, and most important, the best way to lose a best friend is to have her father arrested. A very shy person, I only had a couple friends and she was such a good friend, I didn't want to risk anything breaking us up. Plus worry that she and her little brothers would get beaten up and her family would have to move away and become poor themselves if her dad got arrested and lost his job. All of these not because of what he did, but because of his skin color.

So I kept my mouth shut and tolerated his abuse, not knowing what else to do. A pattern began of—he'd do something sexual to me, within a couple days I'd get my period. I'd stay away from my best friend's house for about a month until I ran out of lies about why I couldn't come visit, or my own family was driving me so crazy with physical and verbal abuse, that her home became my only refuge - my only place to escape to although it meant him pawing over me, etc. He'd do something sexual, I'd go back home the next day, within a couple days get my period and begin another month's avoidance of her home until the pressures built up again. And so the sexual abuse kept circling until he died when I was seventeen.

When the trauma goes unresolved and the brain becomes stuck on the event, a vicious PTSD cycle can be set in place where anything related to the trauma (sound, smell, word, or something else) can trigger the event, bringing about a flashback (a conscious or unconscious reliving of the event). When the flashback is experienced, there is an emotional or behavioral response based again on fight/flight/freeze, and again a feeling of being overwhelmed by what's happening in the memory even though the abuser may be long gone. Example -

## 2. Repeat Trauma Cycle



*A consequence of his abuse is that my PMS period became a **trigger** for me, becoming very volatile when it occurs at Easter-time. Times of paranoia, vividly relived **flashbacks**, irritability, emotional and sexual frigidity. [**response**] My vagina was conditioned into being hyper-vigilant towards anything that tried to enter it - be it a penis, a doctor's speculum, or my own fingers. Soon as it knows something is going to try and invade it, my vaginal muscles will tighten up as hard as the rock covering Jesus' tomb to keep intruders out. Making intercourse and my yearly pelvic exam extremely painful with occasional tearing and bleeding (even though physically my vaginal opening has the capacity to stretch pretty wide, as evidenced when I gave birth vaginally to a nine pound baby). Anyways, I always feel **overwhelmed** until my period arrives and the cycle is over for another month.*

So here I am today, forty years old and still triggering at Easter time. My best friend's father has been a dead skeleton decomposing in the ground for the past twenty-three years. But the couple days before my period, he'll come to mind as clear as if he were resurrected. And because my cycle is anywhere from four to six weeks, if my PMS is dragging, sometimes I have to rape myself to a flashback in order to get my period to start and find relief from the memories. That sounds strange and sick, raping myself (meaning I masturbate to a memory of him raping me), and it is. But it's also a coping skill though it plays into, reinforces the pattern (which I just now realized while typing so I'll be bringing a copy of this article to my next counseling session). And PMS at Easter-time is the worst.

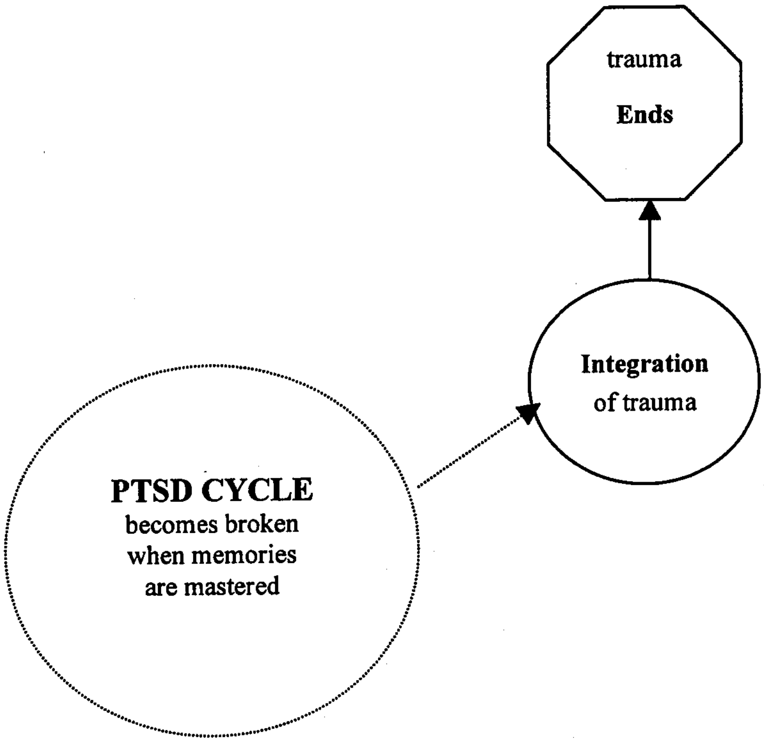
I've lost boyfriends because of this. Even though they knew my trauma history, they didn't understand why at Easter time I would become emotionally cold and extremely standoffish towards them, flinching if they even came near me. Not just men, but women too haven't understood why I get so paranoid and on edge just before my period. Some women also have disrespected my expressed need to keep their distance at certain times and have touched me after I repeatedly asked them not to. Male or female, when I say don't touch me I mean it and if they do anyways, it's like fingernails on a chalkboard and a potential friendship is broken by distrust.

Some professionals and peers have said, "Well, that happened over twenty years ago. He's dead. Get over it."

I wish it were that easy. One of the rotten things I've found out in my recovery process is that finding out the source of my problem doesn't always make it go away. For this trauma incident, there is more work to be done because of the deep impact it's had on me for over half of my life. As I continue to chip away at different aspects of its effects, I still have hope that at some point there will be an end to all the trauma-reactions related to what he did and he'll finally stay dead in his grave.

## 3. Trauma Closure Pattern

For the PTSD cycle to become broken, some type of mastery over the memories occurs, leading to an integration of the trauma where the brain becomes unstuck and is able to put the past back into the past where it belongs. This integration process may only need to occur once, or a number of times depending on how many different ways the trauma has affected the person. There is also no one set way to master the memory as different things work for different people, whether it's through education, therapy, medication, external removal of a trigger (see example below), time and maturity, or something else. Example -



*Back in 1981 when I was twenty, outside a Job Service center I'd just left after filling out an application, I was approached by a strange young man who tried to coerce me to go with him to do drugs and have sex. Fortunately, there where a lot of people on the busy, city street and it was broad daylight. To finally get away from him, I ducked into a public library. He followed me in and though he kept his* *distance, he kept watching me so that I didn't feel safe leaving the library. Because he hadn't actually done anything, I didn't believe I could approach library staff or security about him. So I called my dad, told him I was lost, and asked if he could come pick me up (for ACOA reasons I didn't feel safe telling him the truth). He was pissed but came anyways and I left the library with my dad, the strange man glaring at me from behind a book stack.*

*I dealt with the trauma situation without getting attacked but for years afterward, whenever I would see a white, cube-shaped Job Service building I would flashback to that moment and break out into a cold sweat. I would be so overwhelmed by the trauma memory that I never went back to that Job Service center in Green Bay and couldn't enter the ones in Elkhorn or Madison either when I was living in those areas and looking for work years later.*

*Talking over the incident with a therapist and taking a Chimera self-defense course helped me master the memory so it no longer had a hold on me. My brain integrated the event by accepting that even though I could have dealt with the situation better by telling library staff anyways (guilt feelings of "did he go after someone else?") or my father the truth (anger feelings because I didn't feel safe being honest based on my ACOA childhood experiences with him), I dealt with it the best I could at that time considering my background and learned coping skills. Thus, the trauma ended.*

The eventual demolishing of the cube-shaped Job Service buildings (as they moved into more generic-looking business buildings) also helped break the PTSD cycle by removing my visual trauma trigger. Today, I have no problem entering the Job Center on Aberg Ave. (which is good since I'm currently unemployed and in need of their different services and programs).

In conclusion, I want to bring up how my unresolved trauma from my teen years has affected my daughter's life. My daughter was born on Good Friday, and I brought her home on Easter. Next year, her golden birthday falls on Easter Sunday. It would be nice to say that her birthday erased the PTSD but it didn't. In fact, she fell victim to one of my PTSD episodes when she was five so that now she lives in long-term foster care and I can only have supervised visits with her. I repeated on her the abuse done on to me by my best friend's father and though that might explain why I did it, it doesn't excuse that I did it. Now I am a PTSD trigger for my daughter who has a pattern of stressing out whenever she sees me, no matter how well the visit goes. I accept full blame for her reactions because he didn't do it, I did. I also accept the consequences, like losing my job last September because of what I did to her six years ago, and only getting to see her a couple times a year, when she's ready for a visit.

In the meantime, I go to parenting classes and support groups, actively participate in counseling and my daughter's monthly team meetings, and call the social workers every week. And continue to advocate for something - classes or support groups or treatment programs - for women who sexually abuse children because I know from reading the local papers that I'm not the only one but in going for help, there are self-help books and recovery programs for male perpetrators but not females. For us, there's nothing but footnotes and closed doors, even denial by the system as when I first reported it to Dane County human services and was asked by the intake social worker, "Why are you wasting my time with this?"

Because I wanted help - for me and my daughter - so I'd never do that again and she wouldn't repeat the abuse on to her own or other kids when she grows up. That social worker didn't open the case but fortunately, my daughter told a therapist she was seeing about what happened and a different social worker did open the case. I told the police, therapists, and social workers every detail I remembered. Now my daughter is getting the recovery help she needs to help break both her PTSD cycle and the abuse patterns I passed on to her.

My current therapist is evaluating me to see if I'm a good candidate for EMDR, an eye movement therapy that's been very helpful in providing integration to other people's PTSD symptoms. I hope I qualify. Another hope is that in the next ten years, whenever I finish menopause, my PMS-PTSD pattern will be broken by having that trigger removed. Then Easter can become a time for peaceful renewal, not painful remembrance.

There's a song that goes: "May the circle be unbroken..." but if the circle is warped, by all means break it. Break those wobbly old circles and build healthy new paths with safety exits for when times are tough. Do it for ourselves, our relations with others, and especially our children who deserve a better inheritance than our trauma histories.

# ANNA'S STORY: THE EFFECTS OF SEXUAL ABUSE, THE SYSTEM'S FAILURE TO RESPOND AND THE EMERGENCE OF A NEW, TRAUMA-BASED PARADIGM[*]

From the age of 13 to her recent death at the age of 32, my daughter Anna was viewed and treated by the mental health system as "severely and chronically mentally ill." Communication about who she was, how she was perceived and treated, and how she responded took place through her mental health records. A review of 17 years of these records reveals her being described in terms of diagnoses, medications, symptoms, behaviors, and treatment approaches. She was consistently termed "noncompliant" or "treatment resistant." Initially recorded childhood history was dropped from her later records. Her own insights into her condition were not noted. When she was 22, Anna was reevaluated after a suicide attempt. For a brief period, she was rediagnosed as suffering from acute depression and a form of post-traumatic stress disorder. This was the only time in her mental health career that Anna agreed with her diagnosis. She understood herself not as a person with a "brain disease" but as a person who was profoundly hurt and traumatized by the "awful things" that had happened to her.

## What happened to Anna?

Anna was born in 1960, the third of five children, a beautiful healthy baby with a wonderful disposition. At the age of about 2 1/2, she began to scream and cry inconsolably. At age 4, we took her to a child psychiatrist who found nothing wrong with her. When we placed her in nursery school, her problems seemed to lessen.

That Anna was being sexually abused and traumatized at the time is clear now, verified in later years by her own revelations and by the memories of others. Her memories of abuse by a male babysitter were vivid, detailed, and consistent in each telling over the years. They were further verified by persons close to the perpetrator and his family, one of whom witnessed the perpetrator years later in the act of abusing another child.

Evidence that Anna was betrayed and sexually violated at an even earlier age by another perpetrator, a relative, came to light eventually through the revelations of a housekeeper in whom Anna had confided at the time. She had told this woman that a man "played with her where he wasn't supposed to" and that the man "hurted her." This abuse was kept secret for nearly 30 years. Anna remembered trying to tell us, as a little child, what was happening, but there was no one to hear or respond. When she told me a man "fooled" with her, I assumed she meant a young neighborhood boy and cautioned his parents. When we took her to a physician, she experienced the physical examination as yet another violation: "I remember the doctor you took me to

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[*] Ann Jennings © 1999. National Empowerment Center, Inc. All rights reserved. Available at: http://www.power2u.org/trauma/annas_story.html.

when I told you. He did things to me that were disgusting (pointing to her genital area)."

The trauma Anna experienced was then compounded by the silence surrounding it. She tried to communicate with her rage, her screams, and her terror. She became the "difficult to handle" child. Her screaming and crying was frequently punished by spankings and confinement to her room. No one then could see or hear her truth; sexual abuse did not "exist" in our minds. When later, as a young girl, she withdrew within herself, somehow different and apart from her peers, we attributed it to her artistic talent or independent personality. We did not see or attend to the terror, dissociation, loneliness, and isolation expressed in her drawings, nor did we heed the hints of trouble expressed by her behaviors. Two grade school psychologists were alone among the professionals we encountered in sensing the turbulence underneath her silence. "Anna is confused about her sexual identity," one reported. "You must help her." The other wrote, "It would seem that Anna has suppressed or repressed traumatic incidents."

Chaos and parental conflict existed in Anna's family from the age of 11 to 13. Although her four brothers and sisters survived the multiple geographic moves, alternative lifestyles, disintegration of their parents' marriage, and episodic violence and alcoholism, Anna did not. She "broke" at age 13. A psychiatrist prescribed Haldol to "help her sleep." She suffered a seizure in reaction, requiring emergency hospitalization. Thus was she introduced to the mental health system.

### *Anna's invisibility in the mental health system.*

Anna was a client of the mental health system for 19 years, until the age of 32. For nearly 12 of those years, she was institutionalized in psychiatric hospitals. When in the community, she rotated in and out of acute psychiatric wards, psychiatric emergency rooms, crisis residential programs, and locked mental facilities. Principle diagnoses found in her charts included borderline personality with paranoid and schizo-typical features, paranoia, undersocialized conduct disorder aggressive type, and various types of schizophrenia including paranoid, undifferentiated, hebephrenic, and residual. Paranoid schizophrenia was her most prominent diagnosis. Chronic with acute exacerbation, subchronic, and chronic courses of schizophrenia were identified. Symptoms of anorexia, bulimia, and obsessive compulsive personality were also recorded. Treatments included family therapy; vitamin and nutritional therapy; insulin and electroconvulsive therapy; psychotherapy; behavioral therapy; art, music, and dance therapies; psychosocial rehabilitation; intensive case management; group therapy; and every conceivable psychopharmaceutical treatment including Clozaril. The use of psychotropic drugs comprised 95% of the treatment approach to her. Although early on there were references to dissociation, her records contain no information about or attempts to elicit the existence of a history of early childhood trauma.

> Anna was 22 when she learned, through conversation with other patients who had also been sexually assaulted as children, that she was not "the only one in the world." It was then that she was first able to describe to me the details of

her abuse. This time, with awareness gained over the years, I was able to hear her.

Events finally became understandable. Sexual torture and betrayal explained her constant screaming as a toddler, her improvement in nursery school, and the reemergence of her disturbance at puberty. It explained the tears in her paintings, the content of her "delusions," her image of herself as shameful, her self-destructiveness, her involvement in prostitution and sadistic relationships, her perception of the world as deliberately hurtful, her isolation, and her profound lack of trust. I thought with relief and with hope that we now knew why treatment had not helped. Here at last was a way to understand and help her heal.

The reaction of the mental health system was to ignore this information. When Anna or I would attempt to raise the subject, a look would come into the professionals' eyes as if shades were being drawn. If notes were being taken, the pencil would stop moving. We were pushing on a dead button. This remained the case until she took her life, 10 years and 15 mental hospitals later.

Believing herself to be "bad," "disgusting," and "worthless," as child sexual abuse victims often do, she hurt, mutilated, and repeatedly revictimized herself. She put cigarettes out on her arms, legs, and genital area; bashed her head with her fists against walls; cut deep scars in herself with torn-up cans; stuck hangers, pencils, and other sharp objects up her vagina; swallowed tacks and pushed pills into her ears; attempted to pull her eyes out; forced herself to vomit; dug her feces out so as to keep food out of her body; stabbed herself in the stomach with a sharp knife; and paid men to rape her.

Again and again, as victims of sexual assault often do, Anna sought relief through suicide. She tried to kill herself many times-slashing her wrists, attempting to drown herself, taking drug overdoses, poisoning herself by spraying paint and rubbing dirt into self-inflicted wounds, slitting her throat with a too-dull razor, and hanging herself from the pipes of a state hospital. Many of the mental health professionals she encountered were highly skilled in their disciplines. Many genuinely cared for Anna, and some grew to love her. But in spite of their caring, her experience with the mental health system was a continuing reenactment of her original trauma. Her perception of herself as "bad," "defective," a "bad seed," or an evil influence on the world was reinforced by a focus on her pathologies, a view of her as having a diseased brain, heavy reliance on psychotropic drugs and forced control, and the silence surrounding her disclosures of abuse.

Just 4 days after her 32nd birthday, after another haunted sleepless night, she hung herself, by her T-shirt, in the early morning bleakness of her room in a California state mental hospital. She was found by a team of three night staff who were on their way in to give her another shot of medication.

## *The wall of silence.*

The tragedy of Anna's life is replicated daily in the lives of many individuals viewed as "chronically and severely mentally ill." Unrecognized and untreated for their childhood trauma, they repeatedly cycle through the system's most expensive psychiatric emergency, acute inpatient, and long-term institutional services. Their disclosures of sexual abuse are discredited or ignored. As happened during their early childhood, they learn within the mental health system to keep silent.

Clinicians who acknowledge the prevalence of traumatic abuse and recognize its etiological and therapeutic significance are deeply frustrated at being denied the tools and support necessary to respond adequately. Sometimes, as Anna's psychologist did, these clinicians leave the mental health system entirely, deciding they can no longer practice with integrity within it.

## *The biological paradigm = the inability to see.*

Although rehabilitative, psychotherapeutic, and self-help approaches operate within the system, the dominant paradigm within which these approaches are subsumed is clearly that of biological psychiatry. Thomas Kuhn, in his analysis of the history and development of the natural sciences, brought the concept of "paradigm" into popular usage. He viewed paradigms as the conceptual networks through which scientists view the world. Data that agree with the scientists' conceptual network are seen with clarity and understanding. But unexpected "anomalous" data that do not match the scientific paradigm are frequently "unseen," ignored, or distorted to fit existing theories.

In the field of mental health, a biologically-based understanding on the nature of mental illness has for years been the dominant paradigm. It has determined the appropriate research questions and methodologies; the theories taught in universities and applied in the field; the interventions, treatment approaches, and programs used; and the outcomes seen to indicate success.

Paradigmatically understood, the mental health system was constructed to view Anna and her "illness" solely through the conceptual lens of biological psychiatry. The source of her pain, early childhood sexual abuse trauma, was an anomaly—a contradiction to the paradigm—and, as such, could not be seen through this lens. Her experience did not match the professional view of mental illness. It did not fit within the system's prevailing theoretical constructs. There was no adequate language available within the professions to articulate or label it. There were not reimbursement mechanisms to cover its treatment. It was not addressed in curricula for professional training and education, nor was there support for research on the phenomenon. There were no tools—treatment, rehabilitation, or self-help interventions-for responding to it. And there was no political support within the field for its inclusion. Screened through the single lens of the biological paradigm, Anna's experience could not be assimilated. It had to be unseen, rejected, or distorted to fit within the parameters of the accepted conceptual framework.

As a result of this paradigmatic blindness, conventionally accepted psychiatric practices and institutional environments repeatedly retraumatized Anna, reenacting and exacerbating the pain and sequelae of her childhood experience.

## The emerging trauma paradigm.

Although paradigm shifts mark the way to progress and opportunity, they are always resisted initially. They cause change, disrupt the status quo, create tension and uncertainty, and involve more work. Resistance to a sexual abuse trauma paradigm has existed for more than 130 years, during which time the etiological role of childhood sexual violation in mental illness has been alternately discovered and then denied. In 1860, the prevalence and import of child sexual abuse was exposed by Amboise Tardieu, in 1896 by Sigmund Freud, in 1932 by Sandor Ferenczi, and in 1962 and 1984, by C. Henry Kempe. Each exposure was met by the scientific community with distaste, rejection, or discreditation. Each revelation was countered with arguments that in essence blamed the victims and protected the perpetrators. Freud, faced with his colleagues' ridicule of and hostility to his discoveries, sacrificed his major insight into the etiology of mental illness and replaced his theory of trauma by the view that his patients had "fantasized" their early memories of rape and seduction. Today, 100 years later, in spite of countless instances of documented abuse, this tradition of denial and victim blame continues to thrive.

Psychiatrist Roland Summit refers to this denial as "nescience" or "deliberate, beatific ignorance." He proposes that "in our historic failure to grasp the importance of sexual abuse and our reluctance to embrace it now, we might acknowledge that we are not naively innocent. We seem to be willfully ignorant, 'nescient'".

At this point in history, however, multiple and divergent forces are confronting nescience with truth. Although these forces will continue to meet resistance, they appear to be forming a powerful movement that will help to protect children from adult violation and will promote acceptance of a trauma-based paradigm recognizing the pain of individuals like my daughter and offering them "the radical prospect of recovery".

# *K'S STORY*[*]

The process of claiming my own sense of personal power has been a slow one. Even though I have been living with acute PTSD for at least the last 10 years, it wasn't until eight years ago that I finally began to make some positive steps forward.

The first step in regaining my own sense of personal power was in choosing a therapist. Until that time I was in a chronic state of crisis, I had had a series of therapists and psychiatrists who treated me as if I had borderline personality disorder. This diagnosis, in turn, determined what services were offered to me as well as the attitudes of those who offered them. I was told I could not contact my therapist by phone outside of office hours. So my crises went unresolved until they were acute enough to require hospitalization every three to four weeks. This, because of my borderline diagnosis, was deemed to be inappropriate use of the hospital and a new treatment plan which strictly limited my use of the hospital was drawn up. Part of the treatment plan involved using crisis homes in place of the hospital. I willingly went along with the treatment plan, knowing that resisting would only strengthen their resolve to treat me as a borderline. But there was a problem with crisis homes too. It seemed I over-utilized them just like the hospital and as a result limits were placed on my use of the crisis home. With each limitation that was put on me, I went into a deeper state of crisis because my needs were not being addressed.

In choosing a new therapist I knew only one thing. I needed a therapist whose sense of reality I could trust and who could avoid a power struggle with me at all costs. My connection with reality felt fairly tenuous and I needed someone who could help me stay grounded while teaching me how to trust myself. In terms of power struggles, I had been locked into them on several fronts: with my previous therapists and psychiatrists over my diagnosis; and, with the hospital and crisis home people over the frequency of my stays. I knew I couldn't take much more. I knew that the final power struggle would result in me taking my own life. Finding a new therapist was probably the smartest move I've made in the past ten years, because out of that relationship I learned to trust myself and reclaim my power.

The next step, one instigated by my new therapist, was to redefine the hospital and crisis home treatment plans. It took time and it was scary, but with her help we were able to reframe for my care providers my use of the hospital and crisis homes. With my new therapist the diagnosis of borderline personality disorder was discarded and replaced with PTSD/major depressive disorder. And instead of limiting use of hospital and crisis homes to once per month, an arrangement that was more suited to the caregiver's convenience than my own needs, we set things up so that I could use the hospital as needed. I began to feel like I would be supported in a crisis rather

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[*] Anonymous (2002). Written for the *New Partnerships for Women Consumer Curriculum*. Author has asked that her story not be reprinted.

than abandoned and surprise of surprises, the amount of time I spent in crisis markedly decreased.

Finally there was the diagnosis of borderline. I discovered as a result of a routine staffing in a day treatment program, that the hated diagnosis was still on some of my records. I was crushed and angry. I had worked hard, had made many changes and assumed greater and greater responsibility for myself and I was still being followed around by this diagnosis. People were no longer treating me as a borderline, but just the fact that it still occupied space on my records was unacceptable. So I confronted my psychiatrist, who had filled out the form. I did so as respectfully as possible, recounting for him my many changes and improvement and he responded by apologizing. He redid the paperwork and the word borderline was removed. This may seem like a technicality, but to me it meant a lot - it meant that my progress was recognized and appreciated.

Probably the most important thing I have learned in the past eight years is to surround myself with supportive trustworthy people and to listen to my gut. It is definitely a learning process, one in which I am still engaged. I was not raised to do either of those things but they are definitely skills that can be learned at any age.

# A COUPLE OF BARB'S STORIES[*]

Sometimes the very people we go to for help hurt us even more. Once, when I had cut myself pretty badly I went to the E.R. to get stitches. I had lost quite a bit of blood and since cutting myself is not about suicide and I didn't want to get an infection, I went for help. I really didn't want to because getting stitches hurts and by then I was feeling things again. I wasn't feeling when I cut; that was part of the reason I did it. It wasn't a choice, I HAD to cut. Well, when the doctor came in to put in the stitches he told me that he wasn't going to numb my arm because I *liked* pain. I must have fought him because I remember them tying me down. I don't remember much else because I went away somewhere deep inside my head.

* * *

For many years people with mental illnesses didn't get even minimal health care so it was a big step forward for hospitals to routinely give physical exams to patients when they were admitted. But sometimes a good thing can go wrong.

Once, when I was admitted to the state hospital, they told me I had to have a physical, given by a med student from the UW. I agreed because I was too depressed to argue with them but I told them I couldn't let them do a pelvic exam. Now I'm crazy, not stupid, and I know the importance of PAP smears etc. but as an abuse survivor I can't handle that. They said I had no choice. I said NO! They told me I would have to stay in seclusion (with no clothes on, suicide precautions) until I had the exam. They said I couldn't be with the other patients because I could have a contagious disease. Well, I could have been in seclusion for a very long time. I knew they would win so I said I would try. I did try. But during the exam he hurt me and I freaked out. He was sitting on one of those little three-legged stools with wheels and I planted my foot in the middle of his chest and sent him flying into the wall. I didn't do it on purpose, I just reacted. Well then they put me in seclusion for being violent. I got so depressed I stopped eating, talking, even moving. Eventually they forced me out of the seclusion room and locked me out so I had to be with the other patients. Eventually, I got *better* and went home.

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[*] Barbara Hennings, NPW and Yahara House (2002). Written for the *New Partnerships for Women Consumer Curriculum*. Author grants permission to reprint this article. Citation of the source is appreciated.

# AN OUTRAGE OF INSTITUTIONS*

What can happen to a person when they are institutionalized and abused within a controlled setting where there is no way to report abuse because the abusers are the people who are supposed to be the protectors? A woman was raped in jail and had no known way to report the incident because the people who raped her were the deputies themselves. This happened too many times to count, and the woman woke up bruised and naked and didn't know where to turn. The only people she could turn to were the deputies and they were the ones who did it. The woman kept telling her lawyer she woke up in the cell naked, yet he would not believe any story the woman told him. She had nowhere to turn and did not know how to call out for help. The message she was given was violence was okay by the very officers who are supposed to protect her. Her faith in the police system was broken: the woman was shattered and torn, and these memories forever became a part of the woman's nightmares. This is institutionalization at its worst possible outcome.

The experience shaped this woman's future existence into a scared, frightened, victim of Post-Traumatic Stress. She can still overcome, as have many victims of Criminal Justice Systems in many countries that have outcomes of tortured prisoners and victims that for years are too afraid to come forward.

*The sun shines today and what does this woman say? She can be strong for she is a survivor. She can speak out for she is a speaker. She can say she refuses to be abused. She is woman, she is strong. This will only prove us to be strong.*

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* Anonymous (2002). Written for the *New Partnerships for Women Consumer Curriculum.* Author grants permission to reprint this article. Citation of the source is appreciated.

# Appendix 4

# Suggested Readings for Chapter 4: Symptom Management

N P W
NEW
PARTNERSHIPS FOR
WOMEN

# PSYCHOLOGICAL OR EMOTIONAL SYMPTOMS*

## Beginning Ritual

To begin work on this topic, write four good things that happened to you in the last two days:

______________________________________________

______________________________________________

______________________________________________

______________________________________________

## Experiencing Symptoms Caused by Abuse

If you were abused, you probably developed certain symptoms in response. The symptoms may have happened right away or, in some cases, months or even years after the abuse.

Some symptoms, such as fear, anger, or sadness, are obviously connected to the abuse. Other symptoms, such as paranoia, dissociation, or panic attacks, may have caused a bit more confusion for you. The feelings and behaviors may have been so upsetting and overwhelming at times that you felt as if you were going crazy. In fact, all of these symptoms were signs that abuse had occurred. Some were immediate responses to the abuse, others were attempts to cope with the abuse and prevent it from happening again, and still others were ways to deny that it had ever happened at all so that you could go on living.

As you begin to think about your symptoms differently, it will be up to you to decide what you want to do about particular feelings and behaviors. Some you will want to control yourself, some you will need help from medication or counseling to control. Some symptoms will be easy for you to let go. In other cases, you might decide to hold on to a symptom for a while, in case you need it.

Many signs of abuse have been mistaken for symptoms of mental illness or biochemical brain imbalances, such as chronic depression, bipolar disorder, manic depression, or schizophrenia. If you've sought help from health care providers,

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* Copied with permission from New Harbinger Publicatins. Mary Ellen Copeland and Maxine Harris © 2000. Healing the Trauma of Abuse: A Woman's Workbook (pp. 175-193). New Harbinger Publications, Oakland, CA www.newharbinger.com.

perhaps you were told that your symptoms were signs of a disease or a mental illness instead of being the markers of abuse. You may have been given a diagnosis and some medication and never even asked about your abuse. It may be tempting to focus on one view of the problem, but when you see your emotions, biology, and everyday experiences as part of an integrated whole, your recovery will make more sense to you.

Some traumatized women receive treatment at mental health clinics for years for symptoms of anxiety, withdrawal, and dissociation, receiving diagnoses of major depression, bipolar disorder, and borderline personality disorder. Meanwhile, the underlying problem is ignored. Rather than help, diagnoses that obscure the role of trauma just make many women feel bad about themselves. When a woman begins to see her symptoms as connected to years of physical and emotional abuse, she may feel an enormous sense of relief, as if a cloud of confusion had lifted. She may also, however, feel sad and angry because her underlying problem—the trauma—was never really treated.

In this topic, some of the symptoms and feelings associated with abuse will be described. (Addictive and compulsive behaviors will be addressed in topic 20.[3]) For any of the symptoms you have, or have had in the past, write down your answers to the series of questions we've listed. At the end of the exercise there are additional spaces for you to write about other symptoms or feelings that are not listed here.

Dissociation—feeling as though you are out of your body, watching what is happening to you from a distance. For example, when Ann's counselor mentioned troubling times in Ann's childhood, Ann would protect herself by feeling disconnected from her body. She found she could relieve this symptom by telling the counselor she wanted to change the subject and discuss something pleasant that was happening in her life now, like the course she is taking or an outing with a good friend.

I currently have, or have in the past had, this symptom.

__________ Yes

__________ No

Why is this feeling hard for you?

______________________________________________________________

______________________________________________________________

______________________________________________________________

Where do you think it may have come from?

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[3] This refers to a chapter in the Copeland and Harris book Healing the Trauma of Abuse: A Woman's Workbook.

______________________________________________________________

______________________________________________________________

______________________________________________________________

How have you tried to help yourself feel better when you experience this symptoms?

______________________________________________________________

______________________________________________________________

______________________________________________________________

How effective has it been?

______________________________________________________________

______________________________________________________________

______________________________________________________________

Excessive anxiety—Worry accompanied by feelings of nervousness or jitteriness and sometimes shortness of breath, weakness in the arms and legs, and profuse sweating. For example, Nancy experienced anxiety every time she went to visit her parents because she anticipated that an uncle would stop by who had been abusive to her when she was a child. To relieve this anxiety, Ann asked her parents to tell the uncle in advance of her visit that he was not welcome. She learned deep breathing and relaxation and stress-reduction exercises that she practiced regularly. In addition, she cut down on the amount of caffeine she was using.

I currently have, or have had in the past, this symptom.

__________ Yes

__________ No

Why is this feeling hard for you?

______________________________________________________________

______________________________________________________________

______________________________________________

Where do you think it may have come from?

______________________________________________

______________________________________________

______________________________________________

How have you tried to help yourself feel better when you experience this symptom?

______________________________________________

______________________________________________

______________________________________________

How effective has it been?

______________________________________________

______________________________________________

______________________________________________

Disturbed sleep—having a hard time falling asleep, waking often during the night, or waking very early and being unable to get back to sleep. This may be the result of recurring nightmares, even though a woman sometimes can't remember them when she wakes. Mary Ellen has addressed this problem by doing relaxation exercises several times during the day, doing journal writing before going to bed, and taking herbal supplements recommended by a health care professional.

I currently have, or have had in the past, this symptom

__________ Yes

__________ No

Why is this feeling hard for you?

______________________________________________

______________________________________________

______________________________________________

Where do you think it may have come from?

______________________________________________

______________________________________________

______________________________________________

How have you tried to help yourself feel better when you experience this symptom?

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How effective has it been?

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______________________________________________

Losing track of time—you can't account for where you were and what you were doing at certain times. For example, Marcy kept finding clothes in her closet that she couldn't remember buying. Sometimes people came up to her on the street, actingas if they knew her well, and she had no recollection of who they were. She is dealing with this in three ways: through counseling with a therapist who has experience treating people who have been abused, by practicing being in the moment (discussed in topic 7[4]), and by involving herself in grounding activities such as cooking and cleaning when she is feeling stressed.

I currently have, or have had in the past, this symptom

__________ Yes

__________ No

Why is this feeling hard for you?

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[4] This refers to a chapter in the Copeland and Harris book Healing the Trauma of Abuse: A Woman's Workbook.

______________________________________________

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______________________________________________

Where do you think it may have come from?

______________________________________________

______________________________________________

______________________________________________

How have you tried to help yourself feel better when you experience this symptom?

______________________________________________

______________________________________________

______________________________________________

How effective has it been?

______________________________________________

______________________________________________

______________________________________________

Fear of leaving the safety and security of your living space—In extreme cases, you might be unable to go outdoors at all. For example, Robin only felt safe in the house because of traumatic events that had happened when she left the security of her home. She worked on relieving this problem by leaving the house for short periods of time and going only to safe places, often accompanied by a supporter. She very gradually increased the length of time she could be away and the number of places she could go, and eventually began spending more time away from home on her own.

I currently have, or have had in the past, this symptom

__________ Yes

__________ No

Why is this feeling hard for you?

Where do you think it may have come from?

How have you tried to help yourself feel better when you experience this symptom?

How effective has it been?

Hypervigilance—Feeling as though you are always on edge, expecting something bad to happen, always expecting the worst, and feeling tense all over in anticipation. For example, Pasty grimaced every time someone touched her because she expected the touch to be abusive. Patsy explained the problem to several friends and worked with them, practicing being touched without grimacing until she was able to enjoy friendly touch. Whenever this issue comes up she reminds herself that she is no longer in the abusive situation that she believes was responsible for this symptom.

I currently have, or have had in the past, this symptom

__________ Yes

__________ No

Why is this feeling hard for you?

______________________________________________________________

______________________________________________________________

______________________________________________________________

Where do you think it may have come from?

______________________________________________________________

______________________________________________________________

______________________________________________________________

How have you tried to help yourself feel better when you experience this symptom?

______________________________________________________________

______________________________________________________________

______________________________________________________________

How effective has it been?

______________________________________________________________

______________________________________________________________

Uncontrollable rage—Yelling, screaming, or hollering at someone, something, or nothing. For example, Jan would have screaming fits toward her husband. Sometimes these fits were unprovoked, and other times they began as the result of a minor incident or misunderstanding. She felt this rage was left over from the physical and emotional abuse she experienced as a child. She learned to deal with this symptom by noticing early warning signs that she was getting stressed; sometimes she was able to recognize a certain circumstance that was likely to lead to an outburst. She would then stop what she was doing, go to a quiet place she had designated in the house, listen to quiet music, and do a relaxation exercise.

I currently have, or have had in the past, this symptom

__________ Yes

__________ No

Why is this feeling hard for you?

Where do you think it may have come from?

How have you tried to help yourself feel better when you experience this symptom?

How effective has it been?

Flashbacks—When you experience a vision of past traumatic event along with strong feelings relating to the trauma. For example, while she was involved in some enjoyable activity, Diane would suddenly see in her mind a frightening incident of abuse with her ex-husband. This seemed to drain away all her energy and fill her with fear. Diane learned to deal with this symptom by immediately reminding herself that flashbacks are "old news" that have noting to do with her present circumstance. She would then take a few deep breaths before resuming her other activities.

I currently have, or have had in the past, this symptom

__________ Yes

__________ No

Why is this feeling hard for you?

______________________________________________________________

______________________________________________________________

______________________________________________________________

Where do you think it may have come from?

______________________________________________________________

______________________________________________________________

______________________________________________________________

How have you tried to help yourself feel better when you experience this symptom?

______________________________________________________________

______________________________________________________________

______________________________________________________________

How effective has it been?

______________________________________________________________

______________________________________________________________

Hallucinations—Seeing, hearing, feeling, and thinking things that are not based in reality. For example, Marlene had times when her whole life felt out of control. Nothing seemed real. All of her senses seemed to be distorted. She would tell others about things she had seen and heard that made her upset and they knew these things had not really happened. Marlene learned to watch for possible triggering events and early signs of hallucinations. When they occurred, she took time off from work and spent one or several very quiet days at home, doing relaxation exercises, journaling, and engaging in activities she enjoys.

I currently have, or have had in the past, this symptom

__________ Yes

__________ No

Why is this feeling hard for you?

______________________________________________

______________________________________________

______________________________________________

Where do you think it may have come from?

______________________________________________

______________________________________________

______________________________________________

How have you tried to help yourself feel better when you experience this symptom?

______________________________________________

______________________________________________

______________________________________________

How effective has it been?

______________________________________________

______________________________________________

______________________________________________

Low self-esteem—Feeling as though you have little or no value as a person. For example, Jodie kept trying and trying to do things that would make her feel good about herself. She got a doctorate as well as a master's degree, had a successful career, and she still couldn't feel like she had any value. She felt this way because she was told over and over as a child that she was "no good for anything." Jodie worked on raising her self-esteem by repeating over and over the affirmation, "I am a wonderful person with lots of talents to share with others." In addition, she started avoiding people who gave her negative feedback about herself, spending more time with people who were positive and affirming.

I currently have, or have had in the past, this symptom

__________ Yes

__________ No

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Why is this feeling hard for you?

________________________________________

________________________________________

________________________________________

Where do you think it may have come from?

________________________________________

________________________________________

________________________________________

How have you tried to help yourself feel better when you experience this symptom?

________________________________________

________________________________________

________________________________________

How effective has it been?

________________________________________

________________________________________

________________________________________

Inability to trust—Being unable to connect closely and bond with others because of fears of rejection or abuse. For example, Jane often felt lonely and separated from others. However, whenever people attempted to establish a connection with her she would become fearful, avoiding the person and not responding to their invitations. She felt she was unable to trust others because when she was a child her parents had physically and emotionally abused her and neglected her basic needs. To address this issue in her life, she interviewed several counselors until she found one with whom she felt comfortable. They worked together to develop a trusting relationship. The counselor then introduced Jan to a support group of other women who had been abused. In this group she learned to share personal information with others who had similar experiences and who respected her confidentiality. She developed close friendships with several of the women in the group, getting together with them for walks and movies. With these successful trusting relationships, she began to take more risks, becoming friendly with people at work and at her church.

I currently have, or have had in the past, this symptom

__________ Yes

__________ No

Why is this feeling hard for you?

______________________________________________

______________________________________________

______________________________________________

Where do you think it may have come from?

______________________________________________

______________________________________________

______________________________________________

How have you tried to help yourself feel better when you experience this symptom?

______________________________________________

______________________________________________

______________________________________________

How effective has it been?

______________________________________________

______________________________________________

______________________________________________

Use the following spaces to address other symptoms and feelings you experience as a result of abuse.

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**Feeling or symptom:**

Why is this feeling hard for you?

Where do you think it may have come from?

How have you tried to help yourself feel better when you experience this symptom?

How effective has it been?

**Feeling or symptom:**

Why is this feeling hard for you?

Where do you think it may have come from?

How have you tried to help yourself feel better when you experience this symptom?

How effective has it been?

**Feeling or symptom:**

Why is this feeling hard for you?

Where do you think it may have come from?

How have you tried to help yourself feel better when you experience this symptom?

How effective has it been?

## Your List of Tools

As you review the responses to your symptoms above, you will discover that you developed some successful tools for relieving symptoms and feelings associated with abuse. What are they?

You will find other ways to relieve symptoms in topics 6, 7, and 13[5]. Review the work you did in those topics and make a list of the tools you have started to use or plan to try.

_______________________________________________

_______________________________________________

_______________________________________________

_______________________________________________

_______________________________________________

You may want to make a copy of this list of tools to hang on your bulletin board or refrigerator for easy reference. Use them whenever you have emotional or psychological symptoms or feelings that are uncomfortable or distressing. The more you practice these skills, the easier they will be to use. After a while you will notice that you are using them almost automatically. Your symptoms will become less of an issue in your life and you will feel better and enjoy your life more. This change happens gradually over time.

## Ending Ritual

Describe something you are looking forward to that is happening soon.

_______________________________________________

_______________________________________________

Describe something you are looking forward to that will happen in the more distant future.

_______________________________________________

_______________________________________________

## Optional Activities

1. Spend at least one hour each day doing something you really enjoy. Note how you feel before and after this activity.
2. The next time a symptom or a bad feeling occurs, stop, write the name of the symptom or feeling on a piece of paper, and put the paper in a safe place. As

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[5] These refer to chapters in the Copeland and Harris book Healing the Trauma of Abuse: A Woman's Workbook.

you are doing this, tell yourself, "I can control this feeling. I don't need to experience this right now if I don't want to."

## Things to Remember Every Day

- I'm not crazy. The symptoms and feelings I experience are normal responses to trauma and abuse.
- I recognize symptoms of trauma and abuse. I relieve them by using the tools I have discovered on my own and through this work.

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# TAKING BACK CONTROL OF YOUR LIFE*

In my studies I have found that many people who experience psychiatric symptoms or have had traumatic things happen to them feel that they have no power or control over their own lives. Control of your life may have been taken over when your symptoms were severe and you were in a very vulnerable position. Family members, friends and health care professionals may have made decisions and taken action in your behalf because your symptoms were so intrusive you couldn't make decisions for yourself, they thought you wouldn't make good decisions or they didn't like the decisions you made. Even when you are doing much better, others may continue making decisions in your behalf. Often, the decisions that are made for you and the resulting action are not those you would have chosen.

Taking back control of your life by making your own decisions and your own choices is essential to recovery. It will help you to feel better about yourself and may even help you to relieve some of the symptoms that have been troubling to you.

There are several things you can do to begin this process. You can do these things in whatever ways feel right to you. You may want to use a journal to list or write your thoughts and ideas as a way to stay focused on what it is you want, to motivate yourself and to record your progress.

1. Think about what you really want your life to be like. Do you want to:
    - Go back to school and study something of special interest to you?
    - Enhance your talents in some way?
    - Travel?
    - To do a certain kind of work?
    - Have a different home space or to own your home?
    - Move to the country or the city?
    - Have an intimate partner?
    - Have children?
    - Work with an alternative health care provider on wellness strategies?
    - Make your own decisions about treatment?
    - Stop putting up with disabling side effects?
    - Become more physically active?
    - Lose or gain weight?

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You can probably think of many more ideas. Write them all down. You may want to keep them in a journal.

2. List those things that have kept you from doing the things you wanted to do in the past. Perhaps it has been lack of money or education. Maybe your symptoms have been too severe. Maybe your treatment makes you lethargic and "spacey". Maybe someone in your life insists on making decisions for you.

Then write down ways you could work on resolving each of the problems that keep you from doing the things you want to do and being the kind of person you want to be. As you do this, remind yourself that you are a intelligent person. You may have been told that you are not intelligent because you have a "mental illness". Experiencing psychiatric symptoms does not mean that your intelligence is limited in any way. You have the ability to find ways to resolve these problems slowly or quickly. You can take small steps or big steps—whatever feels right and is possible for you. But you must do it if you want to take back control of your life.

In the process of taking control of your own life, you may need to change the nature of your relationship with some of the people in your life. For instance, instead of your doctor telling you what to do, you and your doctor would talk about your options and you would choose the ones that felt best to you. You may need to tell a parent or spouse that you will make your own decisions about where you will live, what you will do and whom you will associate with. You may have to tell a sibling who has been overprotective that you can take care of yourself now.

3. Know your rights and insist that others respect these rights. If your rights are not respected, contact your state agency of protection and advocacy (every state has one—you can find it under state listings in your phone book or by calling the office of the governor).

   Your rights include the following:

   - I have the right to ask for what I want.
   - I have the right to say no to requests or demands I can't meet.
   - I have the right to change my mind.
   - I have the right to make mistakes and not have to be perfect.
   - I have the right to follow my own values and standards.
   - I have the right to express all of my feelings, either positive or negative.
   - I have the right to say no to anything when I feel I am not ready, if is unsafe, or it violates my values.
   - I have the right to determine my own priorities.
   - I have the right not to be responsible for others' behavior, actions, feelings or problems.

- I have the right to expect honesty from others.
- I have the right to be angry.
- I have the right to be uniquely myself.
- I have the right to feel scared and say, "I'm afraid."
- I have the right to say, "I don't know."
- I have the right not to give excuses or reasons for my behavior.
- I have the right to make decisions based on my feelings.
- I have the right to my own needs for personal space and time.
- I have the right to be playful and frivolous.
- I have the right to be healthy.
- I have the right to be in a non-abusive environment.
- I have the right to make friends and be comfortable around people.
- I have the right to change and grow.
- I have the right to have my needs and wants respected by others.
- I have the right to be treated with dignity and respect.
- I have the right to be happy.

These rights have been adapted from *The Anxiety and Phobia Workbook* by Eugene Borne (Oakland, CA: New Harbinger Publications, 1995).

4. Educate yourself so that you have all the information you need to make good decisions and to take back control or your life. Study resource books. Check out the Internet. Ask people whom you trust. Make your own decisions about what feels right to you and what doesn't.

5. Plan your strategies for making your life the way you want it to be. Figure out the best way for you to get what it is that you want or to be the way you want to be. Then start working at it. Keep at it with courage and persistence until you have reached your goal and made a dream come true.

## A Possible First Step

One timely way you could choose to begin the process of taking back control of your life is to get involved in the upcoming election. You could begin by thinking about and listing the political issues that are most important to you. They may include things like mental and physical health care, the cost of medications, disability benefits, housing, human services, social justice, the environment, education and employment. Jot down some notes about action you would like to see your community, state or the federal government take in regard to these issues. Then study the candidates. Find out which candidates most closely support your view on these issues and will best be able to create favorable change. Then register before November so you can VOTE for that person or those people.

In addition, if you feel ready, you could become further involved if you choose to by:

- Contacting groups that are concerned with the issues that you care about—ask them for information, volunteer to assist them in their efforts.
- Talking to family members, friends, neighbors and co-workers about your views and the candidates you support - - encouraging them to vote for the candidates you prefer.
- Letting others know about your preferences through bumper stickers, campaign buttons and lawn signs.
- Writing a letter to the editor of your newspaper to share your views or calling in on radio talk shows.
- Volunteering to work at the polls, or to work for a particular candidate.

Whether your candidates win or lose, you will know you did the best you could and that through your efforts more people are now informed about the issues. You may even decide that you want to run for office.

# BUILDING SELF ESTEEM*

In my work I sometimes feel that there is an epidemic of low self-esteem. Even people who seem to be very sure of themselves will admit to having low self esteem that often makes them unhappy, keeping them from doing some of the things they want to do and being the kind of person they want to be. In fact they may say that low self-esteem causes, or worsens, their bouts of depression and anxiety. I know it has been a big factor in my life. I feel that I have always been working on raising my self-esteem and that I will always need to do that. There is no one-way to raise self-esteem. There are many different things you can do to work on this. I find that I am always looking for good ways to raise self-esteem. This article will describe several ways you can raise your self-esteem.

## Get Involved

Right now you have an opportunity to do something that will help you to raise your self-esteem. Once every four years, you can vote for the person you would like to be the next president of the United States. You also have the opportunity to vote for other national, state and local officials. Irrespective of the outcome of the election, informing yourself about the candidates and voting for the ones who support issues that are important to you can make you feel good about yourself, raising your self-esteem. Begin the process by thinking about the issues that are important to you—education, health care, the environment, taxes, defense spending, etc. If you don't know how you feel about these issues, read some related articles and talk with people who have the information you need. Then, when you know how you feel, find out which candidates support your views. Then vote for those candidates. If you feel strongly about certain candidates, and have the time, you may want to volunteer to help them with their campaign. Activism will give your self-esteem another boost.

## Take Good Care of Yourself

Another way you can build your self-esteem is to take very good care of yourself. You may take very good care of others and put your own personal care last. Or your life may be so busy that you don't take the time to do things you need to do to stay healthy. You may feel so badly about yourself that you don't bother to take good care of yourself. Some of the things you can do to take good care of yourself include:

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- Eating three meals a day that are focused on healthy foods—fresh fruit and vegetables, as well as whole grain foods and rich sources of protein like chicken and fish
- Avoiding eating food that contains large amounts of sugar, caffeine and food additives—if you can't pronounce the ingredients, you may want to avoid it
- Getting outside and exercising every day
- Spending some time each day doing something you really enjoy
- Spending time each day with people who make you feel good about yourself
- Having regular check-ups with your health care providers

## Change Negative Thoughts about Yourself to Positive Ones

Work on changing negative thoughts about yourself to positive ones. You may give yourself lots of negative self-talk. Many people do. This negative self-talk worsens your low self-esteem. You can decide now not to do this to yourself. That's great if you can do it. However, negative self-talk is often a habit that is hard to break. You may need to work on it more directly by changing these negative statements about yourself to positive ones. Begin this process by making a list of the negative statements you often say to yourself. Some of the most common ones are:

- Nobody likes me.
- I am ugly.
- I never do anything right.
- I am a failure.
- I am dumb.
- Everyone is better than I am.
- I'm not worth anything.
- I've never accomplished anything worthwhile.

Then develop a positive statement that refutes the negative one. For instance, instead of saying to yourself, "Nobody likes me" you could say, "Many people like me". You could even make a list of the people who like you. Instead or saying, "I never do anything right" you could say "I have done many things right." You could even make a list of things you have done right. It helps to do this work in a special notebook or journal.

When you developed positive statements that refute your negative statements, read them over and over to yourself. Read them before you go to bed at night and when you first get up in the morning. Read them aloud to your partner, a close friend or your counselor. Make signs that say a positive statement about you and post them where you will see them—like on the mirror in your bathroom. Then read them aloud every time you see them. You can think of some other ways to reinforce these positive statements about yourself.

## Get Something Done

Low self-esteem is often accompanied by lack of motivation. It may feel very hard to do anything. It will help you feel better about yourself if you do something even if it is a very small thing. You may want to keep a list of possibilities on hand for those times when you can't think of anything to do. Things like cleaning out one drawer, washing out the inside of your refrigerator, putting a few pictures in a photo album, reading an article you have been wanting to read, taking a picture of a beautiful flower or a person you love, making a bed, doing a load of laundry, cooking yourself something healthy, sending someone a card, hanging a picture or taking a short walk,

Make a list of your accomplishments. You may not give yourself credit for all you have achieved in your life. Making a list of your accomplishments will help you become more aware of these accomplishments. It will also help change the focus of your self-thoughts to positive ones. You can do this exercise again and again, whenever you notice your self-esteem is low. Get a big sheet of paper and a pen you feel comfortable with. Set the timer for twenty minutes (or as long as you'd like). Spend the time writing your accomplishments. You could never have a paper long enough or enough time to write them all. Nothing is too big or too small to go on this list. This list can include things like:

- Learning to talk, walk, read, skip, etc.
- Planting some seeds or caring for houseplants
- Raising a child
- Making and keeping good friends
- Dealing with a major illness or disability
- Buying your groceries
- Driving your car or catching the subway
- Smiling at a person who looks sad
- Taking a difficult course
- Getting a job
- Doing the dishes
- Making the bed

## Do Something Special for Someone Else

Have you ever noticed the good feeling that washes over you when you do something nice for someone else? If so, take advantage of that good feeling that comes from helping someone else by often doing things that are "nice" or helpful to others to build your self esteem. Watch for opportunities that come up every day. Buy your partner some flowers or even one rose. Send a friend a greeting card. If someone you know is having a hard time, send them a note or give them a call. Go out of your way to congratulate people you know on their achievements. Visit a patient at a nursing home, in a hospital or a "shut-in". Play with a child—read them a book, take them for a walk, push them on the swing. Do a chore for someone that might be hard for him or her, like raking the leaves or mowing the grass. You may even want to volunteer for an organization that is helping.

## Other Quick Things You Can Do to Raise Your Self Esteem

Following is a list of other things you can do to raise your self-esteem. Some of them will be the right thing at one time, while another thing will work another time. There may be some you choose not to do—ever. You may want to post this list on your refrigerator or in some other convenient place as a reminder.

- Surround yourself with people who are positive, affirming and loving
- Wear something that makes you feel good
- Look through old pictures, scrapbooks and photo albums
- Make a collage of your life
- Spend ten minutes writing down everything good you can think of about yourself
- Do something that makes you laugh
- Pretend you are your own best friend
- Repeat positive statements over and over again
- You can add more ideas to this list as you discover them for yourself.

## In Conclusion

**Work on raising your self-esteem may go on for the rest of your life. However, this is not a burden. The kinds of things you do to raise your self-esteem will not only help you to feel better about yourself, but will improve the quality of your life while energizing and enriching it.**

# COLLECTIONS*

I collect instances.

I used to collect pigs, cast-iron soldiers. In 1976, I collected all sorts of bicentennial paraphernalia. I wasn't much of a patriot, but is seemed such a milestone in what we call a "nation".

Instances, however, collect my sanity, as I collect instances. Every individual has collected some odd, or not-so-odd, item or another. Instances, however, are every individual's most vital collection in their lifetime. And often the most overlooked.

I would wager most of us neglect instances. Of course, we collect stories. Perhaps less so in this fast-paced age of the internet and the printed word. But we gather stories in some form: family tales, office anecdotes, high school remembrances. Stories make up our lives—collages of memories. More intricate, however, are individual recollections. Now I collect instances in defiance of my long-held beliefs of my self as a loser. A fake. An inept human being.

I grew up basically not fitting in. None of us fit in. Some of us fit in better than other, but the squeeze is harder for some than others. I was a tight squeeze, faced daily with quirks, let-downs and embarrassments.

Disappointments. Failures. Never quite fitting in. A lot of pain. Years of belief that I was a failure, incapable, defective, bad... I have notebooks to attest to this, condemning myself, years of eating disorders to try to destroy myself, tirades upon tirades with myself, with friends, who only remember wishing somehow I could not be so tremendously hard on myself. I could not see otherwise—I was just not good enough. There were not enough instances of goodness in my collection.

Like collecting baseball cards, I didn't opt for the choice cards. Sooner or later, this led to deep isolation. I had no idea how I would get out. I had to start from square one.

I started to look at myself in others' eyes, in particular, in the eyes of one friend I pretty well believed loved me.

I pretty well believed she liked me a lot. This was a leap of faith.

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* Karen Milstein, Wisconsin Consumer (December 2001). Bureau of Community Mental Health, WI Department of Health and Family Services, *Recovery and the Mental Health Consumer Movement in Wisconsin.* Used with permission of the author. Please contact the author through Yahara House for permission to reprint, 608-280-4700.

I watch how she watched me. I watched how maybe she looked to me for confidence, for support. I watched how maybe she needed me. As we all need each other. I looked for instances. Then I looked slightly further abroad. To further instances in my life. People, strangers, smiled at me. At me! When I gave them a chance—an instance—they even sometimes spoke to me. If I gave people space, they sometimes took it. Like slack—it is taken up.

I collect instances. I started taking the more valuable cards. Remembering. Noticing. Collecting them and keeping them for myself.

> Instances also come in the form of events. I made instances out of tasks. My first major task-oriented instance to get me out of isolation was to take on the major task of editing a local feminist newspaper (that is, by the way, no longer in print). I co-edited an edition on women and mental health. It was easier than it sounds: there was a beginning, a middle and an end. I started a task, worked hard and finished. This is a perfect instance to work on, because I knew if I worked on it, I would finish it and have achieved an instance. A fine addition to my collection.

The collection can never be too big. You can trade old cards for new ones. Pack some of the old instances away in the closet and gather new instances in the closet for an ever stronger ego collection.

Tasks. Glances. Achievements. Every piece of successful writing. Instances.

Attention! This collection is not to go to your head! This collection of instances is to give you a gentle pat on the back, a rub on the stomach, warmth in the heart. To fire you up to fire others up. To keep you going to keep others going. To light your eyes to shine in others' eyes.

We fill each others' collections of instances for where else would instances come from?

# 10 WAYS TO DE-STRESS YOUR LIFE*

1. Live simply. Don't clutter up your life with too many things.
2. Take care of yourself. Get enough sleep; eat healthy foods.
3. Think positively. Fill your mind with uplifting images.
4. Be cooperative. Resist the common tendency to want things your own way all the time. Try to see another point of view.
5. Get involved in a good cause. Feel like you are making a difference in the world, even if it's in a small way.
6. Live one day at a time. Make the most of the moment. Yesterday is gone, and today will be, soon enough.
7. Exercise. Do something you really enjoy. Restore yourself.
8. Maintain balance. Devote time to all aspects of your life: spiritual, emotional, family, career, community, physical, mental, material.
9. Give yourself credit where credit is due.
10. Realize you can't do everything.

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* NEC Staff and Affiliates © 1999. National Empowerment Center, Inc. All rights reserved. Available at: http://www.power2u.org/selfhep/10ways.html.

# SAFETY PLANNING*

## A. Numbers to call for help:

1. List names and numbers of friends, relatives, battered person's shelter/agency, hospitals, churches, where you can go for help.
2. Find a safe place to hide the number to the battered shelter/agency, like at a neighbor's, in freezer, plant, tampon box.
3. Post number for battered person's shelter/agency under a fictitious name (first name only) so abuser doesn't know you have it.
4. Keep the police/sheriff's number posted close to the phone.
5. Memorize all important numbers.

## B. House and car keys:

1. Number one rule: keep all keys out of sight of the abuser.
2. Have extra keys made. Give extra keys to friends, neighbors, relatives: people who can be trusted.
3. Tape or hide extra keys somewhere safe: desk drawer, wheel well, out of the house if possible.
4. Try to obtain abuser's set of keys to vehicle, especially if he/she does not use the car or if it belongs to you.
5. If the abuser has a set of your home keys, change the locks to your home.

## C. To prevent the abuser from immobilizing vehicle:

1. Get a lock for the hood and gas cap.
2. If the hood can only be opened from inside the car, keep the doors locked at all times.
3. Try to be sure that the abuser does not have a set of keys to the car.
4. Try to get your keys before the abuser does—always keep your set of keys hidden from abuser.
5. Keep your car parked in places where the abuser will not look for it.
6. If you need glasses to drive, have an extra pair in the car in case the abuser takes/destroys the pair you wear.

## D. To prevent the abuser from entering your home:

1. Get locks on doors and windows. Get double keyed deadbolts for doors.

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* Domestic Abuse Intervention Services (Fall 2001). *Volunteer Training Manual.* Please contact for permission to reprint, 608-251-1237.

2. Keep keys out of sight of abuser. If abuser has set of keys, change locks.
3. Reinforce/repair windows and doors.
4. Obtain alarm or dog.
5. Move to another residence.
6. Get peephole installed.
7. Keep doors and windows locked at all times.
8. Never let abuser into your residence.
9. Install outdoor lights.

## E. Inform neighbors, friends, and relatives of the abuse:

1. Give friends, neighbors, and/or relatives permission to call the police.
2. Set up signals asking for help of indicating danger with these people such as:
    a. Flicking on and off the lights.
    b. Set up a password/sentence which indicates something isn't normal.
    c. A curtain in a certain window is open or shut.
    d. A plant that usually hangs in a certain window isn't anymore.
    e. SCREAM! (scream "fire")
    f. Knocking on the wall
3. Don't give information to untrustworthy people or people that like or trust abuser.
4. Get the OK with friends, neighbors, etc. to come to them in the middle of the night.
5. Teach your children how to call the police. If possible, develop a signal with them.

## F. Telephone

1. Get one if you don't have one.
2. Change your number and make it unpublished.
3. Refuse to argue with abuser on the telephone.
4. It is legal to tape your own phone conversations: you can tape calls from abuser to document abuse.
5. Keep all important/emergency numbers near the phone.
6. Hide a phone in your home to prevent abuser from disconnecting it.

## G. Money:

1. Open a personal account separate from the abuser's.
2. Put aside some money for emergencies. When purchasing groceries or other items, write the check for over amount and put money in your personal account. Borrow money from relatives, banks, and hide it or put it in you bank account.
3. Hide money where it is easily accessible to you.
4. Sell rings, silver, antiques, and other items of value so you have ready cash.
5. Get travelers checks and keep them hidden.

## H. Personal Items:

1. Keep personal items prepared in case you must leave in a hurry. These could include: clothing, medication, baby needs, car seat, cash, personal hygiene products, valuables, addresses/phone numbers, glasses, important papers (driver's license, birth certificates, etc.)
2. Keep items with friends, neighbors, or relatives.
3. Hide important items somewhere (under spare tire, wrapped in freezer, or rent a locker at the YMCA, airport or train station.)

## I. Important papers and documents:

1. Keep important papers and documents prepared in case you must leave in a hurry. These could include: birth certificate, marriage license, divorce decree, social security card, insurance policies, bank papers, stock accounts, bank mortgages, care title, paycheck stubs, driver's license, etc.
2. When possible, keep important papers in safety deposit box at bank.
3. Always have easy access to originals or copies.
4. Hide papers with friends or relatives.
5. Wrap and hide in freezer, plants, etc.
6. Always carry your restraining order with you.

## J. Children:

1. Even small children are affected by violence: explain it to them.
2. Inform babysitter, schools, medical facilities, parents of your child's' friends, etc. that the child should not leave with the abuser.
3. Develop a safety plan with children to use when they are scared or when you give them a signal (where to hide, when to leave, how to call the police).

## K. If there are weapons in the house belonging to the abuser:

1. Hide or throw away all ammunition.
2. Hide weapons or lock them away in the trunk of a car to which the abuser doesn't have keys.
3. Put knives in inaccessible places.
4. If law enforcement is called, ask them to take away the weapons.

## L. Hiding places

1. Be aware of your surroundings.
2. Know good places in your house to hide (close to windows or doors for easy escape if necessary.)
3. Make an escape plan from each room. Get rope ladders hidden in upper story rooms for escape.
4. Make a "safe" room in your house which has a lock on the door, a phone, and from which you can escape the house.
5. Do not lock yourself into a small space such as a car (windows can be broken) or into a room with only one exit.
6. Be aware of your physical capabilities—can you outrun your abuser?
7. Hide underneath a car, in a ravine, shed, etc.
8. Lock yourself in a stranger's car rather than your own if you don't have the keys to drive away.
9. Don't count on a stranger's help.
10. Know in advance where you will go if you need to leave your house.

## M. How to protect yourself when being attacked:

1. Be aware of the abuser's cues (physical behaviors, circumstances) before assault. Try to leave before the assault.
2. Know ahead of time what you are capable of doing to defend yourself, such as gauging eyes, kick to knee or crotch, run, etc.
3. Never pick up a weapon unless you are sure you will use it. (The danger is that when you become afraid to use it, the abuser might take it and use it against you.)
4. Black pepper, chili powder, salt or hairspray in the eyes of the attacker can be effective.
5. If all else fails, roll up in a ball and protect your head.
6. Find a self-defense class in your area. Check it out. If it feels safe and fulfills your needs, take it.

# SOMEONE WHO BELIEVED IN THEM HELPED THEM TO RECOVER*

People who have significantly recovered from mental illness frequently say they were greatly helped by someone who believed in them. One woman stated that there was a doctor who..."believed in me. She never gave up. She was the only one who didn't give up as far as [my] being in the hospital." Another woman stated that for her it was a caring therapist. She said, "He was the first person I encountered out of the ordeal that actually had some sort of feeling. He was sympathetic at least and was understanding. He was really helping me out and motivating. Motivating me to keep on fighting, don't give up...Don't let them get their way, just keep on fighting."

> A nurse working with me reflected that the most important elements to her recovery were, "Having a mentor, a connection and a relationship...someone I made a strong connection to and they made one to me and they believed in me and I knew it...There was a knowing in their eyes that I saw that said I see you and I really believe in you. Someone that carried me. Somehow that encouraged me to not fall backwards."

Another woman in describing the residential counselor as the most important person in her recovery stated, "She believed in me...She sent me a card that said, 'keep up the good work.' She saw a spark in me. She told me from the start I had a good deal going for me. She helped encourage me and put courage in me. She gave me incentive."

The people who work in residential services are often the ones whose belief made a difference in someone's recovery. Jim is an example of such a worker. For 8 years he has patiently and respectably offered his heart and hand to consumer/survivors. Recently he described a priceless moment with a consumer/survivor, Eric, that everyone else had written off. During a walk with Eric, Jim commented on the beauty of the sky, Eric replied, "It is of no importance to me now; why are you telling me about it."

Jim was delighted. It was one of the first times that Eric had expressed a strong emotion directly to another person. It was also one of the first times that he stated that his needs were different from those of others. Jim thinks that Eric now feels safe enough to express strong feeling within their relationship. Over several years, Jim has carefully won Eric's trust through listening to his deepest requests. For instance, Eric has bitterly complained that he has not felt alive on his major tranquilizer. Jim has been able to help Eric to negotiate a much lower dose. Though in the past Eric suffered increased paranoia when his medication was lowered, he has not done so this time. I am sure this is because of his close relationship with Jim which has allowed him to feel safe with greater feelings. Eric has also started to listen to different music. For many years he would only listen to heavy metal which Jim felt

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* Daniel B. Fisher, M.D., Ph.D. © 1999. National Empowerment Center, Inc. All rights reserved. Available at: http://www.power2u.org/recovery/someone_who.html.

he needed to listen to because it was needed to drown out his painful thoughts. Now Eric is able to listen to soft rock and folk.

When I asked other staff about Jim they said he reminds them of Yoda, the wise being from "Star Wars." When he walks into a room everyone feels a sense of calm and peace, yet he can be firm. A consumer called and was abusive to him on the phone. He calmly said, "I won't talk with you when you treat me that way. When you can have a civil conversation call me back." In a few minutes she did and they had a productive conversation. He has a sense of humor. One day a consumer was getting very angry on the bus. Others felt threatened, but Jim suddenly burst out laughing and so did the consumer. When I asked Jim what he felt was most important in his relating with consumer/survivors, he said, "I just accept them, the real person. Then they will present more and more of themselves to you." Such an elusively simple description of the beauty he weaves.

> Jim's manner reminds me deeply of the contact I yearned for and occasionally found in my own journey to recover my own lost self. After a year with an emotionally remote analyst, I sought a different kind of therapist, one that was more human and showed more of himself to me. I made one request at the start of our therapy. "Could you please be a real person with me?" He said he would try to and the combination of his acceptance of my request and his humility planted the roots of trust. There were many tests of our relationship, but he was consistent in his support of me at a deep level. When I told him I wanted to become a psychiatrist he said he would be there for my graduation and he was, even though I was no longer in therapy with him. When I would thank him for an insight he would insist that I had done the work and the healing. He said he had merely provided the setting. When I asked how he felt about my attending a group with another therapist. He said he trusted that I knew what I needed to heal.

Equally compelling is the centering and spiritual renewal coming for the person who does the believing in another. Whether it is for our children, lover, pet or person in need of help, there is deep meaning for the person who can step outside their world to support another's. A client I had seen through many hospitalizations recently had a long period free of such episodes. She clearly had a new light in her eye. When I asked what had changed she said now that she was working as a provider she had a sense of meaning and purpose in her life. Helping others gave her sufficient meaning that she felt her life was worth living.

These observations recall the research of Carl Rogers into the nature of the helping relationships. He stated that "the safety of being liked and prized as a person seems a highly important element in a helping relationship." (On Becoming a Person, 1961). Martin Buber also describes the importance of having someone believe in you. He calls this characteristic "confirming the other... Confirming means accepting the whole potentiality of the other. I can recognize in him the person he has been created to become." Rogers goes on to state that "if I accept the other person as something fixed, already diagnosed and classified... then I am doing my part to confirm this limited hypothesis. If I accept him as a process of becoming, then I am doing what I can to confirm or make real his potential."

These descriptions, however, were mostly for people with moderate emotional problems. When someone is labeled with mental illness, it is as if all that has been learned to be helpful in therapy is thrown out. Medical students are taught to medicate not to converse with mental patients. They are told that people labeled with mental illness have a brain disease and you cannot talk to a disease. Our lived experiences speak otherwise. Our lives show that people labeled with mental illness need a therapist and other people who believe in them.

We who have been labeled with mental illness, remain just as human if not more so than others who are temporarily not labeled. Our needs are human needs of which the most basic is to enter into trusting, loving, and caring relationships. These relationships need to be nurtured and cultivated for us to find the compass of our true self to guide our recovery. Any system of care which disturbs or interferes with these relationship is preventing not promoting recovery.

# THE IMPORTANCE OF HOPE*

I could go back and gripe about my past. It was the standard horror story about the tiniest of little girls suffering incomprehensible sexual, physical, and emotional abuse. It was the story of the teenager who ran away to live on the streets and numb her pain with drugs. It was the story of the woman who married a man just like her father only to see the cycle of abuse continue. And throughout it all, the story of horrible voices and terrible thoughts hurtling me toward self-destruction.

I could write about all that, but what's the point? I can't go back and change a damn thing about it. The best I can do is use it as a learning experience. So this story isn't about all that old stuff. This is about living. This is not about undoing past wrongs, but building a strong, independent woman from them. I have been reborn as a fresh, whole human being!

So how did this rebirth happen? It was purely by accident, and probably because I was ready at last. My life had crashed again. I had just moved back to Wisconsin from Hawaii—a single mother with no income. I was almost totally non-verbal and very poorly functioning; I was just barely existing. The school year was ending and I received a message from the school counselor that I really must get my son into therapy; his behavior was just too much for the teachers to handle. Matt had already seen every kind of counselor, psychiatrist, psychologist, and social worker in his six years and none of them had made an ounce of difference. I put the note aside and went on with my non-life. But as summer passed I began to think I'd better show the school that I was at least trying, so I picked a name out of the phone book and set up an appointment. For the first three sessions, half of the time was spent with Matt alone, and the other half was spent with the two of us together. At the end of that third session the therapist pulled me aside and told me that he thought he would be able to help Matt, but to really be effective I would need to get therapy myself.

I was astounded. Of all the times Matt had been counseled, never once had anyone suggested that I should get help! Of course I was mad. But then I thought about all the times that I'd been hospitalized and given various psychiatric diagnoses. I'd always rejected the thought that there was something wrong with me, so I'd never followed through with the meds or other recommendations. This would be my chance to prove all those doctors and this psychiatrist wrong! I agreed to start my own therapy.

That in itself was an eight-year journey. I had gotten lucky and chosen a very patient and empowering therapist. For the first six months I said almost

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* Judie Robson, Wisconsin Consumer (December 2001). Bureau of Community Mental Health, WI Department of Health and Family Services, *Recovery and the Mental Health Consumer Movement in Wisconsin.* Used with permission of the author. Please contact the author for permission to reprint, 920-236-1276.

That in itself was an eight-year journey. I had gotten lucky and chosen a very patient and empowering therapist. For the first six months I said almost nothing—just the "name, rank and serial number" type of information. But then one day the therapist was offhandedly disclosed something about a mean name his father called him when he was young. The dam broke and I started weeping. I hadn't cried once since I was about six years old; I didn't think I could cry (or laugh) anymore. That was the turning point. Slowly but surely I started trusting and revealing the tangled mass that was my past. I started taking tiny, uncertain steps toward recovery. Each time I said, "I can't," my therapist would gently suggest that I could. He showed faith in my abilities to grow and learn and finally I have a satisfying life. He gave me HOPE. I went from an extremely introverted, isolated, barely-functioning human being to a woman who began asserting herself, taking care of herself, and actively working toward a better future. That hope was intoxicating! It gave me power that I never knew I had. By the time I quit seeing my therapist five years ago, I had earned by second bachelor's degree, been working full-time for three years and was showing signs of frequent happiness.

That's not to say that therapy alone helped me, but it gave me the hope I needed to do other things. I needed medications and started taking them consistently, except for a two-year period when I had no insurance. I also began to build a very small social network and became more active in my community.

> The best thing is that I didn't stop learning and growing when I stopped therapy. That hope was so firmly implanted in me that I've continued on and haven't given up, even when I have a small back-slide. I don't have a perfect life, and I certainly have all the same stressors that everybody else has (whether suffering from a mental illness or not), but I've learned that I can cope with them and move on.

**I'm not a hero, or even a great role model. I'm just a person with hope, and I realized that I have the ability not just to survive, but thrive!**

# RECOVERY IS WORTH THE HARD WORK*

So you come to a point where you want to change things in your life. You are depressed, unhappy, have difficulty in relationships; feel an awful aloneness. This aloneness can be a very painful feeling, akin to a kind of deadness or inner emptiness or a sense of void. Your coping skills are not working. You can feel suicidal, hopeless and helpless. And yet even when one wants to change, the process of change is extremely difficult. It takes tremendous courage to change one's view of the world. We learn our view of the world as children. If parents were there sometimes and other times not, we learn the world is not a consistent kind place. One can be in serious psychological pain and yet to change is like climbing Mount Everest. The patterns we know, though they bring us pain, are what is familiar to us and what we know.

One of the hardest things for me to understand and learn to control is the whole flight or fight response. I know for me and many of my friends the response is such an automated part of one's life that it is hard to see the mind body connection. My boss at work is upset over something and I want to run and hide, the sense of danger is overwhelming. The whole stress response can overtake my life. In a panic attack one can feel like one is dying. In an attempt to get out of this response I am trying several techniques. I am very excited about the Yoga classes and massages at Cornucopia and Yahara House. Nothing is worse than when someone tells you to relax, just relax. One has to learn to relax. Grounding techniques, visual image, etc. and trying to feel safe. It is extremely hard to live with the anxiety; it feels like the body is racing and racing, and each second can be excruciating.

> Another kind of anxiety that can be tremendously debilitating is "separation anxiety". When I was born my mother was very depressed and wanted me to be with her. The whole process of separation and individualization did not occur. A part of her wanted to let go of me, but her own anxiety at being without me and alone was overriding. Kindergarten was the teller of the future to come. I cried hysterically and was told that I was too emotionally disturbed for school. The nun put me in a room by myself because I disturbed the other kids. My mom told me that the teacher was evil and after me. A horrible and terrible year full of depression and nightmares. The whole world was angry with me. My mom would throw me out the door and tell me to go to school sometimes, but most of the time I stayed home. My mom and I were totally intermeshed. In high school we wore some of the same clothes. And then when I was 24 she died and I was out in the world alone. This kind of anxiety makes one feel totally immobilized and unable to function when one is alone. Step by step, and sometimes very painfully, I had to learn to be alone. My mom was so

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*Anonymous (2002). Written for the *NPW Consumer Curriculum.* Permission to copy this article has been granted by the author.

scared of losing me that if I just was upset and went to my room, she was scared that I was going to kill myself. She was terrified of being alone without me.

The words that help me understand myself are the holding introject. For the infant and child to gain significant autonomy, two qualities of experience are essential. The first is narcissistic, related to feelings of personal value; the second is "holding and soothing". Good-enough mothering in early life usually provides essential holding and soothing. With time the holding and soothing provided by the parents is internalized, first as holding interjects and then as psychic structure. If however the mothering is not good enough in providing holding and soothing in the phases of separation-individualization, the child cannot hold and soothe herself and must depend on external objects to provide it. An example of holding and soothing oneself is if one has a bad day at work, the kind nurturing parent tape says things like everyone makes mistakes, it is ok to make mistakes, it might be helpful to watch something funny on TV, a hot cup of hot chocolate might feel good. My parent tape from my mom in this situation would be to tell myself it is not ok to make mistakes, I was a terrible bad person and I would feel like cutting to comfort myself. My mother couldn't soothe and comfort herself so she could not give me these skills.

So if one in childhood does not acquire these soothing and comforting skills one must look externally for it; which is to turn to other people. Thus it becomes a problem when sufficient interaction with external holding self objects (other people) is not existent and intense separation anxiety takes place. This then ensues a rage with a forthcoming regression. This separation is an incredibly painful feeling, akin to a kind of deadness or inner emptiness, or a sense of void. One can feel that one simply does not exist. With the regression, the separation anxiety can lead to annihilation anxiety which can causes suicidal feelings. This anxiety is related to the loss of self and psychic structure. Thus under this sway of regression, one tries through fusion and incorporation, to retain the self-object.

In my life this was played out in a dramatic way. When I first got help, I saw a psychiatrist who gave me for the first time in my life, the soothing and holding neither of my parents where able to give me. It felt so good to have someone to lean on, someone to talk to about my feelings, someone that gave to me unlike my parents who I nurtured as a child. However, from the psychosis from my schizoaffective disorder I deteriorated during the 4 years I saw him. I kept failing at every job I did and my self-esteem was eroded. So in my psychosis I attempted a very serious suicide attempt. I was at work and my experiments kept not working out, so I just lost it to the delusion of my evilness and that I had to kill myself. I was in intensive care for three days and do not remember any of that. Consequently, my psychiatrist said that he could not see me anymore and that I should go on disability and be in the public sector where I could get more help than just he could do. With the extraordinary separation anxiety and regression I became totally psychotic. The pain was unreal, just excruciating. I remember my psychosis of wanting to kill my psychiatrist and myself, but I don't remember the actual reality of telling the nurses this. Due to my threats I then ended up in Mendota. At this point my psychiatrist clearly diagnosed my as having schizoaffective disorder and clearly psychosis. He had also treated my mom the last year of her life and saw the impact of her mental illness on me.

Unfortunately I did not get the help the psychiatrist wanted for me and I just kept getting more and more psychotic. The person that visited me from crisis in Mendota said to me that therapy had fucked me up. I kept calling crisis and they told me not to call anymore. As my current therapist said, that did not mean that my needs went away. In an attempt to fuse back with my psychiatrist I wrote him letters practically every day.

Without any help from the system, I went into my own world of voices and delusions. I lost all contact with the world. People talked to me, but I didn't understand anything they said. I was hospitalized voluntarily 3 times, but I was just seen as borderline and manipulative. The voices told me to get in my car and that they were taking me to a monastery where I would get well. On the road to the monastery the voices told me to trust in God and take my hands off the wheel and I did. I went into a tree and miraculously survived. Fortunately someone saw the accident and called an ambulance. I regained consciousness in the emergency room.

I did not realize that I had an accident. I was hospitalized; but the psychiatrist attributed the accident to borderline acting out and screamed at me, saying that I was a lawyer trying to get money from the accident. This is so ludicrous. As my lawyer friend just told me years later you can't sue a tree. They released from the hospital with no med changes and wanted me to go to the grow program which I thought was on the planet mars. And then my delusion became that I had to have a kidney transplant and go to into a coma and then my old psychiatrist would help make me well. I was trying to fuse back with him so he could give me self soothing. The hospital charged me with trespassing and I ended up in Winnebago for 4 months. When I arrived in Winnebago they told my Dad that I was so psychotic that I would never come back into reality. Fortunately they were wrong.

The good part of this story was that after being released from Winnebago, I went into a group home, got an excellent therapist who specialized in borderline personality disorder and schizophrenia. Also upon leaving the group home I went into a CSP. With the adequate soothing and holding from social workers and my therapist and learning how to incorporate this into my own skills each year, I get better and better. I have psychosis; but with the better medications and help in coping skills, I am learning how to handle it so it does not interrupt my life. I have worked part-time for the last 8 years.

In June 1999 I joined Yahara House which has helped me tremendously. When I come into the building people say HI and it makes me feel so welcomed and part of the community. I feel safe here. It is a place where people appreciate the strength and courage it takes to deal with mental illness. For example, I recently was offered a job interview and came to work support dinner to talk about my anxiety. Again it is about adding skills to my self- soothing and kind nurturing parent tape. We talked about not obsessing about the interview, that I could just see if I wanted the job and that I could believe in my competency. The more one learns these skills the less anxiety one has and the more competent one feels. It is important that one is not treated like a child and just nurtured and cared about, rather it is about incorporating these skills oneself so one can be an adult in this world and handle the challenges of the adult world. When I look where I was in 1991 when I was in Winnebago to where I am now it is amazing. Recovery is possible and is worth the hard work.

# THERAPY FOR POST-TRAUMATIC STRESS AND DISSOCIATIVE CONDITIONS: WHAT TO LOOK FOR AND HOW TO CHOOSE A THERAPIST*

One of the primary roles of Sidran Institute's Information Service is to assist people who have been traumatized in finding various kinds of help. "Treatment" is usually sought when the behavioral adaptations (usually called "symptoms") typical of trauma survivors become disabling, interfering with work, home life, recreation, sleep, parenting and other aspects of daily function.

Our aim is not only to help people feel better and function better, but also to help them learn to be informed and empowered consumers in general and consumers of mental health services, in particular. We hope trauma survivors find that taking appropriate and well-considered action to improve one's life is made a little easier by the information on this page.

**If you are currently in crisis:** The process of choosing a helpful therapist takes some time, thought, and focus. If you are currently in a crisis, or are worried that you might hurt or kill yourself or someone else, please contact your community's mental health center, hospital emergency room, or crisis hotline. When the crisis has passed, this brochure will help you organize the task of finding a therapist for on-going treatment.

## What is Good Trauma Therapy? A Good Trauma Therapist?

Historically, mental health treatment has been treated according to the "medical model": the "sick" patient treated by the powerful doctor, who has the responsibility, the expertise, and the tools cure the illness. The patient's job is to be compliant and to follow orders. With some practitioners, this model continues to this day.

Recently, however, some therapy models recognize that individual distress is often caused or made worse by poor social, political and economic environments as well as by harmful family dynamics. Trauma survivors are generally best served by therapists who work from an environmental framework, or "trauma model", as they are also more likely to see their clients as experts in their own lives, and as partners in healing.

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* The Sidran Institute © 1995-2002. All rights reserved. Reprinted with permission. Available at: http://www.sidran.org/howtochoose.html. The Sidran Institute, a leader in traumatic stress education and advocacy, is a nationally-focused nonprofit organization devoted to helping people who have experienced traumatic life events. For more information and resources, visit their web site at: www.sidran.org.

Later we will look at some of the different disciplines, approaches and techniques most appropriate to trauma therapy. Suffice it to say, however, that good trauma therapists come from every discipline, work in all settings, use a variety of approaches and techniques, and have a wide range of credentials and experience.

There are aspects, however, that the best trauma therapists have in common. We will start by discussing what constitutes good trauma therapy, and then explore how to find it.

> As Dr. Bessel van der Kolk of Boston University explains, most trauma survivors benefit from one-on-one psychodynamic therapy. It "allows disclosure of the trauma, the safe expression of related feelings, and the reestablishment of a trusting relationship with at least one person".
>
> Therapists do rest much of their practice on the basis of their professional training. But perhaps as much as anything else, they rest their practice on their integrity and personal talents—on their perceptions, feelings, insights, intuition, and the degree to which they can hear unspeakable truths. "Pay *more* attention to the therapist's intellectual and emotional equipment than theoretical system," Dr. van der Kolk advises survivors. "Pay attention to whether the therapist really wants to hear the troubles you have to tell. Ask yourself, 'Do I feel validated? Is the therapist really listening to my story?'"
>
> If validation is one important selection criterion, Dr. Judith Herman, Director of Training at the Victims of Violence Program at Cambridge Hospital in Cambridge, Massachusetts, makes clear a second criterion and one that seems of equal importance: An effective trauma therapist empowers the survivor rather than imposes a cure.
>
> The dual formulation of validation and empowerment seems to be fundamental to post-traumatic therapy.
>
> *Excerpt from* Unspeakable Truths and Happy Endings: Human Cruelty and the New Trauma Therapy, *by Rebecca Coffey, Sidran Press, 1998, pp. 85-86.*

The idea of the therapist and client working together as partners, sharing responsibility and expertise is still radical in many mental health settings. But for trauma survivors, this is in many ways the key to success in therapy.

> When treater and client share the trauma perspective they can collaborate. A shared perspective allows collaboration between the individual, who has expertise on him or herself (the client), and the individual who has expertise on the process of healing (the helper). Helper and client collaborate to identify the central concerns of the

survivor. They work together to improve the survivor's life. Treatment requires both people's active participation. The trauma model is also an empowerment model. The helper has useful information to impart, but is not "the expert" or "the authority" on all matters concerning the survivor. The client is an important member of his or her own treatment team, and everyone on the team needs to collaborate to help the client move forward.

The four most important things a therapist has to offer a survivor are as follows:

- Respect
- Information
- Connection
- Hope

With these four components, any relationship can promote healing.

Excerpt from *Risking Connection: A Training Curriculum for Working with Survivors of Abuse*, K.W. Saakvitne, L.A. Pearlman, S.J. Gamble, and Beth Tabor Lev, Sidran Press, 2000, p. 13.

## Before You Begin

Although many trauma survivors find it difficult, now would be a good time to get a complete physical (medical) examination, especially if you have not had one in the past two years. This is important for at least three and possibly four reasons:

- Many medical illnesses (such as thyroid, diabetes, and seizure disorders) might mask or contribute to mental health conditions and interfere with appropriate psychological assessment and treatment. It makes sense to see your physician first to rule out any potential medical causes of your distress.

- If you are eventually going to see a psychiatrist for prescribing antidepressant, anti-anxiety or other symptom-reducing medications, the psychiatrist will require a current medical evaluation, and will want to consult with your personal physician.

- Posttraumatic stress disorder has both psychological and physiological symptoms. The best way to proceed toward recovery is to attend to medical and emotional needs in a simultaneous and integrated way. Ideally, your physician and your therapist should consult periodically about your progress.

- If you have a trusting relationship with a family doctor, internist or general practice physician, he or she might be a good source of referrals to a mental health specialist in your community.

Before you actually begin the process of selecting a therapist, it is important to have a working knowledge of the range of professional options (and there are many). It is important to remember that credentials do not necessarily ensure quality. Still, qualifications are a good starting point in evaluating a therapist, and should you ever have a harmful therapy experience, you may have some recourse through a complaint to a licensing body or professional association.

## Types of mental health care providers: Alphabet Soup!

The words "therapist" and "counselor" are unregulated, generic terms. They can be used to refer to anyone providing treatment, and can be used as a title by anyone, with no requirement of special training.

In some states, anyone can hang a shingle on their door and practice "therapy" with nothing more than a high school diploma, so beware of "therapists" with unfamiliar titles.
No ethical professional therapist should mind being asked about his or her educational or professional backgrounds. You should likely stay away from individuals who don't have at least a Master's degree (e.g. M.S., M.S.W., C.S.W., M.A.).

### *Psychologists*

In the U.S., Doctors of Philosophy (Ph.D.), Psychology (Psy.D.), or Education (Ed.D.) must complete at least four years of post graduate school, however, only those who have been licensed can call themselves psychologists. Clinical psychologists are specifically trained in assessing a client to determine the problem and to respond by providing treatment. In most states, if medication is needed in addition to therapy, a psychologist will refer the client to a psychiatrist for that aspect of treatment.

However, not all psychologists are experienced therapists. Some specialize in areas such as statistical research or industrial psychology, and may have little experience treating people. Also, don't assume that Ph.D. always indicates a psychologist. Many people have earned Ph.D. degrees in unrelated academic fields, and may decide to practice therapy without being clinically trained or licensed.

### *Social Workers*

Clinical Social Workers (CSW) usually have earned at least a Masters' Degree (two years of graduate school) and some may have doctoral degrees. Clinical Social Workers credentials may vary by state, but these are the most common: B.S.W. (Bachelor's of Social Work), M.S.W. (Master's of Social Work), A.C.S.W. (Academy of Certified Social Workers), or D.C.S.W. (Diplomate of Clinical Social Work. Although there are exceptions, most licensed clinical social workers generally have an "L" in front of their degree (e.g. L.C.S.W.).

## *Marriage and Family Therapists and Professional Counselors*

Marriage and Family Therapists (LMFT), and Professional Counselors (LPC) may have two years of graduate school and have earned at least a Masters' Degree such as: M.A. (Master of Arts), M.S. (Master of Science) or M.Ed. (Master of Education). Marriage and Family Therapists have additional specialized training in the area of family therapy.

Professional Counselors, most typically drug or alcohol abuse specialists -- C.A.C. I, II, or III (Certified Addiction Counselors) -- may have a variety of more generalized training in the area of psychology and counseling. A *Counselor* may or may not have a master's degree. Counselors are trained for supportive therapy. They usually focus on behavioral problems not clearly classified as mental illnesses. Counseling is usually less intensive than psychotherapy.

Many other categories of professionals also provide mental health care services in private practices or in agencies.

***Pastoral Counselors*** are clergy, who have the credentials M.Div. (Master of Divinity) or Th.D. (Doctor of Theology) and have a degree from a seminary or rabbinical school, with additional training in therapy.

***Psychiatric Nurses and Nurse Practitioners*** comprise a growing segment of mental health treatment professionals. They display the credentials R.N. (Registered Nurse), R.N.P. (Registered Nurse Practitioner) or M.S.N. (Masters of Science in Nursing). A Psychiatric Nurse Clinical Specialist is a registered nurse with a master's degree who has been trained in individual, group, and/or family psychotherapy.

***Psychiatrists,*** M.D. (Medical Doctors), complete a medical degree like any other physician, followed by a four-year psychiatry specialty. Psychiatrists' fees are likely to be the highest of all mental health providers. In this day of managed care, psychiatrists rarely provide "talk therapy". It is generally not necessary for a person with a trauma disorder to use a psychiatrist as a primary therapist. However, for those who have complex or co-occurring medical and mental health conditions, a psychiatrist has the advantage of being a trained M.D. Psychiatrists often work together with other non-medical psychotherapists to provide prescription and medication management services when needed.

The term ***psychoanalyst*** refers to any therapist trained in or practicing in the Freudian or analytic styled psychodynamic approach.

***Hypnotherapist*** refers to anyone trained in or practicing hypnosis. A twelve-step *Sponsor* or a *Mentor* can provide support for those seeking help, but they cannot take the place of a psychotherapist.

A 1997 *Consumer Reports* readers survey showed people in therapy generally rated psychologists, clinical social workers, and psychiatrists about as equally effective. Marriage counselors were rated significantly worse, according to patient's rating of their own improvement.

In general, the most helpful therapists are:

- genuine,
- willing to share information about themselves as helpful and appropriate,
- have respect and a high positive regard for their clients,
- are warm and empathic,
- responsive and hopeful,
- have firm boundaries but are not domineering.

Helpful therapists also have:

- a variety of clinical skills to address the specific needs of the client;
- an understanding of the power imbalance that exists in therapy and a willingness to work towards empowerment of the client;
- a view of the client as the expert on his or her own life and as an active partner in therapy.
- awareness of their own biases and the limits of their skill, and willingness to refer you to other professionals if necessary.

Consumers of mental health services have contributed to the following list of things to look for in a therapist:

- Find a therapist you feel comfortable with. Therapy is not an easy process and your therapist is not there to be your friend.
- Find a therapist who respects your individuality, opinions, and self.
- Find a therapist who will not get upset if you disagree with what they have said, but instead encourages you to express yourself when you do not agree.
- Find a therapist who never minimizes your experiences and always respects your feelings.
- Find a therapist who will not try to force you to talk about things that you might not be ready for.
- Find a therapist that does not spend time talking about their own problems. Those sessions are for you, not your therapist.
- Find a therapist who wants neither a friendship nor a sexual relationship with you outside of your counseling sessions.
- Find a therapist who is more than willing to discuss problems that might arise between the two of you within the therapist/client relationship.
- Find a therapist who will help teach you new and healthier ways to cope.
- Find a therapist who will never make you feel like a failure or cause you to believe they are disappointed in you if you have a slip or a relapse.

## Objectives of Therapy to Address Trauma Issues

Effective psychotherapy for trauma survivors usually involves helping the survivor maintain safety, manage symptoms, and work through the traumatic experience(s). While the techniques employed vary, the primary goals of psychotherapy for trauma survivors are:

- to examine the role of the traumatic experience in the context of the person's life, currently and historically
- to make meaning of the experience
- to learn skills to manage symptoms and to develop alternative ways of coping
- to build or rebuild the ability to trust within a relationship in order to view the world as an increasingly tolerable place to function

There has been a lot of controversy about therapy that focuses on memories of past trauma. Because the nature of traumatic stress is to distort memory in a variety of ways (remembering too much about traumatic experiences or too little, and in some cases both), therapeutic discussions of the meaning of past events are important. It is not necessary to use special techniques to discover hidden memories of violence or abuse. In the course of addressing problems in current daily function, the opportunity to discuss past events and the ability to recall them will evolve naturally as part of therapy.

## Types of Therapy

There are many approaches to therapy, and most good therapists are trained in several and use them in combination. Approaches may be long or short-term, and may be focused primarily on the past or on the present, but all should aim to alleviate distress, and help clients learn how to acquire more effective coping strategies.

***Psychodynamic*** approaches attempt to help the client discover the origins of the problem in the past as well as how it affects life today. A ***Behavioral*** approach tends to focus on changing current behavior with little emphasis on past events. The ***Cognitive*** approach focuses on changing the client's way of thinking, and a ***Family Systems*** approach aims to change unhelpful patterns in families.

Formats for therapy include individual (or one-on-one) therapy, couples' therapy, family therapy, and group therapy. Some therapists use a combination of these formats.

Today, many therapists describe their work as Eclectic, meaning that they draw from a wide variety of approaches in order to best meet the needs of each individual client. Research indicates that the quality of the therapeutic relationship is often more important than the particular methods employed. In therapy for traumatic stress, the relationship is particularly important, as rebuilding interpersonal trust is often a key objective of treatment. The most important thing to remember is that your needs are paramount; choose a therapist whose approach seems most appropriate for you.

## Getting Referrals

You can begin the process by getting referrals. REMEMBER: when choosing a therapist, you are a consumer of service, and it is your right to shop around.

First, make a list of names of two or three therapists from whom to choose. Your family doctor may be able to make a referral for you, although doctors may not know therapists who have particular experience with trauma survivors. Sidran Foundation has a list of therapists around the world who have made a commitment to addressing the needs of trauma survivors. We would be happy to provide names of therapists in your area, from which you can choose. Referral agencies or a women's resource center in your area may also be able to assist you in your search.

You might also ask people you know who've been in therapy to make recommendations. A therapist who's right for someone else may not be right for you, but someone you trust who has actually worked with a particular therapist can share very helpful information.

## The Interview

When interviewing a potential therapist, keep in mind your needs and goals for therapy, as well as the particular qualities you feel are important in a therapist. We often hear about the need for a "match" when selecting a therapist and there is a lot to be said for feeling comfortable with the person you choose. Although your objective is not to build a friendship with the therapist, you will be spending a lot of time together, and you will need to feel comfortable enough to discuss sensitive, confidential thoughts and feelings.

Don't forget (or avoid) talking about money. You need to know before you start how you are going to pay for treatment. Therapists may take a variety of insurance payments: private insurance, Medicare, or state medical assistance; others will offer a payment plan or work on a sliding scale, based on what a client can afford. Rarely, a therapist may offer to do "pro bono" work (treat one or a few clients at no charge). As appealing as this may seem, it is not really a good idea, and may under some circumstances be unethical. This dynamic reinforces the power imbalance that is inherent in the therapy relationship, and the client may come to feel the "debt owed" interferes with therapy.

After the first meeting with the potential therapist, you will need to ask yourself some questions: Did you feel comfortable and able to begin discussing your problems? Did the therapist seem to understand what you were talking about? Did you feel your concerns were taken seriously and that you were treated with respect? Were the two of you in general agreement about the problem and your expectations for therapy? Were you satisfied with the therapist's answers to your questions? Did you feel that you could grow to trust and work with this person?

Pay attention to your intuition; choosing a helpful therapist will require trusting your own thoughts and feelings. Remember that you are a consumer of a service and that it is your right to choose a therapist who best meets your needs.

## Taking Stock

Throughout the course of therapy, you will need to be mindful that your work is productive and continues to be helpful. In helpful therapy relationships, the client feels understood and supported, and while therapy is not always a comfortable experience, there should be a sense of trust and warmth.

If you don't feel respected, valued or understood, or if your experience is being minimized or distorted, it may be a sign that your therapy is not working. If you feel there is something wrong in your therapy, or if you get upset or angry with your therapist, discuss it in your session. If your therapist discounts your feelings or responds in a defensive manner, you can choose to switch to a different, more respectful therapist.

If you are working with a helpful therapist, you will begin to be able to better recognize and understand your feelings, thoughts and behaviors. You will also begin to develop new, more effective coping strategies, and you should have a sense of change and increased satisfaction in your life. Over time, you should begin to feel more and more independent and able to use the skill and insights you are learning in therapy to solve your own problems.

## How do I choose a helper?

Below you will find a list of questions that may help you interview helpers to determine who suits your needs the best. You may find it helpful to take this list with you on interviews along with a pad of paper to record your information.

**Questions:**

1. What are your credentials?
2. What are your specialties?
3. What professional organizations to you belong to?
4. How long have you been conducting therapy?
5. What experience have you had in treating traumatic stress conditions?
6. How do you approach treatment of traumatic stress conditions?
7. What do you charge?
8. Do you accept insurance? If so, what kinds?

9. Do you have a sliding fee scale? If so, how is payment determined?
10. Do you bill people, or is payment expected at the time of the session?
11. How do you protect client confidentiality? Who (besides you) will have access to my files?
12. How long is each session? Are there exceptions to this?
13. Has anyone ever lodged a formal complaint against you?
14. Have you ever been censured by a professional organization?
15. If I were in crisis, would I be able to reach you? How do you handle crises?
16. What is your policy about missed sessions?
17. What is your policy about physical contact with clients?
18. What is your policy about contact outside of the session?
19. Do you arrange vacation coverage?
20. What happens if one of us decides to terminate without the other's agreement?
21. Do you think you can help me?
22. Is there anything I should know about your services that I didn't think to ask about?

**My impressions: check all that apply**

☐ I felt safe and reasonably comfortable
☐ I felt understood and taken seriously
☐ I was treated respectfully
☐ We agreed about the nature of the problem
☐ This feels like it could be a good "match"
☐ My questions were answered adequately
☐ My treatment goals were addressed
☐ This individual is clinically qualified
☐ I can afford it
☐ I can get there with reasonable ease

**Overall impression:**

☐ Good
☐ Fair
☐ Poor

# TREATMENT OF PTSD*

## Introduction

This fact sheet describes elements common to many treatment modalities for PTSD, including education, exposure, exploration of feelings and beliefs, and coping skills training. Additionally, the most common treatment modalities are discussed, including cognitive-behavioral treatment, pharmacotherapy, EMDR, group treatment, and psychodynamic treatment.

### *Common Components of PTSD Treatment:*

Treatment for PTSD typically begins with a detailed evaluation, and development of a treatment plan that meets the unique needs of the survivor. Generally, PTSD-specific-treatment is begun only when the survivor is safely removed from a crisis situation. For instance, if currently exposed to trauma (such as by ongoing domestic or community violence, abuse, or homelessness), severely depressed or suicidal, experiencing extreme panic or disorganized thinking, or in need of drug or alcohol detoxification, addressing these crisis problems becomes part of the first treatment phase.

- Educating trauma survivors and their families about how persons get PTSD, how PTSD affects survivors and their loved ones, and other problems that commonly come along with PTSD symptoms. Understanding that PTSD is a medically recognized anxiety disorder that occurs in normal individuals under extremely stressful conditions is essential for effective treatment.
- Exposure to the event via imagery allows the survivor to reexperience the event in a safe, controlled environment, while also carefully examining their reactions and beliefs in relation to that event.
- Examining and resolving strong feelings such as anger, shame, or guilt, which are common among survivors of trauma.
- Teaching the survivor to cope with post-traumatic memories, reminders, reactions, and feelings without becoming overwhelmed or emotionally numb. Trauma memories usually do not go away entirely as a result of therapy, but become manageable with new coping skills.

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* Modified from a National Center for PTSD Fact Sheet, http://www.ncptsd.org/facts/treatment/fc_treatment.html. Information is presented for educational purposes only. It is not a substitute for informed medical advice or training. Do not use this information to diagnose or treat a mental health problem without consulting a qualified health or mental health care provider. All information contained on these pages is in the public domain and may be copied and distributed without restriction. For more information, telephone 802-296-5132 or email ncptsd@ncptsd.org.

## *Therapeutic Approaches Commonly Used to Treat PTSD:*

- ***Cognitive-behavioral therapy (CBT)*** involves working with cognitions to change emotions, thoughts, and behaviors. Exposure therapy, is one form of CBT unique to trauma treatment which uses careful, repeated, detailed imagining of the trauma (exposure) in a safe, controlled context, to help the survivor face and gain control of the fear and distress that was overwhelming in the trauma. In some cases, trauma memories or reminders can be confronted all at once ("flooding"). For other individuals or traumas it is preferable to work gradually up to the most severe trauma by using relaxation techniques and either starting with less upsetting life stresses or by taking the trauma one piece at a time ("desensitization").

  Along with exposure, CBT for trauma includes learning skills for coping with anxiety (such as breathing retraining or biofeedback) and negative thoughts ("cognitive restructuring"), managing anger, preparing for stress reactions ("stress inoculation"), handling future trauma symptoms, as well as addressing urges to use alcohol or drugs when they occur ("relapse prevention"), and communicating and relating effectively with people ("social skills" or marital therapy).

- ***Pharmacotherapy*** (medication) can reduce the anxiety, depression, and insomnia often experienced with PTSD, and in some cases may help relieve the distress and emotional numbness caused by trauma memories. Several kinds of antidepressant drugs have achieved improvement in most (but not all) clinical trials, and some other classes of drugs have shown promise. At this time no particular drug has emerged as a definitive treatment for PTSD, although medication is clearly useful for the symptom relief that makes it possible for survivors to participate in psychotherapy.

- ***Eye Movement Desensitization and Reprocessing (EMDR)*** is a relatively new treatment of traumatic memories which involves elements of exposure therapy and cognitive behavioral therapy, combined with techniques (eye movements, hand taps, sounds) which create an alteration of attention back and forth across the person's midline. While the theory and research are still evolving with this form of treatment, there is some evidence that the therapeutic element unique to EMDR, attentional alteration, may facilitate accessing and processing traumatic material.

- ***Group treatment*** is often an ideal therapeutic setting because trauma survivors are able to risk sharing traumatic material with the safety, cohesion, and empathy provided by other survivors. As group members achieve greater understanding and resolution of their trauma, they often feel more confident and able to trust. As they discuss and share coping of trauma-related shame, guilt, rage, fear, doubt, and self-condemnation, they prepare themselves to focus on the present rather than the past. Telling one's story (the "trauma narrative") and directly facing the grief, anxiety, and guilt related to trauma enables many survivors to cope with their symptoms, memories, and other aspects of their lives.

- ***Brief psychodynamic psychotherapy*** focuses on the emotional conflicts caused by the traumatic event, particularly as they relate to early life experiences. Through the retelling of the traumatic event to a calm, empathic, compassionate and non-judgmental therapist, the survivor achieves a greater sense of self-esteem, develops effective ways of thinking and coping, and more successfully deals with the intense emotions that emerge during therapy. The therapist helps the survivor identify current life situations that set off traumatic memories and worsen PTSD symptoms.

## Psychiatric disorders commonly co-occurring with PTSD

Psychiatric disorders commonly co-occurring with PTSD include: depression, alcohol/substance abuse, panic disorder, and other anxiety disorders. Although crises that threaten the safety of the survivor or others must be addressed first, the best treatment results are achieved when both PTSD and the other disorder(s) are treated together rather than one after the other. This is especially true for PTSD and alcohol/substance abuse.

### Complex PTSD

Complex PTSD (sometimes called "Disorder of Extreme Stress") is found among individuals who have been exposed to prolonged traumatic circumstances, especially during childhood, such as childhood sexual abuse. Developmental research is revealing that many brain and hormonal changes may occur as a result of early, prolonged trauma, and contribute to difficulties with memory, learning, and regulating impulses and emotions. Combined with a disruptive, abusive home environment which does not foster healthy interaction, these brain and hormonal changes may contribute to severe behavioral difficulties (such as impulsivity, aggression, sexual acting out, eating disorders, alcohol/drug abuse, and self-destructive actions), emotional regulation difficulties (such as intense rage, depression, or panic) and mental difficulties (such as extremely scattered thoughts, dissociation, and amnesia). As adults, these individuals often are diagnosed with depressive disorders, personality disorders or dissociative disorders. Treatment often takes much longer, may progress at a much slower rate, and requires a sensitive and structured treatment program delivered by a trauma specialist.

# RECLAIMING YOUR POWER DURING MEDICATION APPOINTMENTS WITH YOUR PSYCHIATRIST[*]

Meeting with a psychiatrist during "medication appointments" is usually a very disempowering experience. The meetings usually last for 15 or 20 minutes. During the meeting we are expected to answer a few perfunctory questions and to leave with prescriptions for powerful drugs that can dramatically alter the quality of our lives. In these meetings the psychiatrist assumes a position of power and we usually fulfill the expected role of being a quiet, unquestioning, passive patient. Subsequently we will be praised for merely being compliant or scolded/punished if we fail to comply with prescribed medications. Over the years I have developed a number of strategies for changing the power imbalance during medication meetings with psychiatrists. I would like to share some of these strategies with you.

## *Strategy #1: Learn to think differently about medication.*

1. **There are no magic bullets.** Recovery is hard work. No pill can do the work of recovery for me. If I sit back and wait for a pill to make me better, I will not get better. If I patiently wait for a drug to cure me I may become a chronic, helpless patient who swallows pills on command, but I will not recover. Recovery means taking an active stance towards the problems and challenges I face.

2. **Medications are only a tool.** Psychiatric medications are one tool among many other tools that I can use to recover. Physical exercise, eating well, avoiding alcohol and street drugs, love, solitude, art, nature, prayer, work, and a myriad of coping strategies are equally important to my recovery.

3. **Using medications is not a moral issue.** There was a time when I thought using medications was a sign of weakness or that people who no longer used medications were better than I was. I no longer think this way. There is no right or wrong way to recover. What matters to me is taking care of myself in such a way that I have a chance to become the best person I can be. There are periods of time when I do not use medications and there are times when I do. It is a personal choice that I make.

4. **Learn to use medications.** Today I do not simply take medications. Taking medications implies a passive stance. Rather I have learned to use medications as part of my recovery process. Learning to use medications within the recovery process means thoughtfully planning and following through with medication trials, medication reductions and/or medication withdrawal.

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[*] Patricia Deegan, Ph.D. © 1999. National Empowerment Center, Inc. All rights reserved. Available at http://www.power2u.org/selfhep/reclaim.html.

means thoughtfully planning and following through with medication trials, medication reductions and/or medication withdrawal.

5. **Always use medications and coping strategies.** There are many non-drug coping strategies that can help alleviate symptoms and distress. Take the time to learn strategies for coping with voices, delusions, paranoia, depression, obsessive thinking, self-injury, flashbacks, and so forth. I have found that learning to use a variety of non-drug coping strategies helps to minimize the amount of medications I take or, with practice, can actually eliminate the need for medications.

6. **Learn about medications.** It is easy to feel intimidated by all the big words and technical jargon that get used about psychiatric medications. However, there are a number of ways that I have found helpful in getting reliable and accessible information about the medications I am considering using. I am careful to ask the psychiatrist I am working with about the medication he/she is prescribing. However, I often find this information insufficient. A great source of information is talking with other people who have used the drug. Perhaps the cheapest and easiest way to get more information is to ask a pharmacist who will give you a written fact sheet describing what the drug is supposed to do, what the unwanted effects are, and precautions including drug interaction information. These drug fact sheets are written in nontechnical jargon, but unfortunately leave out a lot of detail that might be important to you. If this is the case you can always ask your pharmacist for drug-insert information. The drug-insert information is essentially the same information that is contained in the Physicians Desk Reference (PDR). It is printed on a small roll of paper and inserted in the box of medications that the pharmacist receives. There is a lot of technical jargon in the insert but the information is more thorough than the fact sheet. In addition you can go to the library and use the Taber's Cyclopedic Medical Dictionary to look up words you are not familiar with. There are also a number of good books that can help you get answers to your questions. These include Clinical Psychopharmacology Made Ridiculously Simple (John Preston and James Johnson, published by MedMaster, Inc.) or Instant Psychopharmacology (Ronald Diamond, published by W.W. Norton) or Toxic Psychiatry (Peter Breggin, published by St. Martin's Press) or Natural Healing for Schizophrenia (Eva Edelman, published by Borage Books, Eugene Oregon) or Living Without Depression & Manic Depression (Mary Ellen Copeland, published by New Harbinger). If you have access to the Internet there are lots of resources including these:

- Dr. Bob's Psychopharmacology Tips at http://uhs.bsd.uchicago.edu/~bhsiung/tips/tips.htmll.
- Healthtouch, with an excellent data base of over 7,000 prescription and over the counter drugs at http://www.healthtouch.com/level1/p_dri.html.
- Medline at http://www/ncbi.nlm.nih.gov/pubmed.

## *Strategy #2: Learn to think differently about yourself.*

1. **Trust yourself.** You know more about yourself than your psychiatrist will ever know. Begin to trust yourself and your perceptions. Sometimes I found it hard to trust my perceptions after being told that what I felt, thought, or perceived, was crazy. Part of recovery is learning to trust yourself again. Even during my craziest times there was a kernel of truth in all of my experience. If you are experiencing unwanted drug effects such as a feeling of apathy, constipation, loss of sex drive, double vision, or the like, trust your perception. Don't let others tell you that such side effects are "all in your head." Check with the pharmacist, or with friends who have used the drugs, and check the books or the Internet. Chances are that you are not the first person to have these drug effects.

2. **It's your recovery.** Too often I have heard people say that "the drug made me feel better." Don't give all the credit to the chemical! Even if you found a drug helpful, look at all the things you have done to get well and stay well. A drug can sometimes open a door, but it takes a courageous human being to step through that door and build a new life.

3. **Your questions are important.** Anyone who has been on psychiatric drugs for a period of time is probably going to ask these important questions:

- What am I really like when I am off these medications?
- What is the "real me" like now?
- Is it worth taking these medications?
- Are there non-drug methods I can learn to reduce my symptoms instead of using medications?
- Have my needs for medications changed over time?
- Do I have tardive dyskinesia that is being masked by the neuroleptics I am taking?
- There are no long-term studies on the medication I use. Am I at risk? Do I want to take the risk of not knowing the long-term effects?
- Am I addicted to these medications?
- Has long-term use of these medications resulted in memory loss or decreased my cognitive functioning?

There is nothing crazy about having such questions. What is unfortunate is that most mental health professionals do not recognize that these questions are to be expected. A recovery oriented system would have detox centers and other supports available so that people could plan a rational withdrawal from medications in order to explore these important questions.

## Strategy #3: Think differently about psychiatrists.

1. **Most psychiatrists are too busy for our own good.** We would be wrong to assume that most psychiatrists have a thorough knowledge of their clients' treatment history. In an age of managed care psychiatrists have less and less time to spend with more and more clients. Many psychiatrists have never read the full case record of the people they prescribe medications to. Even fewer could identify all of the various drugs and drug combinations that you have tried over the years and what the outcomes of those drug trials were. In light of this I have found it important to begin to keep my own record of what medications I have tried, for what symptoms, at what dosages, and for what period of time. Whenever a psychiatrist suggests a new drug or a new dose, I always check my record just to be sure it hasn't been tried before. I don't want to repeat ineffectual or even harmful drug trials.

2. **Psychiatrists often have conflicting interests.** It would be comforting to think that psychiatrists were serving our individual interests. But this assumption would be naive. Many psychiatrists complain of the competing interests that tear at the ethical fabric of their practice. Especially if I am working with a psychiatrist who is part of a managed care system, I feel it is important to ask what, if any, caps on services he/she is working under. In other words, some psychiatrists receive their paychecks from managed care corporations that require them to prescribe one type of drug rather than others that are expensive. If this is the case, we should have this information!

3. **Sometimes psychiatrists are wrong.** Most psychiatrists do not encourage us to seek second opinions regarding diagnosis, medications, or other somatic treatments such as ECT. However, at certain times I have found it important to seek out a second opinion. Even with a managed care plan or if you are on Medicaid or Medicare, it is possible to get a second opinion on an issue you deem important. It can take a lot of work, phone calls and even a friend to help advocate, but it can be done and you are worth it!

4. **Psychiatrists are not experts on everything.** Most psychiatrists believe in the primacy of biology. Most have a mechanized and materialist world-view. Thus, chances are that if you have a diagnosis of major mental illness and you talk to your psychiatrist about ecstatic spiritual experiences, mystical experiences, psychic abilities, or similar experiences, these will be perceived as crazy or symptomatic. One way of taking back your power is to recognize that you have control over what you share with a psychiatrist and what you choose to keep private.

A meeting with a psychiatrist need not be a confession! Talk with mystics about your mystical experiences. Talk with psychics about telepathy, etc.

## Strategy #4: Prepare to meet with your psychiatrist.

1. **Set your agenda for the meeting.** I have found it important to set my agenda for a meeting with a psychiatrist rather than simply reacting to what he/she does or does not do. In order to set an agenda it is important to define your immediate goals. Possible goals might include starting medication, discussing a medication change, planning for a medication reduction, planning for a medication withdrawal, checking for tardive dyskinesia, finding a solution for unwanted drug effects, or reporting on a medication trial. Try, if possible, to set one goal for each meeting.

2. **Organize your thoughts and concerns.** I have also found it important to prepare ahead of time for a meeting with a psychiatrist. I have developed a form that helps me organize my thoughts and to put things in writing. A copy of this meeting preparation guide is available through the National Empowerment Center.[6]

3. **Be specific.** The more specific we can be about our concerns, the more control we can exercise during a meeting with a psychiatrist. For example, if a psychiatrist begins a meeting by asking, "How is that new medication working?" a vague answer would be "Oh, it's helping a little I think." Imagine how empowered you would feel if, instead, you were able to answer, "Well, before I began this medication trial I was so depressed that I missed seven days of work, spent 14 days in bed and lost 3 pounds. But during the last two months, since starting the drug and using the new coping strategies, I have only missed 2 days of work, have regained the weight I lost and I have only spent 4 days cooped up in my apartment." Notice how this level of specificity puts you squarely in the driver's seat of your life and positions the psychiatrist as a co-investigator, as opposed to being the authority over your life. Getting this specific may sound difficult, but it is not. It simply requires that you learn how to record your medication and/or self help trial on a daily basis and that you summarize this information before seeing your psychiatrist. A guide to recording your medication and/or self-help trial is available through the National Empowerment Center.

4. **Write your questions down.** Write your questions down before seeing your psychiatrist. Bring the questions with you to the meeting. My experience is that these meetings can be stressful and that having my questions written down allows me to relax a bit. If you are considering trying a new medication, be sure to ask the following questions:

- Exactly how will I know if this medication is working for me?
- How long before I should start to notice an effect from this medication?
- What are the unwanted effects or side effects associated with this drug?
- If I should experience unwanted side effects, what should I do about it?

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[6] Available through the National Empowerment Center by calling 1-800-POWER-2-U.

- How can I contact you if, during this medication trial, I have questions or concerns I want to check out with you?

5. **Role-Play.** Sometimes it can be helpful to role-play with a friend or someone you trust before seeing your psychiatrist. Learning to talk to a psychiatrist from a position of personal power is a skill that can be learned and must be practiced. Be patient and give yourself time!

## Strategy #5: Take charge of the meeting.

1. **Bring a note pad and pen to the meeting.** Most of us have had the unnerving experience of talking to a psychiatrist while he/she busily jots notes that we never get to see. Bringing your own note pad and pen, and taking your own notes is a good way to break the habit of being a passive patient. It gives you something concrete and active to do while in the meeting. Writing notes can also help you remember important points.

2. **Tape-record the meeting.** I can get very anxious when meeting with a psychiatrist and thus a lot of information passes by me. I have tape-recorded meetings so that I can listen to them afterwards and pick up on the information I may have missed. I have always asked permission before recording. Although some psychiatrists don't feel totally comfortable with the idea (they fear lawsuits), all have agreed to it when I explain why I am taping the meeting.

3. **Announce your agenda at the beginning of the meeting.** If you have done your meeting preparation work, then you know what you want to get out of the meeting with your psychiatrist. There have been many times when I bring two copies of a one-page, written statement of my agenda, concerns, and observations to the meeting. I hand a copy to the psychiatrist and begin the meeting by reading my statement out loud. My experience has been that most psychiatrists initially object to my starting this way. They are accustomed to starting meetings with their own agenda, which is usually vague and centered on the notion that they will observe me for significant clinical signs and symptoms while I answer the questions. But if I insist on beginning the meeting with my statement and assure them they can talk later, I find they soon come to understand the value of my preparation. In fact, some of the psychiatrists I work with keep the copy of my agenda and statement and add it to the clinical record. For a sample copy of an opening statement, contact the National Empowerment Center.

4. **Bring a friend or advocate.** Many people bring a friend or support person when they see a dentist or have a physical exam. It makes sense to bring a friend to a meeting with a psychiatrist, especially when you are first breaking out of the role of passive patient and are learning to reclaim your power.

These strategies have worked for me. Together these strategies have helped shift the balance of power between me and the psychiatrist I am working with.

Perhaps some of these strategies will make sense to you. I am sure that you will come up with your own strategies as well. What is important is to realize that you can take your power back and become the director of your own recovery and healing. If you would like a free information packet with a guide to meeting preparation, organizing your own medication/self-help trial, and a sample meeting agenda statement, just call our toll free number (1-800-POWER2U) and we'll be glad to send you one.

# HOW TO TALK WITH YOUR DOCTOR ABOUT YOUR MEDICATIONS[*]

## Questions:

1) I feel (choose what applies):

dizzy
tired
hungry
nauseous
wired (can't sleep)
a bad taste in my mouth
my hands tingle
can't sit still
stiff
legs shake
blurry vision
dry mouth
constipation
diarrhea
difficulty with sexual functioning
discharge from breast/nipple
skin rash or acne
sunburned easily
headache
hand tremor, shakiness
difficulty urinating
movements I can't help (arms, head, face)

**How can we change either the dose of kind of medication I am taking so this doesn't bother me so much?** Sometimes medication dosages can be adjusted without having to stop them altogether. Reducing the dose may reduce side effects of make them go away. For many conditions there are a number of medications that can be used that have different sets of side effects. One of them may produce side effects that bother us less.

2) **If I can't stand the side effects how do I get my doctor to listen to me?** Don't just stop taking your medications, but you need to be assertive on this point. If you let your doctor know that the side effects are so unpleasant that you might stop taking the medication if they don't go away, your doctor will probably work with you. However, when we start a medication there is a period of time when side effects are worse. Have patience through this time, but ask your doctor how long you can expect it to go on before your body gets used to the meds. The final point is not to "cry wolf" about this. Reserve this alternative for time when you really can't stand it.

3) **Will I become addicted to the medicine?** Only with benzodiazepines is there a risk of developing "tolerance" or need to increase the dose to get the same effect over time. That is why benzodiazepines are prescribed cautiously, and usually only for a short time.

4) **What happens if I stop taking my medicine without telling my doctor?** Many medications can have very unpleasant side effects if stopped abruptly. The main case where stopping abruptly would cause a life-threatening condition is with benzodiazepines. However, it is never a good idea to just stop taking medication without consulting a doctor.

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[*] Wisconsin Coalition for Advocacy (June 1996). Advocacy Training Manual (pp. 123-124). Community Mental Health Protection & Advocacy Project. Please contact for permission to reprint, http://www.w-c-a.org.

5) **Do I have to stop gradually or all at once?** Most often, gradual reduction is recommended. If we develop a serious side effect, the doctor should stop the medication immediately or very quickly if it is safe to do so.

6) **Will I have to take it all my life?** Those of us with "treatment resistant mental illness" (who have several episodes of psychosis, or who have had to try several medications before we found one that worked) will probably have to take psychiatric-related medication all of our lives. Because of this, clear doctor-to-patient and patient-to-doctor communication is crucial, especially about side effects. It is also important to do what we can for ourselves by eating right, exercising, sleeping on a regular schedule and doing relaxation exercises. All of these "wellness" activities can reduce our need for medication.

7) **What happens if I forget to take my medication?** Usually, if we forget to take medication and are a couple of hours or half a day late, it is recommended that we take the dose when we realize we have missed it. Then we should resume our regular schedule. If the dose missed is more than half a day late, we should not double it or take additional medication. We should simply pick up at the next scheduled dosage and tell the doctor if we feel any symptoms that bother us.

8) **What if I leave town and forget to bring my medicine?** If we leave town without our meds we should find an open pharmacy (many towns have 24 hour pharmacies) and call our psychiatrist to have our prescription telephoned in.

9) **What happened if I run out and the pharmacy is closed?** Many pharmacies have an emergency telephone number. Find out what it is and put it in some place where you can easily find it (like our "Emergency Contacts" sheet). If that doesn't work, you can call your hospital emergency room.

10) **If I run out of medicine and my friend or family member has the same medication, can I take theirs?** Do not take other people's medications! They may be a different brand, dosage, age, or even type of medication (the kind of medication in the bottle may not be the same as what is on the label). Call your doctor and get him or her to phone in a prescription.

11) **Do I have to take medicine just because the doctor says so?** Those of us on Mandatory Outpatient Treatment (MOT) are ordered by a court to take the medications prescribed by our doctor. We do not have the legal right to refuse medications. For all of the rest of us, if we want to refuse medication, we need to make sure we understand what the medications are supposed to be doing for us, the risks of wither taking or not taking them, and the alternative treatments available. If we are able to demonstrate to a court that we understand all of those things, and the court does not feel we will become a danger to ourselves or others, we do have the right to refuse to take medication.

*However, in deciding to try going off medication, many of us have found it is essential to work it out with those folks who are our "support team". That includes our doctor, case manager, family, roommate, and good friends. We have found that making sure those who care about us learn about our meds, their side effects and* *signs of relapse helps everyone approach this in a calmer way, and respond quickly and effectively if things start to go wrong.*

# TAKING MEDICATION SAFELY[*]

> *A woman who has dealt with chronic mood swings for many years and has finally been well for several years says, "I have learned as much as I can about the medications I take. I am very in tune with my body and this helps me in discussions with my doctor. I have read everything I can find about these medications in books, medical journals, the* Physician's Desk Reference, *psychiatric drugs books, and newsletters. I also learn what I can from television and videos."*

The decision to use psychiatric drugs to treat your mood disorder is a decision only you can make. Your decision should be based on the best information available from health care professionals who are truly experts in this area and from your own research. Lack of information can lead to misuse of medication or cause harmful interactions between drugs.

This chapter will help direct your research strategy and will explain how to approach drug therapy in a way that offers you optimal benefits and maximum safety.

Choosing the appropriate medication regime takes time and persistence. Your medication must be tailored to you since your response to a particular medication, and the side effects you experience, are physiologically unique. Just because a member of your support group reports excellent success with Prozac, for instance, does not mean that you will find it helpful. I know that lithium causes me to experience severe tremors, yet a friend of mine can take it without getting them.

Seventy-three percent of the individuals who responded to the research questionnaire for my study said they use psychotropic (mood-altering) drugs to help them keep their moods stable. Of that group, 80 percent said the medication gives them at least some relief from symptoms. Some use long-term medication therapy, which they complement with self-help strategies to enhance their medical treatment. Others use medications for the short term to help strategies to enhance their medical treatment. Others use medications for the short term to allow time to work on issues, set up systems, learn management techniques, and make lifestyle changes that promote and enhance wellness. Some people sense that their moods are too unstable at present to allow them to do this work without the biological support medications can provide.

The most commonly used medications by people in the study were lithium, other mood stabilizing medications, and a wide variety of antidepressants. Some people also take antipsychotic medications and medications that address specific problems such as sleep and anxiety.

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[*] Copied with permission from New Harbinger Publications. Mary Ellen Copeland (1994). Living Without Depression & Manic Depression: A Workbook for Maintaining Mood Stability (pp. 49-67). Oakland, CA www.newharbinger.com.

In some cases the physician is unable to find any medication or combination of medications that relieves symptoms. In other cases, people who find that psychotropic drugs are effective opt to forego them for the following reasons:

- They fear the long- or short-term side effects.
- They feel medications diminish their quality of life.
- They feel that the medications interfere with normal sexual function, memory, intellectual capacity, coordination, vision, digestion, and so on.
- They feel like a failure if they have to use medications to manage their life.
- They have ethical reasons for refusing medications.
- They experience intolerable side effects.

Other people chose not to use medication because they are uncomfortable with the idea of using any medication for the rest of their lives. Some people in my study said lifelong drug therapy makes them feel like they have an incurable illness.

**You may have your own reasons for not taking psychotropic medications. What are they?**

____________________________________________________________

____________________________________________________________

____________________________________________________________

Given your reasons, is your decision in your best interest? If you are unsure, read on.

## Non-Drug Therapies

Psychotropic drugs are not the only therapy available to you. Your health care professional may recommend non-drug therapies such as electroshock treatments or light therapy. See the section on seasonal affective disorder in chapter 5.[7] Find out as much as you can about any recommended therapy before you give your consent. Make several copies of the treatment form that begins on the next page so that you can record the information you obtain. Be sure to add this information to your personal medical files.

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[7] This refers to the book Living Without Depression & Manic Depression: A Workbook for Maintaining Mood Stability

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## Treatment Information

Treatment name: ____________________

Other possible names of this treatment: ____________________

How does this treatment work? ____________________

What do you expect it to do? ____________________

How long or how many treatments will it take to achieve that result? ____________________

How often will I have this treatment? ____________________

Where will I have it? ____________________

What are the risks associated with taking this treatment? ____________________

What kind of effectiveness track record does this treatment have? ____________________

What possible short-term side effects does this treatment have? - ____________________

What possible long-term side effects does this treatment have?

Is there any way to minimize the chances of experiencing these side effects? If so, what are they?

Are there any dietary or lifestyle suggestions or restrictions when using this treatment?

Why do you recommend this particular treatment?

Have you had other patients that have used it? If so, how have they done?

How is this treatment monitored?

Do you have any printed information on this treatment I can have to study?

Where can I get more information about this treatment?

______________________________

______________________________________________________________________

______________________________________________________________________

What tests will I need prior to this treatment?

______________________________________

______________________________________________________________________

______________________________________________________________________

How often will I need these tests while having this treatment?

_________________________

______________________________________________________________________

______________________________________________________________________

What symptoms indicate that the treatment should be changed or stopped?

________________

______________________________________________________________________

______________________________________________________________________

## Making an Informed Choice

Since you are the one who ultimately has to live with the effects of your treatment, don't leave the decision to your doctor. You may need to do your own research so you can intelligently discuss your options with your professional health care team. You may even wish to keep up with the latest scientific research by subscribing to relevant newsletters or journals. People in my study said they found this helpful.

Follow the lead of the individual in my study who said:

> *I have learned everything I could about the medications I take. This has taken personal long-term research. I read the Physician's Desk Reference, and cross-reference that with other sources of information. And I also ask a ton of questions and record the responses and any information acquired. I know that these drugs can cause damage if not monitored carefully. I feel as if I know more than the doctor. It is my body and I always like to know what I am putting in my mouth.*

If you don't do your own investigation, you could unwittingly injure yourself. My experience with lithium illustrates this point. When I was taking lithium, I wasn't aware of how important it was for me to maintain body fluids. A brief episode of acute gastrointestinal symptoms caused severe tremors. Fortunately, a quick trip to the emergency room for intravenous replacement fluids alleviated the problem.

**Lithium Toxicity.** The shaking I experienced was a sign that lithium had reached toxic levels in my body. Diarrhea and nausea also signal the onset of lithium toxicity. If you experience any of these symptoms, contact your physician immediately.

Because lithium is commonly used to treat manic depression and, less commonly, depression, let me share with you the dynamics that lead to lithium toxicity.

Lithium toxicity is an ever-present danger whenever you lose copious amounts of body fluids, whether through sweating when you are working outdoors on a hot day, or when you're sick with diarrhea or vomiting.

Your body needs a certain amount of sodium to perform normal body functions. When you sweat and lose body fluids, you lose sodium along with the fluid. The body tries to maintain its salt level by adjusting the filtering system in the kidneys so less salt then usual gets lost.

According to an informative report in the newsletter of the Topeka, Kansas, Depressive and Manic Depressive Association, "lithium and sodium are almost identical and your kidneys can't tell the difference between the two. When the kidney's filters hold in salt, they also conserve lithium that would normally pass out of your system. That means the amount of lithium in your body remains high. This can cause symptoms of lithium toxicity including shaking, nausea, and diarrhea."

You can counter this effect by using plenty of salt in your diet when you are working outdoors in the heat. Taking extra salt may make the symptoms disappear quickly, because the salt will cause the filters in the kidneys to release the accumulated lithium. (If you are on a sodium-restricted diet, be sure to consult your physician about the right course of action.)

If you get a flu bug, or diarrhea, contact your doctor for advice on how to manage lithium through your illness. Do NOT stop taking lithium or adjust the dosage without consulting your physician first.

Do make sure you are getting plenty of fluids. It is also essential to get your thyroid tested, on a regular basis, since lithium can sometimes cause hypothyroidism. (For more information on lithium, contact the Lithium Information Center which is listed at the end of the chapter.)

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## Working With Your Doctor

The more you know about your own body and the idiosyncracies of the medication you are considering, the better off you are. To ensure your safety, a thorough medical examination should precede any new medication regime. Have your health care professionals make sure that you have no health conditions that could be worsened by a particular medication.

A good medical history will help your doctor choose wisely from the available array of drugs. When you are discussing your options, be sure to tell your doctor if any of the following apply to you:

- You are allergic to any medicine.
- You are breast feeding.
- You have seizures, high blood pressure, heart disease, or glaucoma.
- You are taking blood pressure medication, antihistamines, or any other (prescription or nonprescription) medicine.
- You have any other medical problems.

### Questions To Ask Your Doctor

When you are considering any new treatment regime, there are two immediate issues to consider: length of treatment and length of time on medication before you will feel better. There is currently much discussion in the mental health field about the pros and cons of long-term use of antidepressant and mood stabilizing medications. The potential for long-term damage is reason enough to seek out a physician who is an expert on psychotropic drugs and has up-to-date information on the most current scientific research.

Be sure to ask how long it will take before you'll notice positive effects from the medication. You may not see any improvement for several days to several weeks. Don't expect to feel better overnight. The improvement is likely to be gradual. In fact, most medications take from two to three weeks to work.

Beginning on the next page is a form for recording pertinent information about particular medications. (Before you record any information on this form, you may want to make several copies of it for later use for other proposed medications or treatments.)

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## Using Medicine Safely

Learn everything you can about a recommended medication before you decide if it is the right one for you. Find out what systems of the body it affects, the risks of using it, whether there are side effects that can accompany this drug, and if there are food, vitamins, or other drugs you should avoid when taking this drug. Don't be afraid to ask these same questions of your pharmacist.

### Medication Information

Generic name:

______________________________________________

Product name:

______________________________________________

Product category:

____________________________________________

Suggested dosage level:

________________________________________

How does this medication work?

___________________________________

______________________________________________________

______________________________________________________

What do you expect it to do?

______________________________________

______________________________________________________

______________________________________________________

How long will it take to achieve that result?

_____________________________

______________________________________________________

______________________________________________________

What are the risks associated with taking this medication?

_____________________

______________________________________________________

______________________________________________________

What is the effectiveness record of this medication?

What short-term side effects does this medications have?

What long-term side effects does this medication have?

Is there any way to minimize the chances of experiencing these side effects? If so, what are they?

Are there any dietary or lifestyle suggestions or restrictions when using this medication?

Does this medication cause any adverse reactions when taken with certain other medications? If so, describe them.

Why do you recommend this particular medication?

Have you had other patients that have used it? If so, how have they done?

How is this medication monitored?

What tests will I need prior to taking this medication?

How often will I need tests while on the medication?

What symptoms indicate to you that the dosage should be changed or the medication stopped?

Do you have any printed information on this medication I can have to study? Where can I get more information about this medication?

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If you are already taking medication for depression or manic depression, make sure you follow the guidelines below. Check off those steps that have been or need to be taken.

1. You are under the supervision of a physician who is an expert in the use of psychotropic medications. (Your physician has the responsibility to fully inform you of all risks and benefits of any medication prescribed, whether you ask or not.)

   ☐ I am under the supervision of a physician who has the appropriate expertise.

   ☐ I need to find such a physician.

2. You know the potential side effects of any medication prescribed for you and take personal responsibility to know what goes into your body and what the known side effects are.

3. You have the regular blood tests required for the medication you are taking.

   ☐ I have been given the regular tests required for the medication I am taking.

   ☐ I need to check with my doctor and make sure I am having the required tests for the medication I am taking.

4. You do not change the amount of medication you are taking or stop taking the medication without consulting your physician. (Systems for medication changes and discontinuation vary with each medication and must be monitored carefully to avoid potentially serious reactions. If you are having severe side effects and cannot reach your physician, contact another physician who your doctor have previously recommended as a backup, and ask how to deal with the situation.)

   ☐ I understand that it is dangerous for me to adjust medication dosages in any way. If I feel a change is necessary, I will be in touch with my physician.

5. You are completely honest with your physician if you have forgotten to take the medication a few times, or didn't renew the prescription on time. This will allow your physician to accurately assess the effectiveness of the medication.

6. You give your supporters copies of this information and choose one person you trust who can help you find out what you need to know about medication when you are not well enough to do it yourself.

   ☐ I have designated _________________________ to help me when I cannot do it myself.

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## Making Your Pharmacist Part of Your Safety Team

Consider your pharmacist an active member of your health care team and choose someone who takes a personal interest in you. Also make sure that the pharmacy has a good reputation and a computerized record-keeping system.

I know from personal experience that this is very important. There was a time when I was taking Tegretol, a medicine to control severe mood instability. The medicine helped stabilize me and I was doing well. When symptoms started to recur, my doctor tested the level of the drug in my blood and found that it was below the therapeutic level. He assumed that my body was not absorbing the drug, so he increased the dosage.

At the same time, I ran out of the old prescription and had it refilled. I immediately began having symptoms that indicated I was taking too much Tegretol. When I investigated, I found that the old prescription had been recalled because that batch was not at the correct strength. Unfortunately, my pharmacy—which was part of a large drugstore chain—hadn't taken the trouble to notify me. It took me four months to recover from the effects of changing the strength of the medication and taking too strong a dose. Since then, I've used a small but reputable pharmacy where the pharmacist knows me well.

A good pharmacist will set up a system on the computer that will keep track of how many pills you have left in an old prescription when you change medications. If you ask, the pharmacist could require you to return leftovers before giving you the new prescription. This can eliminate a person's ability to hoard pills for a suicide attempt during a period of severe depression. Consider asking your pharmacist to set up this safeguard for you if you have ever been suicidal or thought of hoarding pills. Check the steps below that you have taken or need to be taken.

☐ My pharmacist takes a personal interest in me, and the pharmacy itself is reputable and uses computerized record-keeping systems.

☐ I need to find a pharmacy that meets all of the above conditions.

☐ I have asked my pharmacist to assist me in preventing suicide by monitoring my purchase of medications.

## Taking Responsibility for Your Treatment Regime

Taking medication can become so routine that it is hard to remember whether or not you have taken your daily dose. One way to make sure you do is to take an empty egg carton, mark each egg container with a day of the week, and fill that container with the medicine you need for that day. A quick glance at the carton will tell you whether or not you've taken that day's medicine. Other people prefer setting out their medicine for the day in cups—one for morning medicine, one for afternoon medicine, and so on. Pharmacies also sell small containers that can be used.

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Some people find that making a simple checkmark on a daily chart does the trick for them. Others make a daily note in a log designed to provide an accurate long-term record of medication use and symptoms experienced.

If you need to take your medication at a certain time each day, a watch with a timer or a small inexpensive timer that you can purchase at your pharmacy can be a helpful reminder.

Don't be hard on yourself if you forget to take your medication. It is not a personal failure. We all forget. Establish a system for yourself that will most easily resolve the problem. When you realize you have missed several doses of medication, check with your physician to see if you should take the missed doses or continue with the regular single dose.

## Guidelines for Taking Medications

Here are some additional safeguards. They were developed by Mary Moller, MSN, RN, CS, of The Center for Patient and Family Mental Health Education in Nine Mile Falls, Washington.

1. Take all medications exactly as prescribed.
2. If the medication may make you drowsy or less alert, curtail activity accordingly.
3. Do not share your medication with others. You never know how your medication could affect another person.
4. Keep all medications in a cool, dry place. Bathroom moisture tends to destroy the effectiveness of medication.
5. Keep all medications out of reach of children and pets.
6. Be sure you have enough medications before vacations and holidays.
7. If you are pregnant or planning on becoming pregnant, tell your physician. Many medications can have a harmful effect on a pregnancy, especially during the first three months.
8. If you are planning to use an over-the-counter medication such as a cold medicine, ask the pharmacist if it can be safely taken with your prescription drugs.
9. Keep all medication in the original bottle. Never mix two medications in one bottle.
10. Remember to tell all your doctors and dentists that you are on medication.

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## Managing Side Effects

Unfortunately, some psychiatric medications that are very effective can cause unwanted side effects. Many of them are manageable. But if you find that you have checked any of the dangerous side effects listed below, report them immediately to your doctor. Don't wait!

- ☐ blurred vision
- ☐ rash or hives
- ☐ nervousness, irritability, shakiness
- ☐ wanting to sleep all the time
- ☐ confusion
- ☐ fainting, seizures, or hallucinations
- ☐ nausea and vomiting
- ☐ slurred speech
- ☐ lack of coordination, stumbling
- ☐ jerking of arms and legs
- ☐ seizures or fainting
- ☐ complete stopping of urination
- ☐ changes in sex drive, impotence
- ☐ rapid or irregular heartbeat
- ☐ sore throat or fever
- ☐ insomnia
- ☐ restlessness, incoordination
- ☐ giddiness
- ☐ numbness in hands or feet
- ☐ mental confusion
- ☐ stomach pains
- ☐ swelling of hands or feet
- ☐ ringing in ears
- ☐ large increase in urination
- ☐ infection
- ☐ changes in menstrual cycle

Some common side effects of psychotropic drugs include constipation, dizziness, dry mouth, dry skin, headaches, impotence, irritable bowel syndrome, loss of libido, nausea, tardive dyskinesia and dystonia, thought deficits, tremors, water retention, and weight gain. These side effects can often be managed.

You may find that the side effects you experience are most severe when you begin the medication. After your body adjusts, they may diminish or disappear. I've noticed that I tire easily during the first several weeks I begin taking a new medication. I deal with it by adjusting my schedule so I have less to do and can get more rest.

There are other safe, simple, and effective ways to deal with such side effects. For instance, one man reported that he takes his tricyclic antidepressants with three or four crackers and a full glass of water one or two hours before his bedtime. This helps him avoid stomach upset.

Another says she manages the side effects with exercise, good diet, and a homeopathic medicine for nausea. She accepts her side effects but watches to make sure they don't get out of hand. When they do, she takes it as a warning of an impending episode.

In general, anything that contributes to your overall sense of well-being tends to lessen the incidence and severity of medication side effects. This includes a high-fiber, low-fat diet, plenty of liquids (check with your doctor to find out how much liquid you need with the medication you are taking), daily exercise, and the regular use of stress-reduction techniques. You may find, as many people do, that when life begins to feel "out of control," side effects tend to get worse. See chapter 5, "Developing a Lifestyle That Enhances Wellness," for ideas on how to adjust your lifestyle to enhance your sense of well-being.

Here are ways to minimize or eliminate specific side effects:

**Constipation.** Many psychotropic medications cause dryness, which increases the likelihood of constipation. This can be prevented by eating high-fiber foods such as whole grains, fruits and vegetables and by getting daily exercise. Using a dietary fiber additive that contains psyllium husks and drinking a quart to a gallon of liquid daily helps elimination. Nonpresciption stool softeners may also be helpful.

**Diminished sex drive and impotence.** When you tell health care professionals about diminished sex drive and impotence, they may minimize the importance of this medication side effect. This is not fair. Clearly people who take medications for psychiatric symptoms deserve full sexual expression just like everyone else. Some people decide to switch medications or discontinue their use because of this side effect. Your health care professional should take it seriously.

**Dry mouth.** According to the National Institute of Dental Research, dry mouth is a side effect of more than 400 commonly used medications, including those prescribed for depression. This occurs because you are not producing as much saliva as you need. Saliva is an important plaque fighter and tooth hardener, and its absence can lead to gum disease and tool decay. The National Institute of Dental Research suggests asking your dentist about an artificial saliva to moisten your mouth.

Some people in the study said they eat hard candies to eliminate dry mouth. However, this also causes dental problems. There are many sugarless candies on the market which can be used as a substitute.

Again, adequate fluid intake is essential to successfully manage this side effect. Small amounts of water or juice taken frequently help.

**Dry skin.** The use of liberal amounts of creams, ointments, and oils helps to alleviate dry skin. There are many unscented products that are acceptable to everyone. Use as little soap as possible and rinse it off quickly. Adequate fluid intake and a healthy diet also help.

**Headache and dizziness.** Headaches and dizziness may be caused by blood pressure changes. Get up and down slowly. Avoid extreme temperature changes. Consult your doctor about this problem.

**Insomnia.** Adjusting the time of day when you take medications may help to reduce sleep problems. Some medications help you to sleep, so they can be taken an hour or two before bedtime. Those that keep you awake should be taken in the morning. See chapter 5, "Developing a Lifestyle That Enhances Wellness," for more information on how to get to sleep.

**Irritable bowel symptoms** (chronic diarrhea alternating with episodes of constipation, and often accompanied by cramps and gas). Symptoms of irritable bowel syndrome are reported by many people who take psychiatric medications or who have mood instability. It is not clear whether the symptoms are caused by the medications, the stress of the instability, or something else.

A study volunteer said, "This can be very disruptive. I've gone to a gastroenterologist and he did a colon examination, found nothing, and prescribed Immodium, which is now available over-the-counter. It works pretty well to stop the spasms and is easier to carry around and quicker acting that Kaopectate. Immodium is actually a narcotic, but it normally doesn't cross the blood-brain barrier, so you can't get high from it."

Dietary fiber additives that contain psyllium husks and an adequate intake of fluid help but do not generally cure this condition. My gastroenterologist says that it takes two weeks to determine how effective it is to use a fiber additive daily. She also recommends Immodium for those times when diarrhea is inconvenient.

A high-fiber, low-fat diet-accompanied by stress reduction techniques, exercise, and adequate rest-may also help to control symptoms.

**Nausea.** If you experience nausea, taking medication with food or milk may help.

**Tardive dyskinesia and dystonia.** Antipsychotic drugs such as Haldol, Loxitane, Mellaril, Moban, Navane, Prolixin, Thorazine, Tindal, Trilafon, Stelazine are sometimes prescribed to relieve symptoms of major depression and manic depression. Cumulative exposure to these medications can cause severe side effects, including tardive dyskinesia and tardive dystonia.

Tardive dyskinesia causes uncontrollable movement, varying in degree from occasional minor twitches to severe involuntary movement. The most commonly affected area is the face, where there may be abnormal movements of the tongue, jaw and muscles around the mouth and eyes. Involuntary movement of the arms, legs, and torso may also be involved. Occasionally a person will experience an irregular breathing rate, speech irregularities, and weight loss.

Tardive dystonia is characterized by muscle spasms that result in involuntary, painful, sustained twisting and distortion of body parts.

These side effects can continue even after you have stopped taking the medication. The movements can be permanent. There is no treatment for tardive dyskinesia or tardive dystonia.

The risk of getting these disorders is about 30 percent for people who have taken the medication for a total of five years (it is estimated that 400,000 to one million people are affected). Occasionally people who have used these medications for a short time develop symptoms. The risk increases as you get older.

Before you begin taking such medication, you should clearly understand the benefits and risks involved. The more you know about the benefits and risks of antipsychotic medications, the more you will be able to make appropriate choices about your treatment. You have a right to know this information, and the prescribing health care professional has a responsibility to help you understand the risks. If you are not well enough to understand the benefits and risks, have a trusted support person assist you in making this decision.

If you take or are considering taking neuroleptic medications, be alert to any signs of tardive dyskinesia.

- Notify your doctor as soon as you notice any unusual movement.
- Have a tardive dyskinesia checkup every three months. (These checkups must be done by your physician, and take from five to ten minutes.)

It is important to remember that tardive dykinesia can be masked by the sedating effect of the medication. When the medication is discontinued, the symptoms may increase.

To reduce symptoms of tardive dyskinesia and tardive dystonia, take the following steps:

- Ask your physician about using high doses of certain benign agents such as Vitamin E, choline, or lecithin.
- Use relaxation techniques and stress management daily. (Stress worsens symptoms.)
- Soak in a hot bath or whirlpool.
- Use moist application of heat, or use ice to help reduce acute symptoms and pain.
- Exercise to improve posture and strengthen muscles.

**Tremor.** Mild to severe tremor affects many people who take psychotropic medications. Adequate rest and strict attention to fluid intake may alleviate this problem somewhat. Relaxation exercises also help.

Soaking in a warm bath sometimes reduces tremors. The effect is enhanced by use of a whirlpool. There are inexpensive whirlpool units available that fit in the bathtub.

**Thought deficits.** Some people experience thought and memory problems when taking certain psychiatric medication (these are also a symptom of depression). A person in the study said, "One frustrating problem I have is difficulty coming up with a word I want to use—it feels like it gets 'stuck' inside my head." His doctor attributed the problem to the anticholinergic—or drying—properties of his medication. I remember not being able to remember a question long enough to give an answer.

It helps to stay calm when these problems arise. The problem worsens if you get anxious or agitated, but it is minimized if you have a relaxed attitude. It also helps if the people you associate with are understanding and nonjudgmental.

If you are anxious or agitated, do the relaxation exercises in chapter 16, "Responding to Symptoms of Depression," and chapter 18, "Responding to Symptoms of Mania."

**Water retention.** If you are troubled by water retention, tell your doctor. You doctor may want you to limit your salt intake.

**Weight gain.** Weight gain is a common side effect of many medications. If you know a particular medication may cause weight gain, make needed dietary adjustments when you begin using it rather than waiting until after you have gained the weight. It's easier to keep from gaining weight than to lose weight. Weight gain can be minimized by focusing on a diet high in complex carbohydrates (vegetables and grains) and low in simple sugars and saturated fats. See chapters 5,[8] "Developing a Lifestyle That Enhances Wellness," for diet information and the resource list below and at the end of chapter 5 for more information on weight control and dietary issues.

## Resources

American Automobile Association, *RX for Safe Driving*. Heathrow, FLA: American Automobile Association.
*This free booklet describes how drugs affect your ability to drive. To obtain copy, send a self-addressed, stamped envelope to RX For Safe Driving, Mail Stop 600, 1000 AAA Drive, Heathrow, FL 32746-5063.*

Barnhart, E. (1993) *Physicians Desk Reference*. Oradell, NJ: Medical Economics Co.
*This book is updated annually and contains technical information on medications. The book isn't all that accessible to the average reader, but it will give you the information you need to ask your health care professionals the right questions.*

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[8] This refers to the book Living Without Depression & Manic Depression: A Workbook for Maintaining Mood Stability.

Gorman, J. (1991) *The Essential Guide to Psychotropic Medications.* New York: St. Martin's Press.
*Check out medication recommendations in this up-to-date reference.*

*Griffith, H. (1993) Complete* Guide to Prescription and Non-Prescription Drugs. New York: Body Press/Perigee.
*This comprehensive reference provides complete information about prescription and nonprescription medications and explains the differences between brand-name medications and generics, and describes the standards for safe medication use.*

*John Hopkins University (1993) John* Hopkins Handbook of Drugs. Baltimore: John Hopkins University Press.
*Gives information about medications and their side effects to physicians, pharmacists, and the Food and Drug Administration.*

Mondimore, F. (1990) *Depression: The Mood Disease*. Baltimore: Johns Hopkins.
A good, medically oriented reference.

Schein, J., and P. Hansten (1993) *The Consumer's Guide to Drug Interactions*. New York: Collier Books.
*This book provides essential information on the effects of taking several different kinds of medications.*

Wolfe, S., R. Hope, and Public Citizen Health Research Group (1993) *Worst Pills Best Pills II*. NY: Pantheon.
*Lists 364 commonly prescribed medications including 119 which should not be used by some people and 113 that should be used only in a very limited way.*

Yudofsky, S., R. Hales, and T. Ferguson (1991) *What You Need To Know About Psychiatric Drugs*. New York: Grove Weidenfeld.
*This book contains easy-to-understand information about all psychiatric medications, including tranquilizers, sedatives, sleeping pills, anti-anxiety medications, mood stabilizers, antidepressants, and antipsychotics.*

## Diet and Medication

Rosenthal, N. (1993) *Winter Blues*. New York: Guilford Press.
*There is a section in the appendix of this book that gives helpful dietary advice that is useful to people who are taking psychotropic medications.*

Fanning, P. (1990) *Lifetime Weight Control*. Oakland, CA: New Harbinger Publications.
A different and very useful approach to weight loss.

Hoffman, R. (1988) *The Diet-Type Weight-Loss Program*. New York: Simon & Schuster.

*This book helps you determine the diet that will work for you based on your lifestyle and eating habits. I found it to be very useful in developing a weight control program for myself.*

Kirschenbaum, D. (1994) *Weight Loss Through Persistence*. Oakland, CA: New Harbinger Publications.
*An excellent, long-term weight loss program based on up-to-date scientific findings.*

Turner, K. (1987) *The Self-Healing Cookbook*. Grass Valley, CA: Earthtones Press.
*This delightful cookbook shows you how to easily change your style of cooking to one that enhances your wellness. It includes a section on foods that actually help you lose weight.*

## Organizations

### For more information on Tardive Dyskinesia, contact:

Tardive Dyskinesia/Tardive Dystonia National Association
4244 University Way Northeast
PO Box 45732
Seattle, WA 98145-0732

National Institute of Mental Health
Neuroscience Center at Saint Elizabeth's
WAW Building, Room 201
2700 Martin Luther King Jr. Ave. Southeast
Washington, DC 20032

### For more information on lithium contact:

Lithium Information Center
Department of Psychiatry, University of Wisconsin
Center for Health Services
600 Highland Ave.
Madison, WI 53792
(608) 263-6171
*This center is a storehouse of information on lithium.*

Betty Blaska (1990). Hospital and Community Psychiatry, 41, 9, 993-998.

# THE MYRIAD MEDICATION MISTAKES IN PSYCHIATRY: A CONSUMER'S VIEW*

Many consumers of mental health services suffer needlessly as a result of being given the wrong medication or the wrong dosage of the right medication or from other mistakes involving medication. The author, a consumer of mental-health services for many years, discusses seven common medication mistakes: incorrect prescribing as a result of misdiagnosis, excessive dosages of medications, too many drugs, downplaying side effects, overlooking the consumer's expertise, discouraging consumers from learning about their medications, and the prescription-sheet relationship between psychiatrist and consumer. She concludes that although mental health professionals should listen more attentively to consumers, consumers bear the major responsibility for seeing that mistakes in their medication are corrected. Thus they must continue to speak up, raise questions, and keep informed.

I am a consumer of mental health services—a 20-year veteran of the mental health system. Over the past two decades I have had 13 psychiatric hospitalizations, have taken 18 or more different medications, have been a victim of electroconvulsive "treatment", and have had opportunities to talk to and suffer with psychiatric service consumers of all kinds, in hospital settings, in support groups, and in consumer networks. I know too well the grave errors that can be committed when psychotropic drugs are prescribed.

Realizing early on that psychiatry was an inexact and far-from-perfect science that demanded a "buyer beware" stance, I bought my own copy of the Physicians' Desk Reference and studied psychiatric journals. I have also become active in the mental health service consumer movement.

Being a moderate in the movement, I believe psychotropic medications have a legitimate place in the array of treatment options. I am not antipsychiatry, or antimedication. However, I have seen and experienced a great deal of abuse and many mistakes. For example, there has been an alarming trend recently toward involuntary treatment that usually involves prescribing drugs and nothing else. Too many of these patients get seen by a physician only once a month or once every three months, even though more frequent intervention in their drug regimen may be needed. In addition, the general public often become alarmed when mentally ill people quit taking their medication for reasons the public doesn't understand.

I think it is important to remind both the public and professionals that many mistakes are made in prescribing drugs, that psychotropic drug side effects can be

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harrowing, and that mentally ill patients can become frustrated and quit taking their medication when mistakes aren't corrected. In addition, I think consumers who take medications—and most of us will continue to take them—need frequent admonitions to become assertive in our psychiatrist-patient relationships and to take the lead in voicing complaints, observations, and preferences.

## The Consumer's perspective

Recently I was asked to present the consumer's perspective on taking psychotropic medications to a graduate sociology class. In my speech I discussed the hazards of taking psychotropic medication. The following synopsis of my speech outlines seven common mistakes in prescribing medication for psychiatric patients.

**Mistake 1: Incorrect prescribing as a result of misdiagnosis.** Psychopharmacology practitioners' gravest error is misdiagnosis. It usually results in prescribing medications that not only don't help but that also worsen a patient's condition. It is curious that a person who is misdiagnosed rarely gets rediagnosed, despite failure after failure with drug trials predicated on the misdiagnosis.

I suffered from depression from age 12 to 18. When admitted to a university hospital in 1969 at age 18, I acquired the labels "schizoid personality" and "schizophrenia." After drug trials on Melaril and Stelazine, side effects of akinesia and akathisia, worsened depression, and suicide attempts, I threw the pills out and went to a general practitioner—a nonpsychiatric physician—at the university student health clinic. Not mentioning my previous three hospitalizations, I told him that I was a little depressed and needed Elavil (that was what my hospital roommate had said helped her). And it worked! After six years of depression, I felt normal for the first time.

That was back in 1969. But I'm dismayed to see that clinicians are continuing to misdiagnose today, with concomitant prescribing errors and refusal to reassess the diagnoses. In particular, it seems that people with affective disorders are often misdiagnosed with schizophrenia, perhaps because the flat affect and social withdrawal of depression look like the negative symptoms of schizophrenia, and the hallucinations and inflated delusions of mania look like the positive symptoms of schizophrenia.

Mental health consumers will attest to the difficulties associated with medications used for the treatment of schizophrenia. One such difficulty is depression. Johnson[1] found a greater likelihood of depression in patients who were prescribed higher doses of neuroleptics, an excess of depression among patients with drug-induced extrapyramidal symptoms, and an akinesia syndrome simulating depression in 7.5 percent to 12.5 percent of patients free from extrapyramidal symptoms.

In a recent report of several case studies, symptoms worsened in patients with psychosis who were treated with neuroleptics.[2] These patients acquired neuroleptic-induced catatonia, early neuroleptic malignant syndrome, and severe drug-induced parkinsonism; they also became actively suicidal. From the author's discussion I gathered that in these cases, which involved relatively young females, it was more fruitful to view the illness as delusional depression than as psychosis with affective features because neuroleptics in modest doses actually worsened the syptomatology.

**Mistake 2: Excessive dosages of medications.** In my 20 years as a mental health service consumer, I have seen the suffering of people—too many people—who were loaded up on high doses of drugs. Excessive drug dosages usually results in side effects that may completely obviate the intended therapeutic effect. The "therapeutic window" posits that a given drug is effective for a given patient only within a certain range that is neither too high nor too low.

Cohen and Baldessarini[3] discussed what they called an "apparent development of tolerance to the therapeutic effects of antidepressants," followed by attempts to recover an initially positive drug effect by repeatedly administering higher and higher doses. Asberg and colleagues[4] suggested that therapeutic failure might be due to "a too low or too high plasma level" of antidepressant drugs. Likewise, Whyte and associates[5] suggested that "high plasma levels of antidepressants in patients may be associated with rather poor clinical responses."

Although the problem in such cases may be the excessive dosage, the patient gets the label "treatment resistant." Hence the doctor should take note and be more careful, keeping the patient at a low dose a bit longer before raising it. More attention should be paid to the possibility that excessive dosage is causing the treatment failure.

I claim that the patient is the best authority on what dose is effective and what dose is too high. Allergies and chemical sensitivities seem to be fairly common among psychiatry patients, and it may be that the chemical sensitivity to psychotropic medications is especially acute. Because of this sensitivity, prescribers should routinely obtain detailed medication histories form the patient or the family.

In actual practice, persons often seem to do better on lower doses. Corona and colleagues[6] compared patient response to the tricyclic anti-depressant amitriptyline at 50, 100, and 150 mg per day and found that "the better clinical response was with 50 mg doses." Linden and colleagues[7] studied private psychiatrists' drug prescribing and found that amitriptyline was regularly prescribed at low doses. Although the recommended daily range for this drug was 150 mg to 300mg, psychiatrists in this study reported good results with prescriptions of 30 mg to 50 mg per day. Johnson[8] found that among patients with Beck Depression Inventory scores of 11 or more, only 25 percent were prescribed more than 75 mg of a tricyclic antidepressant per day. Thirty-five percent were prescribed less than 75 mg per day—a dose most would call "subtherapeutic." Perhaps we need a revision of what is considered an effective dose of tricylic antidepressants in view of what psychiatrists are commonly prescribing and what patients are experiencing.

Ziegler and associates[9] suggested the possibility "that at some level of total tricylic the therapeutic effect begins to deteriorate" and concluded that "the widely accepted notion that 150mg/day of amitriptyline represents a therapeutic trial is not true for a large percentage of patients." Bridges[10], though, suggesting progressive increases in antidepressant dosages, with pauses to wait for an effect, conceded that "doses that are too high can be as ineffective as doses that are too low." He counseled that if high doses are found to be ineffective, "there is still the opportunity to observe the effect of a reduction." Furthermore, Moller and colleagues[11] have reported unfavorable responses with antidepressants at levels not only too low but also too high.

Why not start with a low dose of antidepressants and cautiously raise it only after no improvement is observed at that low dose? If persons who once responded favorably to an antidepressant stop doing so, even after successively higher doses, perhaps the therapeutic window for those individuals has been moved down the dosage axis. Doses that were once effective may now be too high for the sensitized individual. Alternatively, the patient's depression may have worsened, necessitating higher dosage.

In a recent report of four patients who responded to antidepressants with worsening depression and suicidal ideation not present before treatment, Damluji and Ferguson[12] noted the intensification of depressive symptoms in patients treated with "therapeutic" doses of antidepressants. I would submit that obviously therapeutic doses and therapeutic drugs vary quite widely among individuals.

People on antipsychotic medication are certainly not immune to errors in dosage. In a study of people with schizophrenia, Hogan and Awad[13] found that doses of fluphenazine had been much higher in a group of patients who committed suicide compared with the doses of a matched control group. They hypothesized that increasingly higher doses of fluphenazine may have been given to "counter symptoms that were actually drug induced: the reduced spontaneity, diminished emotional tone, and lethargy of akinesia, or the restlessness, misperceived as anxiety, of akathisia." The drugs may actually have been the culprit in their mortality.

Rifkin[14] pointed out the risk of responding to akinesia with an increased dosage of neuroleptic, a common practice because the condition may resemble negative schizophrenia symptoms. I share his concern about the proportion of persons with chronic schizophrenia who have "unrecognized akinesia, and to what extent [their] apparent symptoms of residual schizophrenia are iatrogenic—due to medical treatment." Also, I like his reminder to medical practitioners: "Our first obligation toward our patients is to do no harm."

Rapid neuroleptization—increasing the dose of neuroleptic rather quickly and aggressively—among new admissions with schizophrenia is being challenged. Miller and Tanenbaum[15] proved the success of using only 12 mg of haloperidol compared with nearly twice that dosage in two comparable populations of men with schizophrenia. They noted that the "desire to increase the speed, completeness, and quality of recovery may be an important factor" in rapid neuroleptization but reported no evidence that higher dosages accomplished these goals. They allowed that 12mg doses might be excessive and that effective treatment with even lower doses might be achievable.

Schulz and Pato[16] concluded in a recent review that "many patients in the United States have received higher maintenance dosed of neuroleptics than necessary." They emphasized the importance of trying to find the lowest effective dose for a given individual with schizophrenia because studies have demonstrated the "low doses may be as effective as routine doses of medication for maintenance of schizophrenia" and "quality of life of patients on lower doses is better than those of standard doses."

A review by Manchanda and Hirsch[17] indicated that a group of patients with schizophrenia on low-dose neuroleptics had the same rates of relapse (22.4 percent) as patients in a high-dose group (20.2 percent). The disadvantages for the high-dose group were more anxiety and depression and a higher score on measures of retardation and akathisia. The reviewers concluded that "the concept of low-dose maintenance medication should gain popularity—among both patients and physicians." Last, in a study of relapse rates in patients with schizophrenia maintained on low-dose neuroleptics, Farone and colleagues[18] found that 12 of 16 patients who stayed in remission for a year after a 50 percent reduction in neuroleptic dose remained stable during a subsequent two year follow-up. In most instances their neuroleptic doses were below the "usual therapeutic range."

**Mistake 3: Too many drugs.** Often when one medication does not help an individual immediately, psychiatrists add a second, a third, or even more medications on the regimen. It is not unusual to see people diagnosed as having schizophrenia prescribed two or three neuroleptics concurrently, and then of course prescribed medication for the side effects of the neuroleptics. People with bipolar illness can be on lithium, carbamazepine or some other anticonvulsant (despite risk of neurotixicity), a neuroleptic, and an antidepressant. Sovner[19] described intraclass polypharmacy—the simultaneous prescription of more than one drug from the same psychotropic drug class—as "almost never acceptable", except transitionally, when switching from one drug to another. Polypharmacy is not inherently bad, but as the Alcoholics Anonymous dictum goes: keep it simple! In relation to psychiatric treatment that means the fewer the drugs, the better.

In the movie *Four Lives,* a documentary about people with bipolar affective disorder, a woman is given lithium for mania and comes out of the manic phase only to go into a depressive one. Her doctor adds an antidepressant, with no remission of depression but no return to mania. He pushes electroconvulsive therapy, but she refuses it. The doctor credits this refusal to "a denial of her illness," an assertion that is ill supported by the woman's own acknowledgements on camera.

The offending drug in this patient's case may have been the lithium. She was not depressed before the lithium; why not try eliminating it? From 20 percent to 40 percent of people with bipolar disorder do not respond to lithium alone.[20] Lithium induces hypothyroidism in some individuals, which is perceived as depression. For patients like this woman there are options other than lithium and an antidepressant, and certainly options other than electroconvulsive therapy. A low-dose neuroleptic may keep her out of mania as well as the lithium does, but without the depression.

Although there are times when two or more drugs may be better than one, the addition of a second drug is not always without complications. One report found that 17 percent of patients with bipolar illness taking both lithium and a neuroleptic developed neurotoxicity (delirium, extrapyramidal effects, or cerebellar effects).[21] Lithium doses were at "therapeutic" levels in both toxic and nontoxic patients, but neuroleptic doses were significantly greater in patients who became toxic. And high-potency neuroleptics were significantly more likely to result in neurotoxicity. The authors questioned whether the benefits of combining lithium with a neuroleptic outweigh the risks and suggested a combination of lithium with benzodiazepines as an alternative.

**Mistake 4: Downplaying side effects.** It is always wise to take the consumer's complaints of side effects seriously. Someone who complains about taking the prescribed medication is likely to have a legitimate reason. I will never doubt a person's objections to drugs because of the harrowing days I spent on Mellaril and Stelazine. I know what it's like to want to die rather than take those drugs at those doses.

A good example of a harrowing side effect is akathisia, which makes a person feel literally unable to sit still. It produces feelings of wanting to climb the walls, intense inner anxiety, and restlessness—a truly unbearable disease.

Drake and Ehrlich[22] reported two cases of impulsive suicide attempts, one by a young man on haloperidol and the other by a woman on fluphenazine, who perceived their symptoms of akathisia (increased anxiety, tension, agitation, restlessness, and psychosis) as a worsening of their illness and concluded that life was not worth living. The authors pointed out that "agitated delusional depression may be inadequately treated or made worse by antipsychotic medications."

Shear and colleagues[23] reported on two men with akathisia who committed suicide by jumping. The men had been experiencing akathitic muscle discomfort, agitation, fidgety feelings, and restlessness from neuroleptics (fluphenazine). Shaw and co-workers[24] reported akathisia, suicidal and homicidal ideation, paranoia, anxiety, tension, and agitation in a 43-year-old man on haloperidol. They suggested that his suicidal ideation may have been a direct pharmacological effect rather than secondary to the akathisia. Unfortunately, many consumers don't complain of drug side effects, especially akathisia, for the not-unfounded fear of having the dose raised. Szabadi[25] reported that "not infrequently the akathisia is made worse by an *inappropriate* [author's emphasis] increase in neuroleptic dosage." Akathisia can be misdiagnosed as an agitation symptom of psychiatric illness, to which the clinician gives more drugs, rather than being seen as an adverse drug reaction, to which the response is less drug[26].

Although Adler and associates[27] prescribed treating neuroleptic-induced akathisia by lowering the neuroleptic dose or switching to lower potency neuroleptics, we've seen both a shift toward higher doses of neuroleptics over the years and a shift from low-potency neuroleptics to higher potency ones.[28] The loser in these trends is the consumer.

A small proportion of patients on antidepressants also experience akathisia[29]. Restlessness, agitation, and hyperactivity have been reported in 10 percent of patients taking antidepressants, and some of these cases represent antidepressants-related akathisia. Psychotropics are not benign drugs.

The doctor who brushes aside patient complaints of side effects is being merciless. A mental health professional who is concerned only with behavioral control and not with the patient's disease will not be an effective and empathic clinician. Furthermore, such professionals should drop all illusions about their "profession."

**Mistake 5: Overlooking the consumer's expertise.** Many of the mistakes previously described come down to one thing: a refusal to see the consumer as an expert on his or her illness. The person with schizophrenia is the authority on his schizophrenia. The person with bipolar illness is the authority on her mood swings. No one should try to subvert these experts' testimony on their illnesses or on their reactions to drugs. Mental health professionals who do not approach a client in this light cannot help that client.

Research has demonstrated that consumers are able to identify what is happening to their bodies when ingesting chemicals. Solovitz and colleagues[30] found that patients were able to discriminate adverse drug reactions from other types of symptoms to a significant degree. In their study, patients correctly attributed symptoms to the target drug 69 percent of the time. And in Manchanda and Hirsch's study[17] of relapse with low-dose neuroleptic maintenance therapy, the authors concluded, "Indeed, the patient may be as able as the psychiatrist in predicting whether he can function without the benefit of continued maintenance treatment."

In my work with consumers in Wisconsin, I am increasingly amazed that the consumers who do the best in maintaining their quality of life and their ability to function on the job are those who consistently push for the fewest drugs and the lowest doses possible—sometimes in the absence or outright contradiction of their psychiatrists.

**Mistake 6: Discouraging consumer education.** I know from the sociology of medicine that specialized jargon and a unique body of knowledge cloak the profession in a mystique that allows mental health professionals a great degree of autonomy and power. That mystique is meant to keep the consumer out. But these are the 1990s. Consumers, and especially consumers of mental health services, are not buying it. We have rights, and we want to be heard.

I count among the best the psychiatrists who encouraged me to learn about my illness, to read the reference books and psychiatric journals, and to be knowledgeable about the drugs I was taking. There was the doctor who lent me books from his library, the one who recognized he had something to learn when I brought in the latest articles on carbamezepine several years ago, and the one who encouraged me to take his "Psychopharmacology Update" seminar.

Conversely, there was the doctor who arrogantly brushed aside the articles I found on monoamine oxidase inhibitors and weight gain, saying he didn't need to read them. There were the ward nurses who wouldn't give me a pass to go to the medical library; they told me I "knew too much already." Finally, there was the resident who complained that I was "trying to play doctor" by reading the psychiatric journals.

It does the mental health professional little good and clients irreparable harm to restrict them from learning more about their illness, diagnosis, drugs, and especially side effects. I do not subscribe to the belief that warning patients of possibly dangerous side effects will cause them to magically acquire them. The benefits of having an informed consumer and good doctor-patient relationship outweigh the irritation that occasionally come with a "hypochondriac" who imagines side effects at the first suggestion of them.

The harm from not knowing about possible side effects is worse. I fell down a whole flight of stairs and later landed facedown on the ground when getting off a bus because I was experiencing muscle ataxia from lithium toxicity and didn't know it. No one had even warned me of lithium toxicity. Carbamazepine can lethally impair white blood cell production. Monoamine oxidase inhibitors interact with tyramine-producing foods to cause hypertensive crises. These potentialities require the consumer to be aware—and to beware. Again, psychotropic drugs are not so benign.

**Mistake 7: The prescription-sheet relationship between psychiatrist and consumer.** A prescription-sheet relationship describes what a consumer has with a psychiatrist who only prescribes drugs. Unfortunately, that's the relationship most of us consumers have with our psychiatrist. Economies of time and money have dictated that we see one professional for medications and another for therapy. Neither treats the "whole person," and neither is really able to do a great job of his or her half. Important clues can be lost when one is divided up so arbitrarily between soma and psyche. The physician needs to know about patient psychology—to see the whole picture of their lives—to understand the drugs' impact on them. The therapist has to consider patient physiology to know what apparently pasychogenic symptoms are in actuality adverse drug effects requiring a medication adjustment.

## Conclusions

To eradicate or decrease these medications mistakes, the consumer must continue to raise questions, keep informed, and listen to his or her body. The medication mistakes I list are common. If consumers are aware that they are mistakes, we can then speak up to our psychiatrists. Professionals, for their part, need to listen to consumers more attentively. However, I hold consumers more responsible for correcting these errors, because I believe we must take responsibility for our lives and our treatment.

I applaud the court decisions that protect citizens' rights to accept or refuse medical interventions, including psychotropic drugs, if they are competent to understand the intended effects and the advantages or disadvantages. As long as there is no cure for psychiatric illness, as long as the biological theories are inexact, as long as drugs are an incomplete or imperfect treatment, as long as drug prescribing is still trial and error, and as long as clinicians continue to make mistakes in diagnosis and prescribing, we cannot humanely allow forced drugging.

Betty Blaska (1990). Hospital and Community Psychiatry, 41, 9, 993-998.

To deny mental health consumers' participation in our own treatment decisions is to strip us of our rights as human beings, as citizens of a progressive and civilized society, and as adults. It is in denying this participation that psychiatry and society contribute to the stigma associated with being a "mental patient." Consumers are pressing for more rights. But we have the rights inherent to our citizenship in a free country. We need to assume responsibilities in line with those rights.

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[30] Solovitz BL, Fisher S, Bryant SG, et al: How well can patients discriminate drug-related side effects from extraneous new symptoms? *Psychopharmacology Bulletin* 23:189-192, 1987

# COPING WITH FLASHBACKS*

## What is a Flashback?

- The involuntary release of fears associated with a traumatic event which may be forgotten.
- A form of spontaneous age regression which is like reliving a specific traumatic event (often forgotten) from the past.

### What Causes the Fears?

Any experience that feels threatening to the physical, emotional or spiritual body. Early fears are often related to the mother's fears. They may result from being an unwanted child, birth trauma or being nursed or fed mechanically. They may also be caused by being ridiculed, ignored or punished for expressing emotions such as anger, grief and fear and needs such as touching and the exuberant expression of love and creativity.

Other common causes of forgotten fears are:

- Sibling birth or abortion.
- Ridicule by anyone, including parents, teachers, siblings or peers.
- Parental conflict and divorce.
- Too much attention for the wrong things, such as illness or other dependencies.
- Too little attention for basic needs such as touch, approval and self-expression.
- Witnessing or experiencing emotional or physical abuse, including sexual abuse.
- Parental or sibling long-term illness, disability or death.
- Emotional absence of the caregiver due to addictive behaviors around alcohol, drugs (including prescribed), food, sex, religion, television, reading, sports, *etc.*

### Why are Such Fears Forgotten?

Shock often accompanies trauma. Shock numbs pain, including painful memories. If we don't get help in working through a painful experience, we may block the memory of it in order to "keep going."

### What are the Symptoms of a Flashback?

- Most flashbacks begin with a feeling of numbness similar to being in shock. This is the numbness that accompanied the original trauma. By habit, most flashbacks end here because a distraction (eating, drinking, reading, sleeping,

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TV, drugs, *etc.*) is used to keep going and to avoid the pain that's coming up. This is a key cause of addictive behavior.

- If the flashback continues, the numbness is often followed by the impulse to run away, to be alone. Many flashbacks end at this point, with resort to distracting behavior.
- If the flashback continues, there is a feeling of physical weakness and vulnerability, similar to the condition we are in when we are vomiting. Often there is involuntary trembling, rapid heart rate, panic, sweating, shortness of breath and a feeling of faintness. If the flashback is related to sexual or other physical abuse, the forgotten physical pain of that abuse may return at this point. At this point, it may be impossible to find any distraction that will interrupt the flashback.
- The physical weakness may be followed by deep emotional pain that feels unbearable.
- At this point, the person having the flashback may return in feeling and behavior to the age they were when the original trauma occurred. They may take an infantile or even fetal position, moaning or crying or gasping.
- An adult having a flashback may feel and look sick or "crazy."

### *What to Do if You're Having a Flashback.*

- Keep breathing as deeply, slowly and steadily as you can.
- If you're with people you trust, let them know what is happening.
- If you're in a situation that does not feel supportive or appropriate, do the best you can to delay the flashback by staying in the numb state until you find a safe place.
- Do not drive or operate other machinery even in the numb state. It's best not to do anything you wouldn't do if you felt like you had to vomit.
- As soon as you can, put yourself in a safe and comforting place (soft lighting and soothing music, etc.).
- Curl up in a ball in a soft place (cozy blanket and pillows, etc.).
- If possible, summon a companion whom you trust and who understands flashbacks, who can remain very calm and who can provide appropriate and supportive touch and remind you to breathe (La Maze techniques are excellent during flashbacks!).
- Let out any sounds or cries or screams that want to come.
- Remember that you are attending to a part of yourself that has been neglected for a long time.

## *What to do if Someone You're With is Having a Flashback.*

- Remain very calm, breathing steadily and slowly.
- Remind them to keep breathing.
- Decide if you are able to be completely present. If you are not, find someone who is.
- Even if you can be available, get some support for yourself if you can.
- Help them find a soft place and a comfortable position, wrap them up in a blanket with pillows, turn down the lights, put on soothing music, and stay very close, offering supportive touch if appropriate. (If the original trauma involved touch, it may not be appropriate.)
- Do not expect them to explain their behavior or even to use words. Encourage them to make any sound or movement they feel like making. Assure them that they are not sick or crazy and that the painful feelings will pass.

## *What to Do if You've Already Had at Least One Flashback.*

- **Spend time with yourself and learn to nurture yourself.**
- **Create a support network** of people who understand flashbacks and who are willing to share the responsibility of supporting you. Make sure they all know each other's names and home numbers and times when they are most likely to be available. Make it clear that you only want their support when they are really available, otherwise you risk recreating the original trauma.
- **Join a self-help recovery group** that is appropriate for you. There are many such groups available and they are free. Make sure the group cultivates listening and doesn't try to fix you.
- **Find a professional caregiver** who is experienced in treating people having flashbacks. Make sure this caregiver is involved in their own recovery process. Make sure this caregiver is willing to cooperate with the support network you have created.
- **Shop for help carefully.** The risk of recreating your original trauma in any kind of self-help or therapy situation is very high.
- **Do not assume that anyone except you has the answer to your recovery.**
- **Remember: A flashback is your inner child trusting you with a life experience you have forgotten. Do the best you can to honor and nurture this trust.**

Bristol Crisis Service for Women. Please contact for permission to reprint:
http://www.users.zetnew.co.uk/bcsw.

# IDEAS FOR COPING WITH FLASHBACKS[*]

1. Tell yourself you are having a flashback and that this is okay and very normal in people who were traumatized as children (or as adults).
2. Remind yourself that the worst is over - it happened in the past, but is not happening now. The "child" inside you who was abused is giving you these memories to use in your healing and, however terrible you feel, you survived the awfulness then, which means you can survive and get through what you are remembering now.
3. Call on the "adult" part of yourself to tell your "child" that she is not alone, not in any danger now, and that you will help her get through this. Let your child self know it's okay to remember and to feel what she feels and that this will help her in healing from what had happened to her. However hard it is for you, she is communicating in the only way she can.
4. Try some of these ways of "grounding" yourself and becoming more aware of the present:
    - stamp your feet, grind them around on the floor to remind yourself where you are now.
    - look around the room, noticing the colors, the people, the shapes of things.
    - listen to the sounds around you: the traffic, voices, the washing machine etc.
    - feel your body, the boundary of your skin, your clothes, the chair or floor supporting you.
    - have an elastic band to hand (or on your wrist)—you can "ping" it against your wrist and feel it on your skin—that feeling is in the **now**, the things you are re-experiencing were in the past.
5. Take care of your breathing: breathe deeply down to your diaphragm; put your hand there (just above your navel) and breathe so that your hand gets pushed up and down. You can also count—to 5—as you breathe out and in. When we get scared we breathe too quickly and shallowly and our body begins to panic because we're not getting enough oxygen. This causes dizziness, shakiness and more panic. Breathing slowly and deeply will stop the panic.
6. If you have lost a sense of where you end and the rest of the world begins, rub your body so you can feel its edges, the boundary of you. Wrap yourself in a blanket, feel it around you.
7. Get support if you would like it. Let people close to you know about flashbacks so they can help you if you want them to. That might mean holding you, talking to you, helping you to reconnect with the present, to remember you are safe and cared for now.

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[*] Modified from a brochure by the same name from the Bristol Crisis Service for Women, available at: http://www.selfinjury.freeserve.co.uk/flash.html. For more information, please visit their web site at: http://www.users.zetnew.co.uk/bcsw, write: PO Box 654, Bristol BS99 1XH, or telephone 0117 925 1119.

8. Flashbacks are powerful experiences which drain your energy. Take time to look after yourself when you have had a flashback. You could have a warm, relaxing bath or a sleep, a warm drink, play some soothing music, or just take some quiet time for yourself. Your "child" and you deserve being taken care of, given all you went through in the past.
9. When you feel ready, write down all you can remember about the flashback and how you got through it. This will help you to remember information for your healing and to remind you that you did get through it (and can again).
10. Remember you are not crazy—flashbacks are normal and you are healing.

# GUIDE TO DEVELOPING A WRAP — WELLNESS RECOVERY ACTION PLAN[*]

The following handout will serve as a guide to developing Wellness Recovery Action Plans. It can be used by people who are experiencing psychiatric symptoms to develop their own guide, or by health care professionals who are helping others to develop Wellness Recovery Action Plans.

This handout, or any part of this handout, may be copied for use in working with individuals or groups.

### *Getting Started*

The following supplies will be needed to develop a Wellness Recovery Action Plan:

1. a three ring binder, one inch thick
2. a set of five dividers or tabs
3. a package of three ring filler paper, most people preferred lined
4. a writing instrument of some kind
5. (optional) a friend or other supporter to give you assistance and feedback

### *Section 1 - Daily Maintenance List*

On the first tab write "Daily Maintenance List." Insert it in the binder followed by several sheets of filler paper.

On the first page, describe, in list form, yourself when you are feeling all right.

On the next page make a list of things you need to do for yourself every day to keep yourself feeling alright.

On the next page, make a reminder list for things you might need to do. Reading through this list daily helps keep us on track.

### *Section 2 - Triggers*

External events or circumstances that, if they happen, may produce serious symptoms that make you feel like you are getting ill. These are normal reactions to events in our lives, but if we don't respond to them and deal with them in some way, they may actually cause a worsening in our symptoms.

On the next tab write "Triggers" and put in several sheets of binder paper.

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On the first page, write down those things that, if they happened, might cause an increase in your symptoms. They may have triggered or increased symptoms in the past.

On the next page, write an action plan to use if triggers come up, using the Wellness Toolbox at the end of this handout as a guide.[9]

### *Section 3 - Early Warning Signs*

Early warning signs are internal and may be unrelated to reactions to stressful situations. In spite of our best efforts at reducing symptoms, we may begin to experience early warning signs, subtle signs of change that indicate we may need to take some further action.

On the next tab write "Early Warning Signs." On the first page of this section, make a list of early warning signs you have noticed.

On the next page, write an action plan to use if early warning signs come up, using the Wellness Toolbox at the end of this handout as a guide.[10]

### *Section 4 - Things are Breaking Down or Getting Worse*

In spite of our best efforts, our symptoms may progress to the point where they are very uncomfortable, serious and even dangerous, but we are still able to take some action on our own behalf. This is a very important time. It is necessary to take immediate action to prevent a crisis.

On the next tab write, "When Things are Breaking Down." Then make a list of the symptoms which, for you, mean that things have worsened and are close to the crisis stage.

On the next page, write an action plan to use "When Things are Breaking Down" using the Wellness Toolbox at the end of this handout as a guide.[11]

### *Section 5 - Crisis Planning*

In spite of our best planning and assertive action, we may find ourselves in a crisis situation where others will need to take over responsibility for our care. We may feel like we are totally out of control.

Writing a crisis plan when you are well to instruct others about how to care for you when you are not well, keeps you in control even when it seems like things are

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[9] This information can be found in the next article in this handbook.

[10] Ibid.

[11] Ibid.

out of control. Others will know what to do, saving everyone time and frustration, while insuring that your needs will be met. Develop this plan slowly when you are feeling well. The crisis planning form includes space to write:

- those symptoms that would indicate to others they need to take action in your behalf
- who you would want to take this action
- medications you are currently taking, those that might help in a crisis, and those that should be avoided
- treatments that you prefer and those that should be avoided
- a workable plan for at home care
- acceptable and unacceptable treatment facilities
- actions that others can take that would be helpful
- actions that should be avoided
- what my supporters should do if I am a danger to myself or others
- instructions on when the plan no longer needs to be used

# DEVELOPING A WELLNESS TOOLBOX*

The first step in developing your own Wellness Recovery Action Plan, is to develop a Wellness Toolbox. This is a listing of things you have done in the past, or could do, to help yourself stay well; and, things you could do to help yourself feel better when you are not doing well. You will use these "tools" to develop your own WRAP.

Insert several sheets of paper in the front of your binder. List on these sheets the tools, strategies and skills you need to use on a daily basis to keep yourself well, along with those you use frequently or occasionally to help yourself feel better and to relieve troubling symptoms. Include things that you have done in the past, things that you have heard of and thought you might like to try, and things that have been recommended to you by health care providers and other supporters. You can get ideas on other tools from self-help books including those by Mary Ellen Copeland including *The Depression Workbook: A Guide to Living With Depression and Manic Depression,* and *Living Without Depression and Manic Depression: A Guide to Maintaining Mood Stability Depression, The Worry Control Book, Winning Against Relapse, Healing the Trauma of Abuse,* and *The Loneliness Workbook.* You can get other ideas from the audio tapes *Winning Against Relapse Program* and *Strategies for Living with Depression and Manic Depression.*

The following list includes the tools that are most commonly used to stay well and help relieve symptoms.

1. Talk to a friend—many people find this to be really helpful
2. Talk to a health care professional
3. Peer counseling or exchange listening
4. Focusing exercises
5. Relaxation and stress reduction exercises
6. Guided imagery
7. Journaling–writing in a notebook
8. Creative affirming activities
9. Exercise
10. Diet considerations
11. Light through your eyes
12. Extra rest

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13. Take time off from home or work responsibilities
14. Hot packs or cold packs
15. Take medications, vitamins, minerals, herbal supplements
16. Attend a support group
17. See your counselor
18. Do something "normal" like washing your hair, shaving or going to work
19. Get a medication check
20. Get a second opinion
21. Call a warm or hot line
22. Surround yourself with people who are positive, affirming and loving
23. Wear something that makes you feel good
24. Look through old pictures, scrapbooks and photo albums
25. Make a list of your accomplishments
26. Spend ten minutes writing down everything good you can think of about yourself
27. Do something that makes you laugh
28. Do something special for someone else
29. Get some little things done
30. Repeat positive affirmations
31. Focus on and appreciate what is happening right now
32. Take a warm bath
33. Listen to music, make music or sing

Your list of tools could also include things you want to avoid like:

1. alcohol, sugar and caffeine
2. going to bars
3. getting overtired
4. certain people

Refer to these lists as you develop your Wellness Recovery Action Plan. Keep it in the front of your binder so you can use it whenever you feel you need to revise all or parts of your plan.

# A WELLNESS TOOL: DEVELOPING AND KEEPING A CIRCLE OF SUPPORT*

In the first column,[1] I described how to develop your own Wellness Recovery Action Plan. When you begin developing your Wellness Recovery Action Plan, you develop a list of wellness tools to be used in planning how you will keep yourself feeling well every day and how you will help yourself to feel better when you begin to feel badly. One of the most important wellness tools for many people is spending time with people you enjoy. They have found that regular contact with family members and friends who are supportive keeps them well. They have found that telling another person how they feel when they don't feel well can help them to feel better. This column will discuss the issue of support and describe things you can do to build yourself a strong circle of friends and supporters.

You may feel that you don't have any supportive people in your life, or that you have so few of these people that you feel lonely much of the time. You may feel that your lack of support and loneliness makes you feel sad or depressed some or most of the time. This problem may be worse if you live by yourself. Most people agree that they would benefit from having at least five close friends and supporters in their life that they really enjoy.

Everyone needs and wants to have friends. They enrich your life. They make you feel good about yourself and about being alive. Friends are especially helpful when you need special attention and care. A good friend is someone who:

- You like, respect and trust, and who likes, respect and trust you
- Accepts and likes you as you are, even as you grow and change
- Listens to you and shares with you, both the good and the bad
- You can tell anything to and know they will not betray your confidence
- Lets you express your feelings and emotions, and does not judge, tease or criticize
- Gives you good advice when you ask for it, assists you in taking action that will help you feel better, and works with you to figure out what to do next when you are having a hard time
- Lets you help them when they need it
- You want to be with, (but you aren't obsessed about being with them)

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[1] Refers to the previous article *Guide to Developing a WRAP—Wellness Recovery Action Plan.*

- Doesn't ever take advantage of you

You can probably think of some other attributes you would like from your friends.

You will find that some friends meet some needs and others meet other needs. Don't expect one friend to meet all of your needs for friendship and support. Appreciate your friends for the things you like about them and don't try to change them to better meet your needs.

Make a list of the people in your life that you feel closest to—those people who you would turn to in times of need. Is there something you could do to improve your relationships with these people? You could invite them to your home to visit, share a meal, play a game, watch a video, or share some other activity. You could do something nice for them or visit them when they are having a hard time.

## Developing New Friendships

How do you reach out to others to establish friendships? This is not an easy task. You may find that you would feel more comfortable staying at home than going to an activity where you can meet other people. Almost everyone feels this way. Try to ignore those feelings and get out to activities in the community where you can meet other people—people with whom you might develop closer connections.

Meet potential friends and supporters by:

- Attending a support group. It could be a group for people who have similar health issues or life challenges, or a group for people of the same age or sex.
- Going to community events, taking a course, joining a church or civic group.
- Volunteering. Strong connections are often formed with people who are working together on projects of mutual interest or concern.

Some friendships develop casually. You may hardly be aware that your relationship with the other person is getting closer and more comfortable. More often it takes some special effort on someone's part to help the relationship grow. You could do this by:

1. Asking the person whom you like to join you for coffee or lunch, to go for a walk or to do something together you both enjoy;
2. Calling the person on the phone to share something you think they might be interested in;
3. Sending a short, friendly e-mail and see if they respond;
4. Talking with them when you see them about something of interest to both of you;
5. Helping the person with a project you are both interested in.

You may be able to think of some other enjoyable activity that the two of you could share. Go slowly. This will give you a chance to decide if this is really a person you want for a friend. And others may be intimidated if you "come on too strong". As you both enjoy each other more the friendship deepens. Notice how you feel about yourself when you are with the other person. If you feel good about yourself, you may be on the road to a fulfilling friendship.

## Keeping Friendship Strong

Keeping your friendships strong needs consistent attention from you. There are many things you can do to help keep your friendships strong.

In addition, if you feel ready, you could become further involved if you choose by:

1. Like yourself. If you don't like yourself, don't feel that you have any value or don't think others will like you, you will have a hard time reaching out to people who may become friends.
2. Enjoy spending time alone. People who enjoy spending time alone and are not desperate to have people around all the time make better friends. Being desperate can drive others away from you. Fill time alone with activities you enjoy and that enrich your life. Perhaps a pet would help.
3. Have a variety of interests. Develop interests in lots of different things that make you an interesting person for others to be with.
4. Friendships must be mutual. Be there for your friends as much as they are there for you.
5. Listen and share equally. Listen closely to what the other person is saying. Avoid thinking about what your response is going to be while the person is talking. If a person is sharing something intense and personal, give them your full attention. Don't share an "I can top that" story. Be willing to listen to your friend share the details of a difficult time over and over again—until they have "gotten it out of their system".
6. Communicate as openly as you can. Tell your friends what you need and want and ask them what they want and need from you. Do not share so much information about details that the other person gets bored. Watch the response you are getting from the other person or people you are talking to so you can know if this is the right time to be sharing this, or the right subject for this person.

7. Avoid giving advice unless it is requested.
8. Never make fun of what the other person thinks or feels. Avoid judging, criticizing, teasing or sarcasm.
9. Never betray the confidence of a friend. Have a mutual understanding that anything the two of you discuss is personal is absolutely confidential, that you will not share personal information about each other with other people.
10. Have a good time. Spend most of your time with your friends doing fun, interesting activities together.
11. Stay in touch. Keep regular contact with your friends and supporters, even when things are going well.
12. Don't overwhelm the person with phone calls or other kinds of contact. Use your intuition and common sense to determine when to call and how often. Don't ever call late at night or early in the morning until you both have agreed to be available to each other in case of emergency (such as if one of you is sick or has gotten some very bad news).
13. Know and honor each other's boundaries. People commonly set limits or boundaries around things like the amount of time and place of getting together, the kind of frequency of shared activities, phone call time limits—time of day, frequency and length, amount and kind of support given, connection with other family members, and the amount of physical touch. Say "no" to anything you don't want. You have the right to ask for what you need, want and deserve.

## Problems In Relationships

If a difficult situation comes up in your relationship with a friend, you will both have to use your resourcefulness to solve the situation and keep the friendship strong. Some things you might try, depending on the situation, include:

- Talking with the other person by describing how you feel rather than making an assumption about how the other person feels;
- Working with your friend to develop a plan for resolving the situation that includes the steps each of you are going to take and when you are going to take them;
- Asking yourself what is really happening and deciding on solutions that will work for you;
- Being clear with yourself and your friends about your boundaries, saying "no" when necessary.

## Ending a Friendship

You may want to end a relationship with another person if circumstances arise that you cannot tolerate or there are issues that cannot be resolved. Some good reasons to end a friendship would be if the other person shares personal information about you with others, does all the talking and no listening, violates your boundaries, puts others or you down, teases, ridicules, "badmouths" friends and family, lies or is dishonest, wants you to be their only friend, wants you to spend all your time with them, wants to always know where you are and who you are with, doesn't want to be seen with you in public, is clingy or very needy, talks inappropriately about sex or personal matters, asks questions that make you feel uncomfortable, asks for risky favors, engages in illegal behavior or is physically, emotionally, or sexually abusive.

You may be tempted to pursue a relationship with someone even though they treat you or others badly. However, it is better not to have a certain friend than to have them treat you badly.

## In Conclusion

The process of developing and keeping a circle of support goes on for as long as you live. I hope this column has been helpful to you in figuring out what you need to do next. Proceed slowly. Take small steps so you don't become overwhelmed. You may want to begin writing about your efforts in a journal. Later you can read about your progress and honor yourself for your efforts. You may want to refer to my new book, *The Loneliness Workbook: A Guide to Developing and Maintaining Lasting Connections* (Copeland, M.E. New Harbinger Publications. Oakland, CA, 2000).

## CRISIS PLANNING[*]

I feel very strongly that anyone who has ever experienced psychiatric symptoms needs to develop for themselves, while they are well, a crisis plan such as the one that follows. This plan allows those of us who experience psychiatric symptoms to maintain some degree of control over our lives, even when it feels like everything is out of control.

Developing such a plan takes time—don't expect to do it in one sitting. Work on it with family members or friends, your counselor, case manager or psychiatrist—whoever feels comfortable to you.

The hardest part for me was uncovering those symptoms that indicate I need others to take over for me. It brought up memories of very hard times in the past. I did it very slowly with lots of support.

Once you have completed the plan, keep a copy for yourself, and give copies to all your supporters.

Update it whenever you need to.

### CRISIS PLAN

When I am feeling well, I am (describe yourself when you are feeling well):

____________________________________________

____________________________________________

____________________________________________

The following symptoms indicate that I am no longer able to make decisions for myself, that I am no longer able to be responsible for myself or to make appropriate decisions:

____________________________________________

____________________________________________

____________________________________________

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When I clearly have some of the above symptoms, I want the following people to make decisions for me, see that I get appropriate treatment and to give me care and support:

I do not want the following people involved in any way in my care or treatment. List names and (optionally) why you do not want them involved:

Preferred medications and why:

Acceptable medications and why:

Unacceptable medications and why:

Acceptable treatments and why:

____________________________________________________________

____________________________________________________________

____________________________________________________________

Unacceptable treatments and why:

____________________________________________________________

____________________________________________________________

____________________________________________________________

Preferred treatment facilities and why:

____________________________________________________________

____________________________________________________________

____________________________________________________________

Unacceptable treatment facilities and why:

____________________________________________________________

____________________________________________________________

____________________________________________________________

What I want from my supporters when I am experiencing these symptoms:

____________________________________________________________

____________________________________________________________

____________________________________________________________

What I don't want from my supporters when I am experiencing these symptoms:

____________________________________________________________

What I want my supporters to do if I'm a danger to myself or others:

Things I need others to do for me and who I want to do it:

How I want disagreements between my supporters settled:

Things I can do for myself:

I (give, do not give) permission for my supporters to talk with each other about my symptoms and to make plans on how to assist me.

Indicators that supporters no longer need to use this plan:

__________________________________________________________

__________________________________________________________

__________________________________________________________

I developed this document myself with the help and support of:

__________________________________________________________

__________________________________________________________

Signed: ____________________________ Date: ______________

Attorney: ____________________________ Date: ______________

Witness: ____________________________ Date: ______________

Witness: ____________________________ Date: ______________

# Appendix 5
# Suggested Reading for Chapter 5: Meeting Women's Basic Needs

# MEETING BASIC NEEDS:
# ADDRESSING ECONOMIC ADVERSITY IN WOMEN'S LIVES*

One of the most consistent findings in community studies of people with mental and addictive disorders is that those at the lowest economic rung of the ladder typically have the highest rates of mental health and substance use problems. In our study of women who use publicly funded mental health and substance abuse services in Dane County, the vast majority of whom report a current mental health or substance use problem, or both, economic adversity and its consequences are major problems with which women need and want help.

Several findings reveal the extent of economic adversity with which women use alcohol, drug, or mental health (ADM) services in the publicly funded system in Dane County grapple with on a daily basis.. First, when we compare these women, whom I will refer to subsequently as "consumers," with other women in Dane County, we find:

- Consumers are less likely to continue their educations beyond high school than other women in Dane County
- Consumers are more likely than other women in Dane County to be unemployed (50% versus 22.5%)
- Among those consumers who are employed, only 35% are employed fulltime compared to 49% of other women in Dane County
- The average monthly income of consumers is $1000, less than a third of that of other women in Dane County ($3,299)
- 77% of the consumers we interviewed reported having had serious money problems, including not enough money for a place to live or food, at some point in their lives

In short, women who receive services in the publicly funded ADM system in Dane County are **significantly disadvantaged compared to other women in Dane County in terms of their access to material resources.**

## How can economic adversity affect a woman's life?

It is difficult to convey the grinding, demoralizing impact that chronic economic difficulties can have on a person's life. We asked the women we interviewed, "During the past three months, did you generally have enough money each month to cover ...?" Their "no" responses to this query are listed below:

- housing (16% said no)

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* Joy Newmann (2002), Principal Investigator, Women and Mental Health Study Site of Dane County. Written for the *NPW Consumer Curriculum*. Please contact the author for permission to reprint, jnewmann@facstaff.wisc.edu.

- food (26% said no)
- clothing (40% said no)
- transportation (20% said no)
- social activities, like movies or eating out in a restaurant (51%)
- medical care (32%)

Indeed, our findings show that not only are insufficient material resources a major life problem for women, it is also a major barrier that undermines a woman's ability to seek and find appropriate services to address her mental health and substance use problems. For example, although many women told us they felt they needed such services, close to half (42.3%) reported that they did not seek care because they did not have the money to pay for services; twenty-seven percent did not have transportation to get to needed services.

## What are some solutions to this problem?

### (1) Make mental health and substance abuse services more affordable and available to poor women.

As part of our efforts to learn how to improve services for women, we asked: "If you were able to change one thing about the mental health or substance use service system in Dane County, what is the first thing you would do?" Interestingly, the most common response, given by 46% of the women, was to *increase access to care*. For many, this involved reducing financial barriers or making services more accessible for working women:

> *"I would have services in evenings so people who work and don't have insurance can go to them and not miss work..."*
>
> *"So many people now days don't have insurance and (agency) have such extensive waiting lists I think more facilities are needed."*
>
> *"I think there should be more structured groups available to the working poor, scheduled at times that they can attend."*
>
> *"I got bounced around for six years before I found (agency), because I didn't have the right insurance. Nobody would take my insurance, so I guess there should be places that people can go that don't have any money."*
>
> *"Its not cheap...the cost is a barrier...more people would use it if it were cheaper."*
>
> *"Make it more affordable."*

### (2) Insure that mental health and substance abuse services are more "recovery-oriented" in the sense of addressing women's economic adversity directly.

Although many women are satisfied with their care providers in the publicly funded ADM system in Dane County, our findings suggest that much more can and should be done to address women's economic problems directly as part of ADM services. Although many caregivers do this, 25% of the women we interviewed stated that their caregivers had <u>not</u> asked them about their current work situation and/or interest in finding a job during the prior six-month period. Moreover, 37% of the women did not feel the services they had received had helped them "do better in school or work."

This is a surprising finding given that many women who are unemployed are eager to find a job, if they can. In fact, we asked women: "What does recovery mean to you?" The most frequent response related in some way to what we conceptualized as: "leading a normal and productive life." Some version of this idea, which was mentioned by 29% of the women we interviewed, typically involved getting more education or getting a job:

> *"I guess the idea of recovery is different for everybody. I am as recovered as much as I am going to be. It is being able to participate in life to the best degree that you can. Just to try and live as normal of a life as I can."*
>
> *"To be able to live my life in a productive manner. Being able to go to work and take care of myself."*
>
> *"It means going back to work and being able to function in normal society without my mental illness limiting my ability to perform. It means getting through the days without being haunted. It means being productive and satisfied with my work. It means pursuing hobbies cheerfully and happily. It means regaining my independence."*
>
> *"Getting back to a normal life and leading a normal life. Not living in Hell. That's what it means to me."*

These statements, which reflect an attitude about one's place in the world as a productive citizen, were frequently linked with "getting out of the system" and becoming economically independent:

> *"Being free from all the programs and everything and not having to deal with the system."*
>
> *"Being off disability and off medication and working full-time again. Taking care of myself monetarily."*
>
> *"Getting off social security, getting a job in (work sector) and moving. I have absolutely nothing in (city) because everyone knows everything about me here...there is no way I could get a job in (work sector). I would like to own a house and have a car...be able to play the stock market and go on trips."*
>
> *"Not needing services from a mental health provider...being able to hold a job...do the functions of life without questioning myself and being free of flashbacks."*

Finally, toward the end of the interview, we asked women: "In looking ahead to the next six months, what do you see as the areas of your life that you would most like to change?" The most frequent response women gave had something to do with what we called ***increasing their material resources***. This group of responses included material resources beyond money and reiterated a theme we heard throughout the interview--a desire to improve one's socioeconomic standing and material well being more generally. Areas of change mentioned, which were coded in this category, included wanting a better job, job training, a bigger home, an education, transportation, or health insurance:

> *"My money situation, I would like more money. I would like to live at the poverty level, not below it."*
>
> *"Housing- I would like to have a home or something that is much bigger than this because it stresses me out that this apartment is so small and I don't have the money to get something more decent."*
>
> *"A better job. A decent job that would take care of me and my kids and I wouldn't have to worry about the bills. That is really important to me...being a single parent."*
>
> *"Get a medical assistance card...I'd be happy if I could just get a medical assistance card. It would pay for the drugs. Now I pay for them myself. There are some drugs, a few of the drugs, that I do get straight from the companies, but I still pay quite a bit for drugs. I could go to the dentist too, get my eyes checked...I just wish I could get a medical assistance card and get my eyes checked...I just wish I could get a medical assistance card...it would make it so much easier for me."*

**(3) Help women singly and collectively address their own needs to improve their work skills, motivation, and access to educational and job training opportunities.**

One of the most heartening experiences during the two years that the Women and Mental Health Study Site was funded was the opportunity to work with many women who have been long-time consumers of mental health and/or substance use services in Dane County. We shared common goals, and some that were different, but we worked long and hard together to make Dane County a better place for women to seek and receive good care for their mental health and substance use problems. Some of this work has continued under the New Partnerships for Women Project. Moreover, it promises to continue into the future through other endeavors. Important questions for the future are: What can be done to insure that you, and other women like you, have an opportunity to continue growing and learning? How can we convert these experiences into viable employment opportunities that recognize your strengths and creativity? Finally, for those of you who are unable to work, what can we do collectively to insure that you have sufficient material resources, including adequate health care, so that you can purchase services that fit your needs?

# DISCUSSING TRAUMA AND PTSD WITH YOUR DOCTOR*

The experiencing or witnessing of traumatic events can lead to psychological (emotional) problems and to physical problems (in addition to any that occurred at the time of the trauma). These symptoms can last for a relatively short time after the event, can last for months or years, or can "surface" months or even years later.

Not everyone who experiences trauma will go on to develop full PTSD. You may suffer from only some problems. Even so, treatments are available for these problems.

You may find it helpful to talk with your primary care physician about your experience(s) and any symptoms you have --- even if he or she does not ask first. Keep in mind that your doctor may not know about the emotional or psychological after effects of trauma or the many-associated medical problems. You can help your doctor understand you better and plan your treatment by sharing this crucial information about yourself. Please note that not everyone who experiences trauma will go on to develop full PTSD. You may suffer from only some PTSD symptoms or problems. Even so, it is important to discuss symptoms or problems with your health care providers, and treatment may be helpful.

At first, individuals may find it hard to discuss their experience(s). Because it may be difficult for you to discuss what happened to you, and the symptoms that you suffer, there is a quick checklist below that you can use to show to your doctor. It may help you to begin to talk about your trauma experience and the symptoms you are experiencing.

## Quick Checklist of Trauma Symptoms

Check those symptoms below that you experience (that may or may not be related to a traumatic event) and make some notes as needed:

I experienced or witnessed a traumatic event during which I felt extreme fear, helplessness, or horror.

The event happened in (day/month/year)____________________.
What happened?______________________________________.

1) I have symptoms of reexperiencing or "reliving" the traumatic event:

☐ Having bad dreams or nightmares about the event or something similar

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* Pamela Swales, Ph.D. and Joe Ruzek, Ph.D. A National Center for PTSD Fact Sheet. Available at: http://www.ncptsd.org/facts/specific/fs_doctor.html. This information is presented for educational purposes only. It is not a substitute for informed medical advice or training. Do not use this information to diagnose or treat a mental health problem without consulting a qualified health or mental health care provider. This article is in the public domain and may be copied and distributed without restriction. For more information telephone (802) 296-5132 or send email to ncptsd@ncptsd.org.

☐ Behaving or feeling as if the event were actually happening all over again ("these are known as "flashbacks")

☐ Having a lot of emotional feelings when I am reminded of the event

☐ Having a lot of physical sensations when I am reminded of the event (e.g. heart races, pounds, or "misses a beat"; sweating, hard to breathe, feel faint, feel like I'm "going to lose control")

2) I have symptoms of avoiding reminders of the traumatic event:

☐ Avoiding thoughts, conversations, or feelings that remind me about the event

☐ Avoiding people, places, or activities that remind me of the event

☐ Having difficulty remembering some important part of the event

3) I have noticed that since the event happened:

☐ I have lost interest in, or just don't do things that used to be important to me

☐ I feel "detached" from people-I find it hard to trust people

☐ I feel emotionally "numb" and I find it hard to have loving feelings even toward those who are emotionally close to me

☐ I have a hard time falling or staying asleep

☐ I am irritable and have problems with my anger

☐ I have a hard time concentrating

☐ I think I may not live very long-so why plan for the future?

☐ I am "jumpy" and get startled easily

☐ I am always "on guard"

4) I experience these medical or emotional problems:

☐ Stomach problems

☐ Intestinal problems

☐ Gynecological problems

☐ Weight gain or loss

☐ Chronic pain (e.g. back, neck, in women-pelvic area)

☐ Problems getting to sleep
☐ Problems staying asleep
☐ Headaches
☐ Skin rashes and other problems
☐ Irritability, "short fuse", "quick temper", other anger problems
☐ Nightmares
☐ Depression
☐ Lack of energy, chronic fatigue
☐ Alcoholism and other substance use problems
☐ General anxiety
☐ Anxiety (panic) attacks
☐ Other symptoms I have are: ______________________

**Here is a list of possible questions that may help you identify what you might like to ask your doctor or counselor:**

- "What do people have to do to recover from PTSD?"
- "Why do I have PTSD and other people don't?"
- "Does having PTSD mean that I'm crazy or mentally ill?"
- "What will happen if I go for treatment?"
- "How long will treatment last?"
- "What will be the likely effects of treatment?"
- "What should I tell my wife/partner/other family members about PTSD?"

**If medication treatment is being discussed, you might like to ask some of these questions:**

- "How is this medication supposed to help me?"
- "How will it affect my symptoms?"
- "How long will I have to take it?"
- "Can I stop it if I don't like it?"
- "How will we know if it is working or not?"
- "What will happen if it doesn't work?"
- "What are the side effects of the medication?"
- "How will it affect my other medications that I'm taking?"

- "Why do I need to go for counseling if I'm receiving medication treatment?"
- "How will medication treatment fit in with my PTSD counseling?"
- "How will medication affect my substance abuse recovery?"

Again, if you think you have PTSD, or even just some of the symptoms, it is important for you to let your primary care physician know. This information is invaluable in planning your medical treatment. It can also help your doctor in providing you with appropriate referrals for other services you may need (e.g., psychologist, social worker, child abuse protective services, lab tests, etc.).

You may find it helpful to bring this and other fact sheets available from the National Center for PTSD to show to your doctor. Fact sheets from the National Center for PTSD can be found on the Internet at http://www.ncptsd.org.

# INFORMATION ON PTSD FOR WOMEN'S MEDICAL PROVIDERS*

## How common is sexual trauma among women?

Estimates vary, but studies suggest that about 13% of women have experienced a sexual assault at some time during their life.[1] Estimates for child sexual abuse are higher, with 27% of women reporting this experience.[2] In some samples (e.g., veterans and current military), these rates tend to be higher).

## Consequences of Sexual Assault

Although many women who have been sexually assaulted function quite well, others have considerable difficulties. Many of the problems experienced by these women are those that may present themselves in the primary care setting. These difficulties include interpersonal, social, physical, and psychological problems that may last for many years. Women who have experienced sexual trauma are also more likely to be high utilizers of healthcare.

**Physical Consequences.** Numerous physical problems have been reported to occur with greater frequency among women with sexual assault histories. These problems include: diabetes, obesity, arthritis, asthma, recurrent surgeries, chronic pelvic pain, irritable bowel syndrome, back pain, headache, eating disorders, poor reproductive outcomes, digestive problems, and hypertension.

Women reporting a history of childhood sexual abuse also report higher rates of numerous problems including venereal disease, pelvic inflammatory disease, surgical evaluation of pelvic pain, respiratory problems, gastrointestinal problems, and neurological problems.

**Sexual trauma and healthcare utilization.** Given the increased reports of health problems, its not surprising that the experiences of childhood and adult sexual trauma are associated with increased healthcare utilization and costs.

A recent study examining HMO health care utilization found that women who reported a history of childhood sexual abuse were more likely to visit the emergency room and had annual total health care costs that were significantly higher than those without abuse histories.[3] These differences held even after excluding the costs of mental health care.

Adult sexual trauma victims also appear to utilize high levels of health care (increased physician visits and outpatient costs), even in comparison to women who have been victims of other types of crime.[4]

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* Erica Sharkansky, Ph.D. A National Center for PTSD Fact Sheet. Available at http://www.ncptsd.org/facts/specific/fs_female_primary.html. This article is presented for educational purposes only. It is not a substitute for informed medical advice or training. Do not use this information to diagnose or treat a mental health problem without consulting a qualified health or mental health care provider. This article is in the public domain and may be copied and distributed without restriction. For more information telephone (802) 296-5132 or send email to ncptsd@ncptsd.org.

Although, women who have experienced sexual assaults may have considerable mental health symptoms, they are significantly more likely to present in medical than in mental health settings.[5]

**Psychological Consequences.** The most widely studied psychological consequence of sexual assault is posttraumatic stress disorder (PTSD). Data from a large scale study comparing the effects of different types of traumatic events suggests that the experience of a sexual assault may be more likely to lead to PTSD than other types of traumatic events.[6]

45% of women in the study who reported having experienced a rape met criteria for PTSD. This was significantly higher than the 38.8% rate of PTSD among men who had experienced combat.

Sexual assault appeared to be extremely difficult for men as well (65% of men who had been raped met criteria for PTSD), but the proportion of men in the study who experienced a rape (0.7%) was significantly smaller than the proportion of women who did so (9.2%).

The experience of childhood sexual trauma was also associated with high rates of PTSD. 26.5% of the women who reported experiencing molestation as their most traumatic experience met criteria for PTSD. This percentage was significantly higher than the percentage of men meeting criteria for PTSD who reported having been molested.

Symptoms of PTSD include reexperiencing the trauma, avoidance of situations associated with the trauma, emotional numbing, and hyperarousal any of these symptoms can present in and around the medical setting. Perhaps the most dramatic trauma related symptom that may be seen is dissociation. Dissociation can involve a range a phenomena from altered awareness or attention to flashbacks and out of body experiences. Dissociation is usually triggered by a strong emotional reaction such as feelings of terror, surprise, or feeling trapped, helpless, shame, or exposed.

There are several aspects of the medical setting that may increase the likelihood that PTSD symptoms may occur. The types of procedures that are performed in the medical office (particularly those performed in primary, GYN and GI clinics) can potentially trigger a posttraumatic reaction in patients who have experienced sexual trauma. In particular, pelvic exams, colonoscopies, endoscopies, and other procedures that involve placing an instrument into a bodily orifice may be sufficiently reminiscent of sexual trauma to evoke a posttraumatic reaction.

Although invasive procedures are the most dramatic examples of triggering events occurring in the medical setting, a number of other features of this setting may also evoke trauma reminders. These include being touched (even in a usually nonthreatening place), the power differential between patient and provider, the removal or absence of clothing, and the focus on bodily pain or disorder.

In one study a large portion of sexual trauma survivors reported unpleasant experiences during a gynecological exam.[7] These included overwhelming emotions, unwanted or intrusive thoughts, having traumatic memories triggered, body memories, and feelings of detachment from the body. Many of these experiences were not reported to the providers.

In this same study, both women who had and had not experienced childhood sexual trauma reported anxiety during a pelvic exam. However, the women who had been sexually traumatized reported that having their sexual organs examined was the primary reason for discomfort, whereas women who had not been sexually traumatized reported that physical discomfort was their most common reason for discomfort.

Because sexual trauma survivors may anticipate these difficulties they may be likely to repeatedly cancel appointments for exams or avoid telling their providers about symptoms (e.g. blood in the stool) that would cause an invasive test to be ordered.

## What you can do

It's generally a good idea to find out whether a female patient has been sexually traumatized. Although most women have never been asked by their gynecological provider about a history of sexual trauma, the overwhelming majority of women indicate that they would like to be asked this question.[7] Few survivors are likely to spontaneously offer this information.

In addition to knowing about your patient's history, there are a number of things you can do to make it more likely to have the patient successfully complete the examination with as little emotional distress as possible, and not increase the likelihood that she will avoid care in the future.

- Reduce the power differential between you and your patient
- Greet the patient in your office (not exam room) while she is still fully dressed
- Give the patient as much control as possible
- Provide health education materials
- View the patient as an expert about herself. Ask her what would be most likely to help her reduce her stress during the exam
- Ask her to predict what will be the most difficult parts of a procedure
- Take a break if necessary
- Provide the patient with as much choice as possible
- Engage in dialogue throughout exam
- Explain everything you do in advance and as you're doing it
- Listen carefully to any concerns
- Check in regularly about the patient's level of anxiety
- Remind the patient why you're doing this exam
- Plan ahead
- Allow extra time: schedule these patients for slower days or late appointments

- Be prepared and willing to reschedule the exam if necessary
- Use distraction
- Consider using relaxation techniques (though for some trauma survivors this is contraindicated) and involve a mental health provider in planning care

## If symptoms do occur

Despite your best efforts to avoid it, posttraumatic symptoms may occur during an exam. If this happens, don't panic and try to use grounding techniques with the patient.

- Speak in a calm, matter of fact voice and avoid sudden movements
- Reassure your patient that everything is okay
- Continue to explain what you're doing
- If at all possible, stop the procedure
- Ask (or remind) the patient where she is
- Offer her a drink of water, an extra gown, or a warm or cold wash cloth for her face
- Provide a change of environment.

## References:

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[7] Robohm, J.S., & Buttenheim, M. (1996). The gynecological care experience of adult survivors of childhood sexual abuse: A preliminary investigation. *Women and Health*, 24, 59-75.

# AFRAID OF THE DENTIST?*

If you are like most Americans, going to the dentist is not your idea of having fun. However, for many of us who are psychiatric survivors and/or survivors of physical/sexual/emotional abuse, going to the dentist can be more than just scary or uncomfortable. It can be re-traumatizing. In order to avoid retraumatization many of us avoid the dentist completely and eventually find our teeth in various state of decay or disease.

Two researchers from New Hampshire have pulled together a brochure entitled, "Dental Tips for Individuals Sexually Abused as Children."[1] These women suggest three major strategies. The first is doing anything that increases your sense of control, such as asking your dentist to explain all procedures before beginning them, or developing an agreed-upon "signal" that indicates to your dentist that you want to stop. The second suggestion is using "mental techniques that you can practice ahead and while at the dentist." One such technique is deep breathing through your nose to relax yourself. The third suggestion involves a list of "other things to do" such as bringing a friend to be with you during the dental procedure, wearing pants rather than a skirt to the dental appointment, educating your dentist, bringing a soothing audiotape to listen to, etc.

Although this brochure is intended for survivors of sexual abuse, the techniques suggested will help anyone with high levels of fear of the dentist. For those of us who have been abused in mental institutions, who have been tied up in restraint and seclusion with staff hovering over us, or who have been force fed or medicated against our will, the dental experience can have similar symbolic/triggering aspects. These include having to lay in the dental chair with the dentist hovering over us; being in a relatively helpless position while alone in a room with a professional/doctor; having intrusive procedures without warning; etc. Thus, even though this brochure is advertised as helpful to survivors of sexual abuse, I think it is also quite applicable to psychiatric survivors.

One final note. In my long struggle to feel more skilled and safe in using dental services, I have found out an important point that is not mentioned in the brochure but that may help you. When children/people are abused, our bodies react with a heightened sense of vigilance, fear, or what is called "hyper-arousal". One of the long-term effects of abuse is that our bodies did not develop the capacity to modulate levels of affective arousal. We seem to jump from 1 to a 10 if a car backfires and startles us. And we tend to stay at "10" or a high level of arousal long after the car had backfired. Our bodies can't "settle down" as quickly as people who do not have trauma histories.

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* Patricia Deegan, Ph.D. © 1999. National Empowerment Center, Inc. All rights reserved. Available at: http://www.power2u.org/selfhep/dentist.html.

[1] NPW editorial comment: The "Dental Tips for Individuals Sexually Abused as Children" brochure is available on two internet sites, http://www.sidran.org/dental.html or http://www.stardrift.net/survivor/bwdentist.html.

For years when I would go to the dentist and get Novocain, my heart would start racing. I was filled with feelings of panic, and I felt like I was going to die. I wasn't afraid of the needle. It was only once the Novocain drug was in my body that I had trouble. Finally I discovered that drugs such as Novocain, which are used by dentists to block pain signals from the nerve, also contain another drug called epinephrine. Epinephrine causes the blood vessels to constrict and can simulate a startle response or "fight/flight" response in the body. In effect Novocain was simulating the human bodies reaction to trauma by triggering a state of hyperarousal.

Once I understood this I talked it over with my dentist. We tried using Novocain-type drugs with no epinephrine in it. This definitely helped to eliminate my hyperarousal and the feeling of panic. However, the numbing effect only lasted a short time and this was bad news when I was halfway into a root canal procedure. So then we tried a numbing drug that had some epinephrine in it, but the dentist injected in very, very slowly so my body could accommodate slowly. We made sure to tip the dentist chair way back so I didn't feel dizzy. The dental assistant kept her hand on my shoulder while the dentist reminded me to breathe deeply. To my joy I avoided the hyperarousal effect and could continue with my treatment without being re-traumatized. Maybe it will work for you!

# THE CAUSE AND EFFECT OF STIGMA AND SHAME*

More often than NOT, people become accustom to accepting the majority point-of-view rather than the minority point-of-view. More often than NOT, women who struggle with a trauma history and mental health or substance use problems tend to accept the overwhelming negative images and stereotypes related to their problems, rather than finding the positive images, (unfortunately the negative images are in the majority, rather than in the minority). Shame then usually follows as a direct result from internalizing these negative messages.

So as we think about this, we can see the interlocking oppressions that women with mental health and/or substance abuse (MH/AODA) problems must face: 1) The negative images of stigma and shame (which, again, is the thinking of the majority) and 2) Then personalizing it (which is also the majority of women's personal experiences with MH/AODA and trauma histories). The end result of these interlocking oppressions oftentimes results in women not getting their basic needs met, mostly due to the impacts of stigma and shame. So as one can see, one of the deadliest killers coming from stigma and shame is personal destruction caused by the societal effect of the negative images of MH/AODA and trauma survivors.

## What is Stigma?

- *It is misplaced blame and fear from ignorance.*
- *It is the use of cruel jokes and stereotypes that serve to isolate people.*
- *It is the careless use of words like yuppie, loony, nuts, batty, wacko, mental case, alcky, druggy, wimp, dike, and a number of others that ridicule individuals.*
- *Stigma causes discrimination in society, employment, health insurance, health treatment, services, housing, and many more.*
- *Exposure to this kind of stigma for anyone, has unfortunate consequences, and may result in personal degradation, causing many people no matter what the label is, life-debilitating hardships as a result of STIGMA.*[1]

Stigma isn't just the use of the wrong word or action. More than that, it is about socialized disrespect, disrespect that often then becomes so internalized it becomes a personal "norm." This level of stigma tends to create a feeling of "demoralized comfort" (an OK unhealthy comfortable feeling within oneself) that unfortunately keeps women from getting their basic needs met. The outcome of this internal shame will then often determine which path women will choose in extremely important decision-making situations.

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* Jessica Barton (2002). New Partnerships for Women. Written for the *NPW Consumer Curriculum*. The author grants permission to reprint. Citation of the source is appreciated.

[1] This definition of stigma was developed by consumers involved in the Women and Mental Health Study Site of Dane County.

Stigma is a barrier that discourages people and their families from getting the help they need due to the fear of being further stigmatized and discriminated against. Furthermore, stigma may even result in women (and their families) feeling they don't deserve to get help. Consumers or survivors will even go as far as to sacrifice their own personal needs to protect themselves, once again, from further being shamed or to protect their identity as having a mental health problem and/or substance abuse problem.

Sacrifices of such basic needs continues a cycle of shame that often contributes to consumers not feeling worthy of having these basic needs met. Some sacrifices that will marginalize consumers into deeper emotional shame are sacrifices of: health, safety, food, shelter, and general well-being. All-in-all, the avoidance of these needs will only hurt the consumer and not change the attitudes of the general public.

## Some Facts About Stigma

- **Do you know that** an estimated 50 million Americans experience a mental disorder in any given year? So in turn you can only imagine how many of that 50 million don't get their basic needs met.[1]
- **Do you know that** stigma is not just the use of the wrong word or action?
- **Do you know that** stigma is about socialized disrespect, and that stigma is about the use of negative labels for, and attitudes towards, people living with mental illness and substance abuse?
- **Do you know that** stigma is a barrier and discourages individuals and their families from getting the help they need due to the fear of being further stigmatized and discriminated against?
- **Do you know that** many people would rather tell employers they have committed a petty crime and were in jail, than admit to being in a psychiatric hospital or having a drinking or drug problem?
- **Do you know that** stigma has allowed companies to provide inadequate insurance coverage for mental health services as well as services at all?
- **Do you know that** stigma results in fear, mistrust, and violence against people living with MH/AODA and any other type of character we find so called different?
- **Do you know that** stigma results in families and friends turning their backs on people with MH/AODA and any other type of character we find so called different?
- **Do you know that** stigma keeps people from getting everyday basic needs met?

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[1] This information was taken from the link/article on shame found on the web site, http://www.mentalhealth.org.

## Steps To Help Create Positive Changes

Below are some suggested **DO'S** that may help bring hope to many women struggling with the stigma and shame associated with MH/AODA and trauma histories and break the barriers of not getting basic needs met. These suggestions can be shared with and used by anyone, we all have internalized negative messages about ourselves and others.

- **Do use** respectful language such as:
    - Person with a psychiatric disability or a person who is recovering from some difficult alcohol or other drug addictive struggles.
- **Do respect** persons who have been challenged with the limitations that stigma has presented.
- **Do respect** the ability and strength that one must have to overcome the stigma and shame that has been placed upon them by their label (MH/AODA/trauma) in order to meet their basic needs.
- **Do emphasize** abilities, not limitations.
- **Do tell** someone if they express a stigmatizing attitude.

Here are some suggestions for things to NOT do that can also help to end the stigma and shame experienced by survivors and consumers. Again, each one of us can practice these principles:

- **Don't use** generic labels such as retarded, or the mentally ill or terms like crazy, lunatic, manic-depressive, slow functioning, or normal.
- **Don't pre-label**, make assumptions about, or re-stigmatize someone before you even meet them.
- **Don't assume** all consumers are alike.

By avoiding some of these, you may help bring hope to many women struggling with the stigma and shame associated with MH/AODA and trauma histories and help break barriers that have prevented basic needs from being met.

Labels such as these will only hinder, not help. It is hard enough that women with MH/AODA must struggle with society's stigma, why add to their hardship? So take a moment to think during the course of a day, how many times you yourself must show identification or label who you are just to get some simple basic needs met?

# Appendix 6

# Suggested Readings for Chapter 6:Skills and Strategies for Effective Self-Advocacy

# A WORKING DEFINITION OF EMPOWERMENT*

"Empowerment" has become a popular term in mental health programs, yet it has lacked a clear definition. In a research project designed to measure empowerment in programs funded by and for mental health services users, we first undertook to come up with a working definition. Key elements of empowerment were identified, including access to information, ability to make choices, assertiveness, and self-esteem. Empowerment has both an individual and a group dimension. Details of the definition are provided, along with a discussion of the implications of empowerment for psychiatric rehabilitation programs.

## Introduction

"Empowerment" is a term that has become very popular in mental health services (at least in the United States). Nearly every kind of mental health program claims to "empower" its clients, yet in practice there have been few operational definitions of the term, and it is far from clear that programs that use the term are in any measurable way different from those that do not. Still lacking a definition, the word has become common political rhetoric, with a flexibility of meaning so broad that it seems to be in danger of losing any inherent meaning at all. Some conservative U.S. politicians have promoted welfare "reform," for example, by claiming that cutting off benefits will "empower" recipients (who would thus, presumably, become self-sufficient)! Such usages make it difficult to claim that "empowerment" is a meaningful concept. The problem of using the term meaningfully becomes even more problematic in other countries and other languages. When I have spoken abroad, I find that the word is usually not translated; the translator merely repeats "empowerment," in English, perhaps hoping that the listeners will be able to draw some meaning from the context. Nonetheless, I believe that the term can have real meaning, and that the first step in making it meaningful is to define it.

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* Judi Chamberlin © 1999. National Empowerment Center, Inc. All rights reserved. Available at http://www.power2u.org/empower/working_def.html. Judi Chamberlin is a psychiatric survivor and a long-time activist for patients' rights. She is the author of On Our Own: Patient Controlled Alternatives to the Mental Health System, as well as numerous articles on the topics of self-help and alternatives. She is affiliated with the Center for Psychiatric Rehabilitation, Boston University, and with the National Empowerment Center, Lawrence, Massachusetts. For information contact the author at the Center for Psychiatric Rehabilitation, 930 Commonwealth Avenue, Boston, MA 02215, USA.

## A Working Definition of Empowerment

At the Center for Psychiatric Rehabilitation, I directed a research project that studied participants in user-run self-help programs for people with psychiatric disabilities.[1] At the beginning of the study, we found that many of these groups included the term "empowerment" in their program definitions. It was clearly a key concept, making it necessary to define empowerment as part of the project. We therefore brought together a group of a dozen leading U.S. consumer/survivor self-help practitioners,[2] who formed the Advisory Board of our project, and we made our first task the formulation of a definition. Although we recognized that empowerment had elements in common with such concepts as self-esteem and self-efficacy, we also felt that these concepts did not fully capture what we saw as distinctive about empowerment. After much discussion, we defined empowerment as having a number of qualities, as follows:

1. Having decision-making power.
2. Having access to information and resources.
3. Having a range of options from which to make choices (not just yes/no, either/or.)
4. Assertiveness.
5. A feeling that the individual can make a difference (being hopeful).
6. Learning to think critically; learning the conditioning; seeing things differently; e.g.,
    a. Learning to redefine who we are (speaking in our own voice).
    b. Learning to redefine what we can do.
    c. Learning to redefine our relationships to institutionalized power.
7. Learning about and expressing anger.
8. Not feeling alone; feeling part of a group.
9. Understanding that people have rights.
10. Effecting change in one's life and one's community.
11. Learning skills (e.g., communication) that the individual defines as important.
12. Changing others' perceptions of one's competency and capacity to act.
13. Coming out of the closet.
14. Growth and change that is never ending and self-initiated.

15. Increasing one's positive self-image and overcoming stigma.

We decided early in our discussions that empowerment was complex, multidimensional concept, and that it described a process rather than an event. Therefore, we did not believe that an individual had to display every quality on the list in order to be considered "empowered." This definition is not necessarily a global one, but is linked specifically to the research project, and is offered as a working definition for the purpose of opening discussion as to whether "empowerment" is a meaningful term that describes a discrete mechanism used by members of the self-help groups in our study. In fact, I have found that in presenting the definition to various groups, it often does begin such a useful discussion, and I have been told by non-English speakers that the definition has been useful in their attempts to translate the word.

## Empowerment: The Elements

Returning to the definition, let us now look at each of the elements:

**Having decision-making power.** Clients of mental health programs are often assumed by professionals to lack the ability to make decisions, or to make "correct" decisions. Therefore, many programs assume the paternalistic stance of limiting the number or quality of decisions their clients may make. Clients may be able to decide on the dinner menu, for example, but not on the overall course of their treatment. Yet, without practice in making decisions, clients are maintained in long-term dependency relationships. No one can become independent unless he or she is given the opportunity to make important decisions about his or her life.

**Having access to information and resources.** Decision making shouldn't happen in a vacuum. Decisions are best made when the individual has sufficient information to weigh the possible consequences of various choices. Again, out of paternalism, many mental health professionals restrict such information, believing restriction to be in the client's "best interest." This can become a self-fulfilling prophecy, since, lacking adequate information, clients may make impulsive choices that confirm professionals' beliefs in their inadequacy.

**Having a range of options from which to make choices.** Meaningful choice is not merely a matter of "hamburgers of hot dogs" or "bowling or swimming." If you prefer salad, or the library, you're out of luck!

**Assertiveness.** Non-diagnosed people are rewarded for this quality; in mental health clients, on the other hand, it is often labeled "manipulativeness." This is an example of how a psychiatric label results in positive qualities being redefined negatively. Assertiveness—being able to clearly state one's wishes and to stand up for oneself - helps an individual to get what he or she wants.

**A feeling that the individual can make a difference.** Hope is an essential element in our definition. A person who is hopeful believes in the possibility of future change and improvement; without hope, it can seem pointless to make an effort. Yet mental health professionals who label their clients "incurable" or "chronic" seem at the same time to expect them to be motivated to take action and make changes in their lives, despite the overall hopelessness such labels convey.

**Learning to think critically; unlearning the conditioning; seeing things differently.** This part of the definition created the most discussion within our group, and we were unable to come up with a single phrase that encapsulated it. We believed that as part of the process of psychiatric diagnosis and treatment, clients have had their lives, their personal stories, transformed into "case histories." Therefore, part of the empowerment process is a reclaiming process for these life stories. Similarly, the empowerment process includes a reclaiming of one's sense of competence, and a recognition of the often-hidden power relationships inherent in the treatment situation. In the early stages of participation in self-help groups, for example, it is very common for members to tell one another their stories; both the act of telling and that of being listened to are important events for group members.

**Learning about and expressing anger.** Clients who express anger are often considered by professionals to be "decompensating" or "out of control." This is true even when the anger is legitimate and would be considered so when expressed by a "normal" person, and is yet another example of the way in which a positive quality becomes a negative once a person is diagnosed. Because the expression of anger has often been so restricted, it is common for clients to fear their own anger and overestimate its destructive power. Clients need opportunities to learn about anger, to express it safely, and to recognize its limits.

**Not feeling alone; feeling part of a group.** An important element in our definition is its group dimension. We believe that it is necessary to recognize that empowerment does not occur to the individual alone, but has to do with experiencing a sense of connectedness with other people. As was brought up numerous times during our discussion, we did not want to leave the impression that we considered the image of "John Wayne coming into town, fixing everything, and riding off into the sunset" to be synonymous with our definition!

**Understanding that people have rights.** The self-help movement among psychiatric survivors is part of a broader movement to establish basic legal rights. We see powerful parallels between our movement and other movements of oppressed and disadvantaged people, including racial and ethnic minorities, women, gays and lesbians, and people with disabilities. Part of all of these liberation movements has been the struggle for equal rights. Through understanding our rights, we increase our sense of strength and self-confidence.

**Effecting change in one's life and one's community.** Empowerment is about more than a "feeling" or a "sense," we see such feelings as precursors to action. When a person brings about actual change, he or she increases feelings of mastery and control. This, in turn, leads to further and more effective change. Again, we emphasized that this is not merely personal change, but has a group dimension.

**Learning skills that the individual defines as important.** Mental health professionals often complain that their clients have poor skills and cannot seem to learn new ones. At the same time, the skills that professionals define as important are often not the ones that clients themselves find interesting or important (e.g., daily bed making). When clients are given the opportunity to learn things that they want to learn, they often surprise professionals (and sometimes themselves) by being able to learn them well.

**Changing others' perceptions of one's competency and capacity to act.** If anything defines the public (and professional) perception of "mental patients," it is incompetency. People with psychiatric diagnoses are widely assumed to be unable to know their own needs or to act on them. As one becomes better able to take control of one's life, demonstrating one's essential similarity to so called "normal" people, this perception should begin to change. And the client who recognizes that he or she is earning the respect of others increases in self-confidence, thus further changing outsiders' perceptions.

**Coming out of the closet.** This is a term we have taken from the gay/lesbian movement. People with devalued social statuses who can hide that fact often (quite wisely) choose to do so. However, this decision takes its toll in the form of decreased self-esteem and fear of discovery. Individuals who reach the point where they can reveal their identity are displaying self-confidence.

**Growth and change that is never ending and self-initiated.** We wanted to emphasize in this element that empowerment is not a destination, but a journey; that no one reached a final stage in which further growth and change is unnecessary.

**Increasing one's positive self-image and overcoming stigma.** As a person becomes more empowered, he or she begins to feel more confident and capable. This, in turn, leads to increased ability to manage one's life, resulting in a still more improved self-image. The negative identity of "mental patient" that has been internalized also begins to change; the individual may discard the label entirely, or may redefine it to convey positive qualities.

## Empowerment and Rehabilitation

Within the research project, the definition was the starting point for the development of a measurement instrument.[3] Although our study was limited in scope, we found that participants in the groups we studied displayed a fairly high level of empowerment.[4] It is hoped that both the definition and the research project will promote the further study of the concept of empowerment for people with psychiatric disabilities. This concept is particularly important within psychiatric rehabilitation programs, since these programs often claim that they are promoting independence, autonomy, and other ideas related to empowerment. It would be extremely useful to find out, for example, whether rehabilitation practitioners believed their programs were promoting empowerment in their clients, and whether clients of those programs agreed. An increase in empowerment scores following participation in a program would be a positive indicator about that program. If scores did not increase, practitioners (and program clients) should try to identify those program elements that interfere with clients becoming empowered.

Operating an empowerment-oriented program has risks, as does becoming empowered. The desire to protect (and to be protected) is a strong one; nonetheless, there are genuine benefits when clients begin to control their own lives, and when practitioners become guides and coaches in this process, rather than assuming the long-term, paternalistic role of supervisors. Such a shift of roles and practices would make rehabilitation services truly transformative in the lives of their clients.

[1] Copies of the project materials and results are available from the author.

[2] A list of the Advisory Board members is available from the author.

[3] Copies of the instrument, "Making Decisions," are available from the author.

[4] An article describing the instrument and the study result is currently in preparation.