

# Advocacy Tool Kit

## Skills for Effective Self and Peer Advocacy

Produced by  
Wisconsin Coalition for Advocacy

Madison Office:  
16 N. Carroll Street, Suite 400  
Madison, WI 53703  
Voice/TTY: 608-267-0214  
Fax: 608-267-0368  
For consumers and their families: 800-928-8778

Milwaukee Office:  
Summit Place  
6737 W. Washington Street, #3230  
Milwaukee, WI 53214  
Voice/TTY: 414-773-4646  
Fax: 414-773-4647  
For consumers and their families: 800-708-3034

Rice Lake Office  
801 Hammond Ave.  
Rice Lake, WI 54868  
Voice/TTY: 715-736-1232  
Fax: 715-736-1252  
For consumers and their families: 877-338-3724

Web site: [www.w-c-a.org](http://www.w-c-a.org)

# ACKNOWLEDGEMENTS

This *Advocacy Tool Kit* was developed in cooperation with the New Partnerships for Women Project of the YWCA of Madison, WI. Special thanks to an ad hoc collaborative work group whose members gave willingly of their time and expertise in this *Advocacy Tool Kit's* development. The Work Group's members included Jessica Barton, New Partnerships for Women; Mary Blondin; Molly Cisco, Grassroots Empowerment Project; Beth Forsythe; Dianne Greenley, Wisconsin Coalition for Advocacy; Heather Hazelwood, New Partnerships for Women; Barb Hennings; Lori Luebke; Ellen Magee, Catholic Charities; Peggy Michaelis, Mental Health Center of Dane County; Jolanda Sallmann, New Partnerships for Women; and Mary Thornton. The *Tool Kit* was compiled by Amy Judy and the layout was designed by Dee Finnegan, Advocate Media.

The convening of the Self- and Peer Advocacy Curriculum Work Group and publication of this *Advocacy Tool Kit* was supported by the Wisconsin Coalition for Advocacy with funding from the Bureau of Community Mental Health, Division of Supportive Living, Wisconsin Department of Health and Family Services. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the DHFS.

For more information on additional copies of the *Advocacy Tool Kit* or other resources from the WCA Community Mental Health Protection and Advocacy project, please visit WCA's web site located at [www.w-c-a.org](http://www.w-c-a.org) or contact WCA by telephone at 608-267-0214 (voice/TTY) and request a brochure of available resource materials and videos.

## COPYING ITEMS CONTAINED IN THIS MANUAL

Many of the articles contained within this *Advocacy Tool Kit* have a copyright and are noted as such with the copyright symbol (©). The Wisconsin Coalition for Advocacy has received permission to reprint the copyrighted articles and include them within this *Advocacy Tool Kit*. Reproduction of copyrighted materials is prohibited without permission from the author; however, you may copy the portions of this Kit that are not copyrighted. To assist you, the following marks (###) will appear at the end of every copyrighted article. For non-copyrighted material please credit the Wisconsin Coalition for Advocacy whenever copies are made.

Wisconsin Coalition for Advocacy, 2005.

# TABLE OF CONTENTS

Introduction . . . . .	1
------------------------	---

## **SELF ADVOCACY**

Getting Started . . . . .	3
---------------------------	---

• Being the Expert on Yourself . . . . .	3
• Believing in Yourself . . . . .	6
• Oppression and Stigma . . . . .	7
• Recovering from treatment . . . . .	8
• Self Disclosure as a Stigma-Buster . . . . .	20
• Self-Awareness of Problem-Solving Strategies . . . . .	22
• Self-Awareness Tool Worksheet . . . . .	22

Communication Skills . . . . .	26
--------------------------------	----

• Styles of Communication . . . . .	26
• Behaviors that Encourage and Stop Communication . . . . .	27
• Levels of Listening . . . . .	28
• Communication Tips . . . . .	29
• Attitudes necessary for self-advocacy . . . . .	34
• Taking Care of Yourself in the Middle of Conflict . . . . .	36

Advocacy Skills and Strategies . . . . .	41
--	----

• Problem Solving Strategies . . . . .	41
• Sample Action Plan Worksheet . . . . .	50
• How to be an Effective Advocate . . . . .	52
• Documentation and Taking Notes . . . . .	53
• Advocacy on the Telephone . . . . .	55
• My Contact List Worksheet . . . . .	61
• Telephone Log Worksheet . . . . .	62
• Advocacy in Writing . . . . .	63
• Advocacy in Person . . . . .	68
• Bureaucratic Tactics of Avoidance . . . . .	74
• Reconciliation: A Brief Conflict Resolution Study Guide . . . . .	76

• Negotiation: A Tool for Change . . . . .	89
Emotional Self-Care . . . . .	96
• Developing a Wellness Toolbox . . . . .	96
• Wellness Toolbox Worksheet . . . . .	99
• Guide to Developing a WRAP-Wellness Recovery Action Plan . . . . .	100
• Presents to Give Yourself . . . . .	102
• What Presents Would You Give Yourself Worksheet . . . . .	104
• Boundaries . . . . .	105
• Patience, Perseverance and Sustenance . . . . .	105

## **PEER ADVOCACY**

• Understanding Your Role as a Peer Advocate . . . . .	106
• Setting the Ground Rules . . . . .	108
• Dos and Dont's of Peer Advocacy . . . . .	112
• Helping Agent Skills . . . . .	113
• Advocacy Oriented Peer -Support . . . . .	115
• Ways to Resolve a Dispute . . . . .	120
• Peer Advocacy Action Plan Worksheet . . . . .	129
• Information Gathering Worksheet . . . . .	131
• Peer Advocacy Telephone Log Worksheet. . . . .	135
• Peer Advocacy Contact List Worksheet . . . . .	136

## **TOOLBOX**

Scenarios to Practice . . . . .	137
Rights for Consumers . . . . .	147
Legal Basics . . . . .	151
Law Books - The Basics . . . . .	157
Legal Resources on the Internet . . . . .	160
Glossary . . . . .	161
Resources . . . . .	170
Rights & Realities II Order Form. . . . .	186

# 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 advocacy that a person can undertake:

- *Self-advocacy*: representing and advancing one’s own interests;
- *Peer advocacy*: representing the rights and interests of someone other than yourself;
- *Systems advocacy*: influencing social, political, and economic systems to bring about change for groups of people; and
- *Legal advocacy*: using 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 so it is most helpful to individuals in Wisconsin. Its focus is on persons who have been labeled with mental health and/or substance abuse problems, but the advocacy skills can be learned and practiced by anyone.

The first section, “Self-Advocacy”, focuses on developing strategies and building skills to speak out and take action for yourself. The second section, “Peer Advocacy”, provides information and skill building exercises that will assist you in advocating on someone’s behalf. In order to be an effective peer advocate read through the issues and practice the skills that are highlighted in the Self-Advocacy section.

Throughout this *Tool Kit* reference will be made to “consumers/survivors.” As used in this document, “consumer” represents any individual who does, could or has received health care or services, or more specifically someone who has been diagnosed with a mental illness and has received treatment in some manner for this diagnosis. A “survivor” is someone who has been diagnosed with a mental illness and has been treated for their diagnosed illness in some manner and endured and come through those experiences. Some individuals who have been labeled with

a mental health diagnosis and received treatment for their diagnosis choose to be referred to as a “consumer” or “survivor” or both, instead of as someone with a mental illness.

### **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 consumers/survivors frequent interaction with service providers, family members, friends, colleagues and others who may not recognize you as a decision-maker disempowers you from being in control of your situation. Learning about and practicing self-advocacy and peer advocacy skills can enhance your role 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!

# GETTING STARTED

## Getting Started

Effective self-advocacy begins with you. Before you can begin to build skills for speaking out and taking action for yourself, you need to understand and educate yourself about yourself so that you can identify how your characteristics interact with self-advocacy. The following articles and exercises will assist you in identifying these characteristics: your style, how you communicate, how you feel about yourself, and identifying your strengths. By recognizing your unique characteristics, you have identified the most important “tool” you can use as a self-advocate -- you.

The initial focus of this section includes articles and exercises to assist you in recognizing the central role you have in the advocacy process. Next, the focus shifts to the importance of believing in yourself to effectively advocate, and the impact that stigma and self-stigma have on our lives. Finally, this section will finish with suggestions and an exercise to assist you in identifying and assessing your unique approach to problem solving.

## Being the Expert on Yourself

(Copeland, Mary Ellen. “Being the Expert on Yourself,” HelpHorizons.com (© 1995-1999). Reprinted with permission.)

You are the best expert on yourself. You have, by far, more knowledge about yourself than anyone else. No one else lives inside your body or inside your brain. No one else has ever experienced exactly what you have experienced. And no one else can know what you want to do with life – your goals and dreams. (I remember when a vocational counselor showed me my file and it contained goals for my life and how I was going to meet those goals – a document I had never seen. I was flabbergasted.)

If you are like most of us, when you come upon troubling times, experience distressing symptoms or need to make some life changes, you look outside yourself for answers. And you will find that there are many people who will be delighted to direct you, make decisions for you and take action in your behalf. You may reach out to your partner or another family member, friends, colleagues, a religious or spiritual advisor, a counselor or therapist, a medical doctor or medical specialist like a psychiatrist, a nutritionist, an acupuncturist – the list goes on and on. And while all of these people may be able to provide some help, information or guidance, you may overlook the most important authority – yourself. If you overlook your own inner guidance as a source of wisdom, your course of action may prove to be less than helpful.

In 1976 I was experiencing another deep depression – one of a succession of depressions that have troubled me through my life. I had never looked at the possible causes of this depression. I thought they were something outside of myself and that I couldn't control them – that these depressions controlled me. This time I decided to reach out for help. I went to see a psychiatrist and described my symptoms. He told me that, like my mother, I had manic depression, and if I took lithium and an anti-depressant I would be fine. I accepted his diagnosis and took the medications he prescribed. In looking back I know that I should have asked him what being manic depressive meant and how he determined that should be my diagnosis. Then I could have decided for myself if the diagnosis really fit. I could have asked him if he thought other issues in my life – like being in an abusive relationship, being overworked and overwhelmed much of the time, bad things that happened to me when I was a child, lack of close friends and supporters, being kept from doing the things I wanted to do with my life – might be causing or worsening my symptoms. I know now that I definitely should have asked him the possible short and long term side effects of the recommended medication, how much water to drink when taking this medication, if there are times I should not take it, what would happen if I took too much of the medication, etc. Based on what I felt and learned, I could have decided whether I wanted to follow his direction and take the medication.

In the years since then, I have reached out to many other sources for help and guidance. They include:

- A nutritionist who told me that I needed more B vitamins and some amino acids,
- A minister who felt my problems would be eased by more involvement in a religious community – that I was out of touch with God,
- Various counselors who told me I should try to heal my relationship with my husband, or that I should leave my husband, and tried to direct me in and out of other relationships,
- A body worker who told me that my healing was dependent on the thoroughness with which I could remember and share childhood trauma,
- A family member who told me that I should “pull myself up by the bootstraps,”
- A well-meaning friend who said I should go home and bake pies for my family,
- A benefits provider that accused me of malingering and being non-compliant.



When I told a psychiatrist that I wanted to write a book, he told me that I was being “grandiose.” Since then I have written 10 books and had them published. The same psychiatrist told me I could never lead a workshop. Since then I have led hundreds of workshops – attended by thousands of people – all over the world.

The most important lesson that I learned from all of this is that in making decisions about me and my life, I first must listen to myself. I must ask myself what I know and feel about myself. Then, if I want to, I can reach out to others for their ideas. As each of them shares their opinion or gives their advice, I can weigh it carefully and see how it resonates with me – does it feel right to me or doesn’t it? If it feels right I can do or believe as they suggest. If it doesn’t feel right, I don’t need to.

You may have received so much advice and been told so many things about yourself over the years that you have no idea how to access your inner knowledge. While it takes time and patience, you can learn, or improve your ability, to listen to yourself and to determine what is best and right for you. Some of the following ideas may be helpful to you. As you work on this, you will discover other ways that help you to know yourself and what you need.

1. **When another person makes a suggestion of something you should do or says something about you, make sure it feels right to you before acting on it.** You may ask yourself, is it a “bing” (right) or is it a “thud” (wrong)? If it is about some action, you could write the options on sheets of paper. Shuffle them. Then choose a sheet of paper. By noticing your emotions about what the paper says, you will know whether or not it is the right answer for you.
2. **Educate yourself so that you know all there is to know about the issue or issues at hand.** As you learn, make sure what you are learning feels right to you. Remember, just because it is in a book by a prestigious author or is on an internet site does not mean it is right, or that it is right for you. For instance, many people who have a psychiatric diagnosis are given erroneous information like: you will never get well, you can never have children, you can never be in an intimate relationship, you can never go to college, or you can never have the career of your choice. Education will help you make your own assessment of each issue. You may decide that you don’t even agree with the diagnosis or that anyone has the right to diagnose you with anything. You may prefer to think about your symptoms as feelings rather than a diagnosis.
3. **Discuss the issue in depth with a person or people you trust, even an “expert” like a doctor or counselor.** Then decide for yourself how you feel about the input you received and what action you are going to take.

4. **Before making a major decision about anything, decide to wait a specified amount of time**, for instance three days (or longer for more major decisions). Often, after reflection, you will change your mind. My mother once jotted down a note that said, “If you haven’t changed your mind lately, maybe you don’t have one.”
5. **Journaling.** The process of writing can be helpful in gaining understanding of how you really feel about something. Don’t worry about penmanship or grammar. Write anything you think or feel. It doesn’t have to be right. It can be pure fantasy. It can be thoughts, feelings, expressions of emotions, ideas, plans – anything you want. You never have to show it to anyone if you don’t want to. Others should respect the privacy of your writings. Read your writings when you feel like it.
6. **Peer counseling.** Ask a friend that you trust to peer counsel with you. Decide how much time you can spend (most people do it for one hour but it could be more or less time). Divide the time in half, and each of you spend your half of the time talking, laughing, crying, ranting, raving – anything that feels right to you – while the other person listens closely without interrupting you.

As you work on accessing the inner knowledge that you possess, and taking action based on what you know about and want for yourself, you may find, as I have, that the quality of your life improves and that your life becomes richer than you could have ever imagined.

## **Believing in Yourself**

(Adaptation from Teacher’s Guide, Freedom Self-Advocacy Curriculum, National Mental Health Consumers’ Self-Help Clearinghouse (April 2000 Pilot Version), p. 6.)

In self-advocacy, attitudes and beliefs are as important as skills are. “Self-advocacy requires an internal belief that you are someone who is worth advocating for,” says Clearinghouse program director Marie Verna. “As mental health consumers, we are often led to believe that we’re not worth advocating for,” she continues, “and we have to change this belief in order to take advantage of advocacy training. A belief in the value of ourselves allows us to take advantage of other aspects of self-advocacy training, such as learning our rights and learning how to write effective letters.”

Many consumers have used positive beliefs to achieve things that they had been told would be impossible. Mary Ellen Copeland, a well-known author and lecturer, and herself a consumer, says, “In the mental health system, people are consistently told what they can’t do.” However,

says Copeland, “I’ve talked with people who’ve become wonderful parents, who’ve become doctors and lawyers, and who run corporations. Nobody else but you can determine the course of your recovery.”

Other consumers who are self-advocates and peer advocates echo Copeland’s sentiment that by believing in themselves, consumers can unlock their potential. Andrea Stephenson, a consumer who offers advocacy training in Washington State, says that it “involves helping people to realize their own strengths.” By teaching consumers about advocacy, she’s learned that, “It didn’t matter what level people were in their recovery, everyone had skills within themselves.”

Consumers who have gotten involved in self-advocacy also agree that once you become involved in advocacy, the rewards multiply. Success serves to bolster your self-esteem. Says Copeland, “The more we reach out and get what we need, the better we feel about ourselves. As our symptoms are relieved, we feel better, but also when we get what we need, we feel better about ourselves.”

Howard Trachtman, a self-advocate and peer advocate from Massachusetts, agrees. “I like challenges,” he says, “and when I feel like I’ve mastered something, I can move on to something else.” He notices that being able to achieve advocacy goals also helps other consumers. “For the purpose of empowerment, it’s best that people do as much as they can to the best of their ability,” he continues.

Keep in mind that although self-advocacy means taking responsibility for getting what you want, it doesn’t mean that you have to be alone: you shouldn’t ignore your existing support systems. In her Texas training sessions, Janet Paleo stresses the importance of peer support. Self-help groups can help you deal with uncomfortable situations that you might encounter in your self-advocacy efforts. If you’d like to locate self-help groups in your area or start one of your own, contact the Grassroots Empowerment Project. (See page 171 of the *Toolbox* for contact information.)

## **Oppression and Stigma**

Issues of oppression and stigma affect people on a daily basis. The next few pieces discuss issues related to oppression, stigma and self-stigma. While it might seem unusual to some that these issues and articles are addressed in this *Advocacy Tool Kit*, recognition of the existence and impact of oppression and stigma cannot be overstated. How we view ourselves and others impacts our effectiveness as self-advocates.

## **Recovering from treatment: The mental health system as agent of stigma**

(Reidy, Deborah E. "Recovering from treatment: The mental health system as agent of stigma," Resources (© Fall 1994), vol. 6, no. 3, pp. 3-10. Reprinted with permission. )

*"I have this concept in my mind: it's called recovery from treatment." Anonymous*

**Of the 46 people interviewed for the study on which this article is based, 34 identified themselves as current or former consumers/survivors. Some were also mental health practitioners or professional advocates. Ten were family members or professionals who did not identify themselves as consumers/survivors. Interviews were open-ended, with a few questions used to generate responses. All participants were willing to be interviewed. Some called a second time or sent articles, letters and cassette tapes. A number of people noted that no one had ever asked them about stigma.**

In 1963, Erving Goffman published his landmark volume, *Stigma: Notes on Management of Spoiled Identity*. In it, he explored the phenomenon of stigma, which he defined as "an attribute that is deeply discrediting." Such attributes included physical deformities, "blemishes of individual character," and "tribal stigma of race, nation and religion." Goffman was especially interested in interactions between stigmatized persons and those he termed "normals." In those interactions, he wrote, "an individual who might have been received easily in ordinary social intercourse possesses a trait that can obtrude itself upon attention and turn those of us who he meets away from him, breaking the claim that his other attributes have on us" – a denial of acceptance, respect and regard.

Since then, many books, articles and research projects in the field of mental health have continued the exploration of stigma. In addition, consumer/survivor, family and professional advocates have mounted campaigns to "stamp out stigma." Task forces, forums and conferences have been convened on the topic.

Despite these efforts, conversations with consumers/survivors within the field indicate that certain aspects of the topic have not been sufficiently addressed. Their stories tell of painful experiences of exclusion, rejection and discrimination, often through hundreds of subtle day-to-day interactions.

And, although people talk about being stigmatized by family, neighbors, friends, employers and others, their stories most frequently point to the mental health service system itself as a primary source of stigma.

L.M. Coleman, in the 1986 article, “Stigma: An enigma demystified,” identified three major effects of stigma: social rejection or isolation, lowered expectations and “internalized stigma.”

Systematic social rejection can lead to segregation of stigmatized people. Often this is accompanied by congregation, where people with similar negatively valued qualities are grouped together, as in institutions. Rejection can also be more subtle and personal, such as when people are ignored in social situations, are not consulted about decisions that affect their lives, are excluded from gatherings.

Stereotyping brings lowered expectations. If people are seen simply in terms of undesired difference, they are unlikely to encounter high expectations. This, in turn, may keep them from opportunities to grow and develop, reinforcing low self-esteem, the hallmark of internalized stigma.

Internalized stigma refers to the process of absorbing negative societal beliefs and expectations. Many who have been stigmatized consider this its most damaging effect, because it becomes independent of external perceptions and so can follow one through life, regardless of external evidence of achievement.

While respondents cited a variety of sources of stigma, most frequently mentioned were the attitudes and practices of the mental health system and its workforce. The following quotes may illustrate these responses:

*Those who stigmatize most are those in the mental health system. They’ve shown very little interest in the opinions of former patients regarding the treatment they’ve received.”*  
(Larry Plumlee)

*“The whole system is set up (not consciously)...to create and preserve stigma.”* (Janet Foner)

*“I have been involved in the academic world as a professor. They were very non-stigmatizing, they didn’t care at all about my mental health background. I have found great stigma in the mental health system.”* (Anonymous)

*“I have this concept in my mind: it’s called recovery from treatment. Treatment is the most stigmatizing thing there is.”* (Anonymous)

*“The greater involvement in the system, the greater the stigma.”* (Bill Butler)

*“Stigma in mental health services? It just goes on and on.”* (Judi Chamberlin)

## **STIGMATIZING BELIEFS AND PRACTICES**

### Power Issues

Issues relating to power and control were most often mentioned as stigmatizing, as dynamics that permeate the practices of the mental health system.

A number of people pointed to the practice of “forced” anything – medication, treatment, hospitalization, activities. And some mentioned threats – of forced treatment, or no treatment – as strategies to keep people in line.

Important issues are linked to the “ownership” of a person’s treatment plan. One person said, “They set a series of goals that the program devises for other people. If the person doesn’t like the goals, or if they have goals of their own, they’re called ‘non-compliant,’ or ‘rebellious,’ or ‘unresponsive to treatment.’”

Others described the following practices as stigmatizing: restrictions on freedom to come and go, being told when to do things, lack of choice about life decisions, being placed in a house or apartment, staff speaking for people served, having one’s preferences, insights, self-knowledge and perspectives ignored.

Why do issues of power and control pervade the mental health system? Because the stigmatization process is dependent upon the negative evaluations of representatives of a dominant group. Once such negative evaluations are made, representatives of the dominant society are then given license (formally or tacitly) to exercise social control over those within stigmatized groups. This dynamic is further complicated by expecting staff to be responsible for protecting and nurturing the people they serve. One professional commented on the tension between the mental health system’s “therapeutic agenda and the custodial mandate.”

### Status differential

One category of experiences was seen as highly significant by most respondents: the fact that people with psychiatric disabilities are perceived and treated as having lower status than mental health staff.

Some instances of this differential were found as symbols or images within the physical environment. As one respondent put it: “You’re shit and I’m not. Why? Because I’ve got the keys.” Others noted the presence of separate and more attractive accommodations, such as staff bathrooms and dining rooms, as symbolizing difference in status.

### Regimentation and deindividualization within the system

Some attitudes, beliefs and practices contribute to stigma that already exists. Other practices actively strip a person of a non-stigmatized identity and replace it with the stigmatized one of “mental patient” -- “a deviant identity and status which the persons gradually begin to accept.” (N.J. Herman, unpublished master’s thesis, 1985.)

Regimented and deindividualizing practices of both institutional and community programs are examples. Herman cites her own and other research on the chief originator of stigma -- the institutional processing that is a dominant feature of mental hospitalization. These include being brought to a hospital like an inanimate object, being subjected to an embarrassing physical examination, having one’s possessions taken away, staff enforcement of rules and regulations, having intimate information about one’s life gathered for case histories (which are then available to all staff), and having enforced interactions with other patients.

Respondents in this study gave examples of their experience of regimentation and deindividualization within programs, both institutional and community. Specifically, they cited the following:

- Dehumanizing admitting procedures -- “During my first hospitalization . . . the first time I was medicated it was very mortifying. They said I could take it by mouth or injection. I refused, they grabbed me and held me down and injected. . . . Then they took my clothes away. I do not minimize the impact of taking my clothes away. I never got them back. I still remember those -- a yellow shirt with green stripes and green pants. . . . During the first month they didn’t allow family, friends and my outpatient psychiatrist . . . they cut my hair.” (Dan Fisher)
- Regimented activities -- In one community day treatment program, consumers were not allowed to use the bathroom during the entire hour of “group.” Others described having to take part in activities (arts and crafts, group therapy) at fixed times, whether they wanted to or not.
- Having to wait for appointments -- Anthony Lehman noted that clinic routines don’t support self-esteem, pointing to the practice of making people wait for appointments or scheduling appointments during the day as if people had nothing better to do. While one interpretation of this phenomenon might be that highly valued professionals routinely overbook their appointments, it has a more insidious function of reinforcing messages about consumers that pervade the entire system -- messages that people are not important, certainly less important than staff, and that their lives are meaningless.
- Being forced to accept the psychiatric label -- “When you go into a psych setting, they get you to admit you’re mentally ill and if you don’t, they say it’s a symptom of your illness. They make you helpless, they break you down. If you’re strong and fight back, they’ll crush you with drugs and shock treatment and cause further brain damage.” Another respondent wrote: “[It] is clear to me that stigmatization is the function of a mental illness diagnosis. There is no way you can claim ‘mental illness’ without all it’s legally stigmatizing ramifications.”

David Hanlin told the following story: “I think it (stigma) is worse within the delivery system than it is in the public. For example, a friend went to a five-day seminar on mental health issues. Three people stayed in a hotel room: my friend, a therapist, and a social worker. When they found out she was a consumer, they had her reassigned. They said, ‘We’re here to learn about mental illness, to get away. We don’t want to be ‘burdened down’” – implying not only that she would be a burden, but also that they, the professionals, were in a position to care for her, even though they had no such official role. Inequities may be embedded in program policies and procedures. Stephen Holochuck described phoning a mental health center to request their brochure. The receptionist asked, “Have you received services here?” He responded, “Why do you need to know?” The answer was, “Because if you’re a professional, we’ll mail it to you. If you’re a consumer, you have to come in and pick it up.”

A number of people mentioned the status differential between people with psychiatric disabilities who were hired to work in mental health programs and other workers in the same programs. Discriminatory treatment of those with psychiatric histories shows how deeply stigma is embedded in the mental health system.

Some people experienced difficulties during the hiring process. Others mentioned that case managers felt uneasy talking frankly around people with psychiatric histories. Questions of confidentiality and disclosure were raised. In some agencies consumer case managers found themselves dealing with unequal working conditions or unequal expectations.

Pat Risser, who worked as a consumer case management aide, said, “We had a hard time transitioning into the role as a professional because we were excluded from the social activities of the ‘normal’ staff.... When we were finally invited to join the others at their weekly TGIF outings, the barrier of stigma from our co-workers finally broke down. We did socialize when given the opportunity and proved ourselves to be equally, fully, human. There still remained huge differences in salary and economic status.... But, breaking down the social barrier was certainly a step in the right direction.”

The effect of stereotypic thinking on the behavior of mental health professionals is strikingly illustrated by David Hanlin: “I went to work as a mental health technician in a psych hospital...I told a nurse about my past psychiatric problems, a trusted co-worker. Next thing I knew, she’d spread this to co-workers. Once they knew, it was amazing the difference in how other staff reacted. They started using patient words on me. Everything I did was ‘inappropriate.’”



### Separation from ordinary life

A number of respondents described as stigmatizing the practice of separating people with psychiatric disabilities from ordinary community life. Several commented on the practice of congregating or grouping people with similar labels.

One person, critiquing the practices of mental health centers with which he was familiar, said, “Mental health centers group people, isolate them, and set up an artificial pseudo-environment. . . . It is harder for people to improve their quality of life if they can’t make it in the society where the rewards come from. Mental health centers reinforce the tendency for people to drop out, stay out, to disengage. . . . The system turns people into monsters. Mental health centers are zoos in the community where mental monsters hang out all day.”

Segregating and congregating people with psychiatric disabilities exemplifies social rejection and contributes to another of the major effects of stigma, lowered expectations. Segregation reinforces the tendency of people to disengage from ordinary life, thereby depriving them of opportunities to develop the skills and confidence to function in a non-segregated environment. They become viewed as people with no future and little to offer.

Not only is segregation a consequence of stigma, but it also contributes to it by reinforcing stereotypes, including the belief that people with psychiatric disabilities are fundamentally different, that they “belong with their own kind,” that they need to be protected from society or society from them.

### Non-developmental approach

The absence of challenge or orientation to growth within the mental health system was also commonly described as stigmatizing. One respondent said, “There has been, for most of my experience with private and public psychiatry, no rehabilitative approach. I was expected to amount to no more than a clerk even though I have a Ph.D.” Several people commented on the beliefs that contributed to a non-developmental approach, the belief, for example, that mental illness is a permanent, chronic and deteriorating condition.

Several people mentioned activities they found stigmatizing in psychiatric hospitals and day or vocational programs: arts and crafts, children’s games, and activities of daily living, instead of developing work and social skills. Interactions with staff often reinforced these low expectations.

Pat Risser, who referred to rehabilitation programs that placed people in menial jobs as “food or filth,” said, “They don’t really train people to do what they want to do, or find what their potential is.” He went on to say, “I went through a severe depression, was in a lot of pain. . . . Instead of sending me to school as a paralegal, they sent me to a sheltered workshop. I was standing next to

someone who was severely retarded and we were counting fish hooks. I was class president in college, I was a law school drop-out. If I wasn't depressed going in, that sure did it." I thought, 'God, have I sunk that low? Is this what everybody thinks?'"

A couple of family members had the same reaction. Louis Vescio said, "Drop-in centers are ill thought-out. Drinking coffee and smoking cigarettes is not a program." Leo and Rae Stack, whose daughter had derived great satisfaction from her "regular job, not a put-up job," noted that some of the so-called work opportunities were detrimental because of the demeaning limitations placed upon people.

The results of this non-developmental approach? "Massive dependency" (Carmen Meek), "low self-esteem/low self-confidence," and finally, no hope: "The system tends to foster no growth. This no-fault thing encourages no growth: 'This is the way you are, nothing can change,' 'incurable,' 'lifetime,' 'once you've got it, you're stuck.'"

#### "Life in a fishbowl"

The lack of respect for a person's privacy – "life in a fishbowl" – was described as stigmatizing. In addition, behavior was said to be "over-interpreted" – any normal feelings and behavior were judged to be pathology or symptoms of one's illness.

One result was the stifling of ordinary emotions. During her time in the hospital, one respondent chose to be very quiet ("I didn't trust them. I wasn't going to tell them life's deepest secrets because I didn't know how it would be twisted, used against me.") However, she was much more animated when she made phone calls to her friends and family. Consequently, in her case record was written: "Question manipulative affect. Brighter when on phone."

Some respondents felt that poverty played a much larger part in influencing life conditions than did the psychiatric disability. Yet their struggles and challenges were treated as symptoms. They were seen through the "lens of diagnosis."

#### Inadequate access to information

Some respondents felt that inadequate access to information was stigmatizing, to both people with psychiatric disabilities and their families. Failure to educate consumers regarding their diagnosis or prognosis was seen as part of what one person called the "unduly mystifying process" of therapy.

People with psychiatric disabilities may be seen as incapable of understanding their diagnosis or prognosis because they lack awareness. Or they may be seen as too fragile to cope with the "reality" of their diagnosis.

Yet a third possibility is that people are seen as merely objects needing to be fixed and as persons are irrelevant to the process of treatment.

#### Inattention to stigmatizing personal characteristics

A few people mentioned aspects of life that, while they might not be under the direct influence of programs, do constitute “media” through which stigma is communicated and that need to be considered and possibly addressed by mental health workers.

One person commented that effects of drugs cause funny movements that draw undue attention to the person. A couple of people referred to consumers’ clothing and behavior. Although program staff may not be directly responsible for causing these stigmatizing aspects of a person’s identity, they do have a responsibility to support individuals who wish to address them.

#### “Second-hand services”

Many saw mental health services as “second-hand.” Some people commented that they had experienced services as low quality or had received therapy from unqualified staff. A couple of people commented on the location of programs in poor neighborhoods or rundown environments. Not only are such practices evidence of the devalued or stigmatized status of service users, but they also contribute to the stigma by conveying the impression that people with psychiatric disabilities do not “deserve” quality services or environments.

#### Cues from asylum era

Ken Terkelsen referred to cues in the physical environment inherited from the asylum era: locking up knives, padlocking refrigerators and medication closets, covered radiators. Such practices represent an overprotective orientation to service.

## **EFFECTS**

#### Internalized stigma

Of the three main effects of stigma – social rejection/isolation, lowered expectations and internalized stigma – most respondents focused on internalized stigma and its consequent feelings and behavior.

Often mentioned was lowered self-esteem. Dan Fisher said, “It took me a long time to regain my self-esteem. I almost did have to become a psychiatrist to regain my self-esteem – to prove to myself, to prove to the world, to overcome the labels. Once they’ve done that diagnosis, you just can’t get rid of it, from your records and your heart.”

Depression was another effect of stigma, although one respondent said, “I’ve been psychologized so much, it’s ridiculous! I’m helpless, hopeless, lost, frustrated, discouraged, confused – not depressed.”

A number of respondents described the feeling that they carried a life-time, all-encompassing label. One person, who has a Ph.D. and is teaching in a university at the graduate level, said, “It’s been only the last two or three years that I stopped calling myself ‘crazy.’ Yet my last hospitalization was in 1980. I used to say, ‘Oh, you can’t do that because you’re crazy.’”

Another man said, “I became supersensitive to anything unusual about myself. I became hypernormal. I would never make any references to interpersonal violence around professionals, even jokingly.”

### Vulnerability

A heightened sense of vulnerability was mentioned. One man said, “I can actually sense people’s attitudes changing toward me. You turn to things to close that vulnerability – booze, drugs, etc. – but it makes things worse.”

Another consequence was described by one man as a “mindset of degradation.” He said, “This is a mindset a lot of us get into because of our label. It degrades us, makes us not care what we look like. It adds to the shiftlessness, allows us to accept being grouped with other mental patients and being publicly identified.”

Neil Robinson wrote, “The first effect stigma had on me was to cause me to withdraw from activities that could have contributed to my recovery process.” Another effect on the behavior of stigmatized persons was the process of “learning to walk on eggshells,” in other words, learning to act like a mental patient: “Speaking softly, being nice, agreeing with others, losing a sense of what one thinks or only remembering it in the middle of the night, certainly not when with people who assert some authority,” was how Larry Plumlee described it.

### Isolation

Relationships with family and friends were also affected. One man felt a deep sense of isolation. He said, “The major consequence of stigma is social death. The only social environment people have is the mental health center. They live in isolation, don’t have people to talk to, often can’t afford a phone. This isolation contributes to ongoing crises people have. Their spirit doesn’t want to die, and eventually people fight back.”

## RESPONSES

People interviewed suggested the following categories of responses, dividing them between those initiated by the stigmatized person and those initiated by mental health workers. Interestingly, although stigma was identified as a systemic issue, most participants focused on individual and personal responses.

### Language and labeling

Respondents' objections to language and labeling fell into seven categories:

1. Objections to language separating the phenomena of stigma from the larger dynamics of oppression: Some respondents were adamant about using words such as "prejudice," "oppression" and "discrimination" to describe the phenomena being addressed, rather than "stigma." Judi Chamberlin said, "Even the word 'stigma' is a bad word. The concept of stigma itself implies that there's something wrong and we have to hide. We need to talk about discrimination and prejudice. It's a civil rights protection problem."
2. Objections to offensive slang, words such as "twisted," "nut," "cripple," "moron."
3. Objections to patronizing or condescending language referring to "our" mentally ill or "the" mentally ill. Others mentioned patronizing or infantilizing tones of voice.
4. Objections to language that obscures reality: One person said, "Psycho-babble like 'We're waiting for the therapeutic effect' bothers me." Another person felt the word 'consumer' was euphemistic: "They changed the language, but they didn't change the practice. It's a lie. There's no market research, the products aren't changed."
5. Objections to language with a medical orientation: Words such as "patients," "mental illness," "sick," were seen as stigmatizing by some respondents, along with the "language regarding symptomology that makes it sound like people have mold growing out of their ears," as Anthony Lehman said. "Decompensating" might be a good example.
6. Objections to language with the implicit assumption of the power to judge: Terms such as "treatment-resistant," "high-" or "low-functioning," "non-compliant," "rebellious," "unresponsive to treatment" and similar terms that tended to pass judgement.
7. Objections to dehumanizing language: One respondent said he felt the term "placing people" was stigmatizing because it was as if people were rocks – inanimate objects.

Two proposals also emerged to counter these objections:

1. Harriet Lefley, a professional and a family member, felt that the way various terms are perceived should be changed, rather than the terms themselves: "Everybody has bought in to the stigmatizing properties of all the terms surrounding mental illness. It's taken us many years to say, 'I have cancer.' Why can't we do that with mental illness? Why can't we proudly say, 'I have a mental illness and I've transcended the barriers'?"
2. Judi Chamberlin proposed that language referring to people with psychiatric disabilities and their roles within the system be considered in context: "You are a client in a program, a member in a clubhouse, and a survivor in the political context."

#### Responses initiated by stigmatized person

**Stay away from the mental health system.** Some participants felt that any contact with the mental health system would stigmatize them without offering corresponding benefits. Stephen Holochuck suggested “radical disengagement” from professionals: “Don’t get invested enough to fight with them.”

**Self-help and peer support.** Other participants recommended contact with others with similar experiences. Judi Chamberlin attributed her minimal experience with stigma to being open about her identity and being active in the consumers/survivors movement.

**Take personal responsibility – attitude adjustment.** Some respondents felt that coming to terms with the fact that most stigma comes from within was the first step to removing it. Bill Butler advised people to “get off that SSI/SSDI mentality.” He also said, “Important messages: Think on your own. Trust your gut.”

**Take personal responsibility – behavioral strategies.** Some examples include: Do a personal inventory; do ordinary things, things that make you feel good; focus on total healing.

**Hide your history.** Some participants advised that people with psychiatric labels refrain from telling anyone. Others advocated selective “telling.”

**Don’t hide your history.** Judi Chamberlin said, “Hiding is internalized oppression.... If someone goes public, there’s no way to blackmail.”

#### Responses initiated by mental health workers

**Understand the dynamics of stigma.** Joel Slack said that people with disabilities must take responsibility to address stigma. However, he also felt strongly that staff have a comparable responsibility: “In a therapeutic environment, if staff understand stigma and its dynamics, they can keep it from growing.”

**Build rapport with people served.** Having relationships based on trust and responsiveness were mentioned by a number of people as effective responses to stigma. Feeling “heard” by staff was important. Some participants suggested giving people more chances to talk, while focusing on building rapport with a single person rather than feeling that one had to treat all people served identically. Also mentioned was one of the most basic strategies to respond to stigma: Treat people as human beings.

**Cultivate a sense of mutuality.** Some people recommend that staff share their own challenges and difficulties in order to relate to people on a more equal level.

Accentuate the positive. Carmen Meek said, “The system lacks motivational tools for people who want to do stuff for themselves. When you do get diagnosed, your self-esteem is totally shot. The thing that works is to build people up.” She recommended focusing on people’s wellness, capability and potential. Others recommended people be given chances to exercise responsibility. More choices, more control. Providing opportunities to have more control over one’s life was a commonly mentioned way of reducing stigma. Respondents recommended changing attitudes and roles of staff: more choice and control for consumers within existing programs; and fundamental change focusing on eliminating coercive treatment.

One respondent recommended that providers ask service recipients, “How can I help?” Consumers could be assisted to play a greater part in determining their own services, with staff seen as consultants.

Within existing programs, specific recommendations included: trusting people to take their own medication; affording opportunities to establish a schedule that fits one’s own life; and providing more choice in activities. In addition, consumer perspectives on case notes and reports were mentioned. At the systemic level, consumer participation and leadership in decision-making on an individual program and systems level were recommended.

More fundamentally, some participants advocated eliminating coercion within mental health services. Ron Thompson, who believes that “forced treatment” is a contradiction in terms, recommended that the two be separated conceptually. He said, “...two things are tied together that shouldn’t be: force – involuntarism – and the practice of medicine.”

Create natural supports. Several participants advocated that connection with family, friends and other community members be fostered by the mental health system. Carmen Meek said, “There’s a difference between the artificial support network of a therapist and the support provided by family or friends. You’re paying those people to be your support. It’s not normal.... What people need is family, friends and the community.”

## **CONCLUSION**

A number of the recommendations described above contribute to valuing people and treating them with respect and dignity. However, our good intentions cannot eradicate the fundamentally oppressive nature of many practices of the mental health system. In fact, one might argue that

respectful and dignified treatment within a structure that is inherently devaluing can contribute to a painful kind of dissonance.

S.L. Supeene writes in *As for the Sky Falling: A Critical Look at Psychiatry and Suffering* (1990): “The conflict lay between the staff’s friendliness on the one hand, and their authority on the other. Because they could be supportive listeners, I felt respected and cared for. But they were also the ‘experts’ and they were in authority; therefore they had the final say on what my problems really were and what would be done about them, so I felt diminished and helpless.” It is hard to avoid comparing this experience with that of the prisoner who relies on small kindnesses from a guard to make each day tolerable, yet who can never forget who is really in charge.

The experiences described above confirm the stigmatizing nature of many mental health practices, while merely scratching the surface of the phenomenon. Stigmatization is not an isolated and incidental feature of an otherwise benevolent system; it is intertwined with the assumptions underlying the mental health system. Nor are the effects superficial and transitory, to be shaken off once people “recover”; rather they have a pervasive and life-defining impact on the very identities of those affected.

How could our systems be made to respond in more human ways? We might start by looking for clues in the values and beliefs that underlie the positive responses identified earlier. If we were to build a mental health system that asserted that people with psychiatric disabilities are full human beings; deserve dignity, respect and an appropriate measure of self-determination; are capable of growth and development; and benefit from leading a life that is as typical as possible, then perhaps stigma would begin to diminish. As simplistic as this may sound, we do well to keep in mind Joel Stanley’s eloquent statement of aspiration: “I’m struggling for existence like everyone else...to exist with dignity and hopes, to carve out a niche for myself, to live with some enjoyment, to find some people who will treat me decently.”

What we need to ask ourselves is: How might we support him to live this kind of life?

### **Self Disclosure as a Stigma-Buster**

(Hopkins, Cindy. “Self Disclosure as a Stigma-Buster.” Austin Travis County Mental Health Mental Retardation Center.

Website: <http://www.atcmhr.com>. Reprinted with permission.)

My name is Cindy Hopkins. I am 33 years old. I live in Austin, Texas. I work at the Texas Department of Mental Health and Mental Retardation as the Mental Health Coordinator of Consumer Affairs. I am diagnosed with bipolar disorder and have struggled with the symptoms of mental illness in my life for 25 years.



When I was 23 years old, I attended a Texas Mental Health Consumers' (TMHC) Conference. This was my first experience seeing and hearing other persons talk about their experience with mental illness. Instead of seeing illness and despair, I saw hope and life. I saw people having fun and sharing strength. I left this conference with confidence. As a result of hearing other persons talk about their mental illness, I lost some stigma I held about my own illness.

After the TMHC Conference, I ran for and was elected Vice-Chair of the TMHC Board. I was later hired as Executive Director of TMHC. Through my involvement with TMHC, I had many opportunities to share my experience as a mental health consumer. These opportunities have built my self-esteem, strengthened my courage, and built me up as a role model for the community, not just for persons with mental illness.

This reduction of my stigma about my mental illness encouraged me to work at MHMR with persons who don't have mental illness and feel equal with my non-disabled co-workers. Working around me has helped eliminate stigma about mental illness in my non-disabled co-workers.

I understand that revealing mental illness can be a difficult challenge, primarily due to the stigma persons face when they are open about their disability. It is especially difficult to be open about a hidden disability, particularly one that faces as much discrimination as mental illness. Revealing a mental illness can be one of the most courageous actions a person takes, but can also be one of the most rewarding, both personally and for the mental health community.

There are some important tips to remember when revealing your disability:

- Be brief – keep it to the key facts so you don't lose your audience.
- Don't exaggerate – mental illness is stressful enough without trying to make it sound too terrible
- When telling your story, provide balance – tell the good and the bad parts
- Shatter myths – use your opportunity to rid the community of untruths about mental illness. This is a key stigma-busting tool in story telling.
- Offer hope – remember that you are a role model when you disclose your disability whether you choose to be or not and you effect the entire mental health disability community, for good or for bad.

Remember, when you self-disclose your disability you send a message to the world that you are OK. Maybe if enough people tell the world that it is OK to have a disability, the world will accept it and stigma will end.

## Self-Awareness of Problem-Solving Strategies

In order to become an effective self-advocate, first you need to understand how you feel and respond to problems. This understanding might assist you to determine what strategies and skills you want to focus on throughout this *Advocacy Tool Kit* to enhance your role as a self-advocate. For example, if I learn from this self-awareness exercise that I am more comfortable and effective problem-solving by writing letters and less comfortable talking with someone, I might want to focus building my advocacy skills around communicating over the telephone or at face-to-face meetings. Also, I might decide that enhancing my letter writing skills to effectively address strategies to solve a problem would be useful.

How each of us feels and responds to problems that arise in our daily lives differs. The following exercise is designed to reflect the diversity of problem-solving strategies that people employ. Keep in mind that while there are many different ways to solve problems, there is no “right” way.

Please complete the *Self-Awareness Tool Worksheet* below to assist in assessing the problem-solving strategies you currently employ.

### Self-Awareness Tool

(Adaptation from Teacher’s Guide, Freedom Self-Advocacy Curriculum, National Mental Health Consumers’ Self-Help Clearinghouse (April 2000 Pilot Version), Form D.)

Think about some of the obstacles that you’ve faced recently. How do you react to obstacles? This isn’t a test and there are no “right” answers! The purpose of this exercise is to help you learn more about yourself.

1. *Check one.* When I face a problem, I usually:

- |   |   |
|---|---|
| <input type="checkbox"/> Blame myself     | <input type="checkbox"/> Investigate who’s responsible  |
| <input type="checkbox"/> Blame others     | <input type="checkbox"/> I feel numb                    |
| <input type="checkbox"/> Blame the system | <input type="checkbox"/> I get teary eyed and feel down |
| <input type="checkbox"/> Blame no one     | <input type="checkbox"/> Other: _____                   |

2. *Check all that apply.* When I face a problem, I usually:

- |  |  |
|--|--|
| <input type="checkbox"/> Feel sad or discouraged | <input type="checkbox"/> Try to find solutions             |
| <input type="checkbox"/> Feel angry              | <input type="checkbox"/> Try to ignore it                  |
| <input type="checkbox"/> Can’t concentrate       | <input type="checkbox"/> Feel overwhelmed about what to do |
| <input type="checkbox"/> Fixate on the problem   | <input type="checkbox"/> Other: _____                      |

3. *Check all that apply.* When a doctor, government employee or service provider tells me something, I usually:
- |  |   |
|--|---|
| <input type="checkbox"/> Believe the person            | <input type="checkbox"/> Look for information on my own |
| <input type="checkbox"/> Ask them additional questions | <input type="checkbox"/> Other: _____                   |
| <input type="checkbox"/> Ask someone else              |   |
4. *Check all that apply.* I discuss problems with:
- |   |   |
|---|---|
| <input type="checkbox"/> Doctors, nurses & therapists | <input type="checkbox"/> A case manager |
| <input type="checkbox"/> Friends and/or family        | <input type="checkbox"/> Peers          |
| <input type="checkbox"/> Co-workers                   | <input type="checkbox"/> Other: _____   |
5. *Check all that apply.* I find the following helpful:
- ☐ Written materials from Social Security, Medicare, or Medicaid or other government agency
  - ☐ Written materials from consumer groups or other advocacy groups
  - ☐ Written materials from my doctor, therapist or service provider
  - ☐ Information on the Internet
  - ☐ Books from the bookstore or library
  - ☐ Talking with other people to learn more
  - ☐ Other: \_\_\_\_\_
6. *Check all that apply.* When I face a problem, I make lists of:
- |  |  |
|--|--|
| <input type="checkbox"/> Important facts   | <input type="checkbox"/> What I will do              |
| <input type="checkbox"/> People to contact | <input type="checkbox"/> I don't make lists, I _____ |
| <input type="checkbox"/> What I want       |  |
7. *Check all that apply.* When I use the phone to solve a problem:
- |  |   |
|--|---|
| <input type="checkbox"/> I am nervous              | <input type="checkbox"/> I give up if my calls are not returned   |
| <input type="checkbox"/> I am confident            | <input type="checkbox"/> I sometimes ask to speak to a supervisor |
| <input type="checkbox"/> I lose my temper or shout | <input type="checkbox"/> Other: _____                             |
8. *Check all that apply.* When I need to write a letter:
- |   |   |
|---|---|
| <input type="checkbox"/> I am nervous               | <input type="checkbox"/> I ask a friend to proofread the letter |
| <input type="checkbox"/> I am confident             | <input type="checkbox"/> I send copies to other people          |
| <input type="checkbox"/> I ask for help to write it | <input type="checkbox"/> Other: _____                           |
9. *Check all that apply.* When I hold a meeting to solve a problem:
- |   |  |
|---|--|
| <input type="checkbox"/> I am nervous   | <input type="checkbox"/> I bring a friend along    |
| <input type="checkbox"/> I am confident | <input type="checkbox"/> I send a letter afterward |

☐ I lose my temper or shout ☐ Other: \_\_\_\_\_  
☐ I have a written plan for the meeting

10. *Rank 1st, 2nd, and 3rd.* My top three choices for resolving a problem are:

1. Using the phone \_\_\_\_\_ 4. Other: \_\_\_\_\_  
2. Writing a letter \_\_\_\_\_  
3. Scheduling a meeting \_\_\_\_\_

11. *Check all that apply.* If a problem isn't solved right away:

☐ I give up or put it off ☐ I talk to people's supervisors  
☐ I get angry ☐ I try to get more information  
☐ I ask someone for help ☐ Other: \_\_\_\_\_  
☐ I feel hurt, blame myself, or assume I did something wrong

12. *Check all that apply.* When someone makes a promise to me but doesn't keep it:

☐ I give up ☐ I contact the person's supervisor  
☐ I get angry ☐ Other: \_\_\_\_\_  
☐ I contact the person

13. *List ways.* I feel effective solving a problem by:

I \_\_\_\_\_

I \_\_\_\_\_

I \_\_\_\_\_

I \_\_\_\_\_

14. *List your goals.* Based on what I learned from this self-awareness exercise, I would like to focus my advocacy skills on:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## Reflecting on what you learned in the Self-Awareness Exercise

(Adaptation from Teacher's Guide, Freedom Self-Advocacy Curriculum, National Mental Health Consumers' Self-Help Clearinghouse (April 2000 Pilot Version), p. 26.)

Look over your answers to the *Self-Awareness Tool*. Think about the following questions as you review your answers:

- When do you feel most effective when trying to solve a problem? Would you like to build on that identified strength?
- How satisfied were you with the way you react when something goes wrong? Would you like to work on this?
- How confident do you feel in analyzing the problems that you face? Would you like to work on this?
- Do you feel like you know how to solve the problems that you face? Would you like to work on problem-solving skills?
- Do you feel like you follow through until a problem is solved? Would you like to work on this skill?

Many of the strategies and skills contained within this *Advocacy Tool Kit* will assist you to build on your personal strengths and enhance your problem-solving skills. Again, there is not one way or “right” way to solve problems. The most important concept to remember from the *Self Awareness* exercise is learning about what works for you and how you can build on those identified strengths to become an even more effective advocate.

# Communication Skills

Self-advocacy involves representing and advancing your own interests. The foundation of effective self-advocacy is communication: how you connect, interact and transmit your thoughts and feelings to another.

There are many forms of communication, such as verbal, written or non-verbal (behavior and/or body language). For each form of communication, there are unique styles that each of us use to communicate. For example, I might write a letter that is more formal and wordy in style. Another person could write a letter on the same topic and use more informal language to describe a situation. Think about any group conversation that you've been a part of. Think of all the different styles of conversation that were used. Add to that picture the body gestures, how they physically positioned themselves, how they used their hands when talking, or where they focused their eyes when listening or talking . . . all of these characteristics represent the many styles of communication we experience.

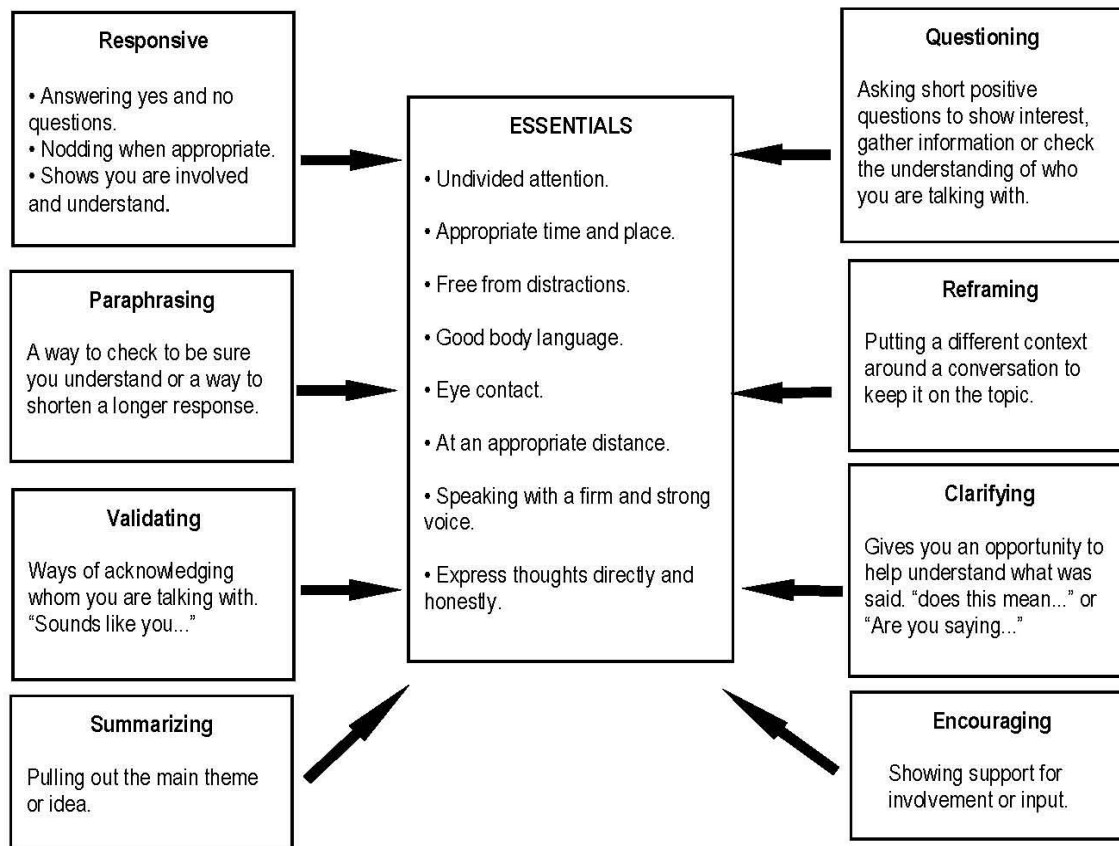
In addition to the differing forms and styles we use to communicate, people respond differently to taking in what it is you are trying to convey. The first section provides you with specific tools you can use to develop and/or enhance your communication skills. It also addresses what behaviors and steps might decrease effective communication. Regardless of whether you're learning new skills or refining long-held ones, remember to practice these skills with yourself and someone you trust. Practicing different scenarios will help you gain confidence to use these newly found or refined communication skills when you are advocating for yourself. Finally, in the last article, Mark Sweet challenges us to think about communication under trying circumstances. He describes how we can learn from ourselves the best ways to communicate during conflict. Understanding what communication style is most comfortable and effective for you can greatly enhance your self-advocacy skills and effectiveness.

## Styles of Communication

(Metro Denver Gang Coalition.)

There are many ways in which we communicate with each other. Pictured below is a visual illustration that describes some of the most important components you can use to promote successful communication. Each of the components described lists some helpful tips about how to engage in open and effective communication. Some of the components will be more useful than others, depending on your own style and the dynamics of the conversation taking place. Take a few minutes and try out some examples of how you would communicate each of these

components, always keeping in mind that the “essentials” apply to whatever style of communication you use.



## Behaviors that Encourage and Stop Communication

(Metro Denver Gang Coalition.)

Effective communication is influenced not only by the styles of communication that we employ, but also by the manner or course of action we choose to take in any given conversation. Described below are several forms of behavior or conduct that influence the effectiveness of communicating with another person. Behaviors that encourage communication promote effective, balanced and respectful dialogue, while those behaviors that inhibit or stop communication do not. Review the descriptions noted below and think about experiences that you have witnessed or participated in that reflect some or all of these behaviors. What behaviors might be most effective for you to employ as you pursue your self-advocacy goal(s)?

### Behaviors that Encourage Communication

- **Description:** Requesting information about ideas in order to more fully understand them; presenting feelings or perceptions that don't imply that others are wrong.
- **Equality:** Treating others with respect and trust; everyone has something to contribute.
- **Openness:** Investigating issues rather than taking sides; solving problems rather than debating.
- **Problem-Orientation:** Working together to define a problem and seek a solution; no predetermined solution, attitude or method to impose.
- **Positive Intent:** Behaving in a way that appears to be spontaneous and free of deception.
- **Empathy:** Reflecting feelings and respect for the worth of the other person; identifies with other people's problems, shares feelings and accepts another's reactions.

### Behaviors that Stop Communication

- **Judging:** Evaluating or judging the other person or their ideas; discounting the ideas or implying the other person is wrong.
- **Superiority:** Communicating a feeling of superiority in position, power, ability, race or gender.
- **Certainty:** Communicating in a manner that implies the person knows all the answers and doesn't need any additional information.
- **Controlling:** Trying to change or restrict someone else's behavior or attitude by imposing a set of values or beliefs on them.
- **Manipulating:** Communicating with a hidden motive in a way that uses others, in a negative way, to meet one's own needs.
- **Indifference:** Showing a lack of interest or concern for the feelings or welfare of the other person; implies that the person is unimportant.

## **Levels of Listening**

(Metro Denver Gang Coalition.)

Effective communication involves not only what you say, but how well you listen. Our willingness to listen and observe another's communication with us often can be challenging. Sometimes we grasp on to a word or phrase that someone has just said, and we begin developing our response or counter-argument while the other person still is talking. As with other forms of communication, passive participation is not effective.

Listening effectively involves being an active participant – even as a listener – in the interaction taking place. There are strategies that you can learn and use to build active listening skills. Described below are three levels of listening. The lowest level or third level reflects a more



passive, disinterested role, while the first level reflects active and attentive listening skills. Strive to achieve Level 1 communication!

### **Level 1 Active listening**

- No judgment;
- Put yourself in other's shoes;
- Try to understand points of view;
- Pay attention to body language;
- Listen to feelings; and
- Acknowledge and respond.

### **Level 2**

- Hearing sounds and words;
- Surface of communication;
- Not listening to the meaning; and
- Concerned with content not feeling.

### **Level 3**

- Listening in spurts;
- Tuning in and out;
- Half listening; and
- Not responding.

## **Communication Tips**

(Advocacy Training Manual. Wisconsin Coalition for Advocacy (1996), p. 108.)

1. **Be Direct.**
2. **Don't lose your composure.**

When you get emotionally upset, you lose respect, trust, logic, and momentum. That's costly.

3. **Use Thomas Gordon's Formula: "When You..., I Feel..., Because...."**

Thomas Gordon, writing back in the late 1970s, introduced the concept of sending "I" messages. For example, "I feel angry when you forget to call when you're going to be late because I worry and can't get to sleep." He set up this formula: "When you X, I feel Y, because Z."

This pattern includes all of the variables – real and verifiable, X has to be an observable behavior. Y has to be a feeling, not an opinion. Z has to be an observable consequence.

Here's an improperly phrased statement that will bring argument: "When you act like a prima donna, I feel you don't care whether this company turns a profit or not because you get your commission no matter what the profit margin on what you told the customer we'd do." Such a comment won't work. "Acting like a prima donna" is a subjective statement. "I feel you don't care..." is an opinion, not a real feeling.

Here's the same sentiment expressed in a way that both parties can deal with: "When you fail to ask me about special discounts you want to offer your customers, I feel angry because we lose money on anything sold more than 20 percent below the retail price." That's a specific behavior, a true feeling, and a verifiable consequence.

**Example:** "When you bring up my mistakes during a staff meeting, other people begin to blame me for things I had no control over. I feel helpless to defend myself or explain. As a result, they disregard my authority on the shop floor."

**Example:** "When you miss your deadline with the numbers on Friday, I can't close out my books and forward the final reports to Denver. And when they don't get the report by Monday morning, they can't issue checks to our suppliers, who add an interest charge on late payments. I feel really angry that I get grief from the Denver people for a delay caused by you."

Such a structure (1) describes the actions, not labels it, (2) lets the other person know the consequences of the action, and (3) brings the related emotion out in the open. The resulting discussion will most likely, then, focus on the issue rather than personalities.

#### 4. **Own Your Own Feelings.**

Accusations frequently begin with "You make me feel \_\_\_\_." Fill in the blank with angry, inadequate, dumb, useless, ridiculous. Think about the meaning of such a line: One individual is saying the other person has control over his or her emotions. The other person will then usually counter with "It's not my fault that you feel \_\_\_\_." The conversation then degenerates into whose fault it is.

Prefer to make statements that show you have control and choice in the matter and at least center on the problem rather than who's to blame. Example: "I feel stupid when you remind me over and over of a deadline. I'd prefer that you state the deadline once and then drop it." Only you

can decide how you feel. Choose differently. Better yet: “I don’t like you to remind me over and over of deadlines. Once is sufficient.”

## **5. Treat Silence as Golden – or Yellow or Amber.**

As an accessory to negotiations, silence changes colors as you need it. Silence is golden when you use it for reflection to avoid popping off without forethought. On other occasions, it may be yellow or amber; it may be taken as agreement or disagreement. When you don’t want to commit yourself, simply listen and think about what the other person is saying.

## **6. Don’t Interrupt the Other Person, and Don’t Let the Other Person Interrupt You.**

Some people think they are saving time by interrupting you in a recitation of the details when they already know them. Don’t permit such interruptions: “Margie, I want to finish explaining what I consider to be the problem.” Say it in a matter-of-fact tone and keep talking. This assertiveness establishes you as a person with a right to be heard. And remember if you’re the person doing the interrupting, the issue is not time, nor even “your version.” The goal is to hear both versions of an event or situation, to piece the truth together, and to sort out the feelings.

## **7. Take Turns for Airtime.**

For all the griping and complaining from drivers ensnarled in traffic or those people taking mass transit, most would agree that the time involved is their own – at least mentally. It is uninterrupted time for listening to the radio, reading, talking or thinking.

When involved in a conflict, try the same principle. Give each other uninterrupted time to talk, say five or ten minutes, and then take turns. You’ll have the best results if one person agrees to paraphrase what the other says to show that he or she listened. Only after the first person “signs off” that the other person has heard correctly does the second person get a turn to talk.

The process has these four benefits:

- It stops arguments because the other person loses immediacy – he/she can’t interrupt impulsively with a counterattack or denial;
- The other person has to listen;
- The plan builds in cool-off periods for emotions; and
- It helps people to summarize and focus on the most important comments and issues because they can’t remember the entire five-minute talk verbatim.

## 8. **Develop Trust.**

To resolve a conflict, both people have to want to resolve it. When both people in a negotiating situation trust each other, they have a natural inclination to want to come to consensus and resolve any differences. When they distrust each other, one person may decide he or she doesn't care if they ever come to agreement. And typically, they won't.

## 9. **Say What's On Your Mind Without Shifting to a Hostile Tone.**

When anger threatens to overcome you, breathe deeply, slow down, and lower rather than raise your voice. Your words and opinions will sound firm and factual, not emotional and irrational.

## 10. **Examine the Payoffs in Continuing Conflict.**

Psychologists have counseled parents for years that sometimes children misbehave because negative attention is better than no attention. The same can be said of adult conflict. Ask yourself what you or the other person has to gain for refusing to end a running conflict. Does a continual uproar in the department create excitement for the group? Does the conflict feed someone's ego? Does the conflict serve as someone's excuse for not getting a task done or done well? Once you know what the payoff is, you can decide if you can meet the need – ego gratification, excitement, or success – in a less emotionally draining or disruptive way.

## 11. **Determine the Nature of the Conflict.**

For the most part, conflicts can be divided into five categories: conflicts over personalities, conflicts over goals, conflicts over circumstances, conflicts over facts, and conflicts over values.

- Conflicts over personalities can be solved by pinpointing traits that annoy or work patterns that irritate and by accommodating the other person's trait or style. Because personalities are difficult to change, the best coping strategy may be to limit contact with this person or overlook the habit or trait.
- Conflicts over goals can be best handled by compromise. Create alternatives that allow both people to get their needs met. If both people can't reach their goals, the goals can be modified.
- Conflicts over circumstances are easier than most to handle. Creative thinking will usually generate new limits, new details, or new choices to alter the bad situation.

- Conflicts over facts fade easily. Facts can be verified or refuted. When both people become clear on the facts, their conflict goes away.
- Conflicts over values cannot be resolved. The difference between attitudes and values is generally time. Attitudes change; values have taken root in a person's life over a long period of time. Values form the basis for how people look at other people, at work, at ideas, and at life in general. If you consider a situation or action immoral or offensive, that judgment is based on values and you will not likely be satisfied with a compromise.

Once you have categorized the kind of conflict staring you in the face, you'll have a clear understanding about the effort involved in resolving it and the potential for a successful solution. Some will be quick; some will be never-ending. Plan your future actions and reactions accordingly.

## **12. Deal With Conflicts Promptly.**

Like hot coals, angry words or bad situations tend to grow hotter when they're allowed to smolder. Friends of mine, a married couple, have a long-time rule in their household of five (two mothers-in-law and a father-in-law, plus the husband and wife): They must deal with any conflict within an hour. If they decide they're too emotional to discuss something immediately when it happens, they call the one-hour-cool-down rule, and then resume their conversation about the problem. Things unattended fester. Hearsay happens. Intentions become suspect. Hurt humiliates. The faster you broach the subject, the less infected the wounds.

## **13. Appreciate the Value of What You Have to Bargain.**

Sometimes people undervalue what they have to trade. Don't forget the intangibles. Attach value to everything before you begin your discussions. For example, as an employee you may own your own transportation to work and so can work early or late on special projects when asked without undue hardship. If that flexibility happens to be important to an employer, consider it a bargaining chip. Other assets of value include dependability, ethical behavior, responsiveness, contacts and networking opportunities, emotional ownership – not to mention any number of other skills or attitudes. Take a fresh look at what you have to offer in any situation.

## **14. Research Your Position and the Situation.**

Take time and make the effort to support your position or requests. Read. Gather statistics. Talk to experts. Survey others for majority opinions. When you get ready to talk, you'll have

adequate facts and opinions to support what you want done. And the more you know, the better your position to negotiate a win for everybody involved.

## **Attitudes Necessary for Self-Advocacy**

(Adaptation from Teacher's Guide, Freedom Self-Advocacy Curriculum, National Mental Health Consumers' Self-Help Clearinghouse (April 2000 Pilot Version), pp. 6-8.)

Many consumers worry that they can't advocate for themselves. Janet Paleo, who works in the Office of Consumer Affairs in Lubbock, Texas, says, "Anyone can be an advocate! My two-year-old son is an advocate – when he wants something, he lets me know." Of course, advocacy is not always so simple, but time and time again, consumers tell stories of surprising themselves with their own power to advocate.

As a preliminary step to achieving your self-advocacy goals, you might need to work on developing the attitudes necessary for self-advocacy. For some people, it means being more assertive, while for some it means taming aggression. Above all, self-advocacy requires believing in yourself.

### **Being assertive**

Once you begin to believe in yourself, you will find yourself becoming assertive. While self-esteem is internal, assertiveness shapes the way we deal with others. It is an important skill for consumers to learn, because for some of us, a lack of assertiveness is a primary obstacle to obtaining the services that we want and need. Teaching assertiveness strategies is a key component of the Freedom Self-Advocacy curriculum.

"When someone is struggling with a psychiatric disability, the idea of standing up to the system is scary," says Clearinghouse executive director Joseph Rogers. To learn more assertive behaviors, we must learn why we are not assertive. For some of us, the moods we experience such as depression or anxiety make us less willing to stand up for ourselves. Some of us might fear reprisals such as revocation of benefits or other punitive measures.

Rather than allowing these emotions to translate into procrastination or silence, many consumers have learned to overcome these obstacles to become self-advocates. Rogers suggests that for many people, "The first step might be simply asking, 'Why?' It's a three-letter word that can make a huge difference. When conditions aren't what they should be, it's often a result of inertia." When consumers disrupt this inertia by asking "why," Rogers says, "A lot can happen when things are set in motion."

Mary Ellen Copeland says that she's found that she can use rewards to make herself more assertive. She suggests that if you have to make a difficult phone call, for example, you can set up a reward (such as something you like to eat) to give yourself after you make the call. "Self-advocacy is hard work, and you deserve a reward," she says.

You don't have to rely solely on yourself: you can become a much more effective self-advocate by working with other people to improve your assertiveness skills. "Assertiveness is really more than an attitude, it's a skill," says Rogers. "You don't need 'assertive genes' you just need to practice the skill and move on to the next level." Many counselors specialize in assertiveness training, and joining a self-help group is another good way to work on your assertiveness skills in a supportive setting.

The motto of the Clearinghouse states, "Knowledge is the key to open new doors," and building your knowledge of rights and entitlements is perhaps the best way to make yourself more assertive. If you know the facts and policies underlying decisions affecting you, then you can more assertively advocate for favorable results.

Dan Roberts, a consumer who advocates for himself in Kodiak, Alaska, reports that he uses public legislative information centers (similar to law libraries) to do research about his mental health rights. His knowledge allows him to be a much more effective self-advocate. "Because I've demonstrated that I am able to find information and go to the next level, the staff of the local community mental health center make an extra effort to meet my requests if they seem reasonable."

An old adage says, "The squeaky wheel gets the grease." People are more likely to respond to you if they fear that you might cause them trouble in the future. Self-advocacy requires persistence but offers great rewards. As Copeland says, "the people who advocate for themselves are the ones who achieve the highest level of recovery."

### **Managing your anger**

Remember that assertiveness is not the same thing as aggression: you should be a persistent and tireless advocate for yourself, but you should not shout at or insult others in the process. As Andrea Stephenson explains, "Assertiveness is being able to say what you need to say in a respectful and dignified manner."

When we perceive something as an injustice, our anger can be an asset if we use it to motivate ourselves to engage in self-advocacy. However, we must be careful not to let our anger become a liability for us. If you don't let your anger transform into shouting or character attacks, then

the other people involved won't be able to use your behavior as an excuse for denying what you want.

Sometimes, you must teach yourself tricks to control your anger. Mary Ellen Copeland suggests that one way to keep your anger in check during a meeting is to "go home and pound pillows" after a meeting. Although learning to control your anger might take hard work, doing so will make you a much more effective advocate.

Having a good support system in place is another way to work on controlling your anger. Just being able to talk with supportive people might help you diffuse some of your anger before you make any decisions that you'll later regret. A self-help group is also an excellent way to work on your anger management: others in your group likely will have the same goal.

## **Taking Care of Yourself in the Middle of Conflict**

(Sweet, Mark. Taking Care of Yourself in the Middle of Conflict. Wisconsin Coalition for Advocacy (2002).)

It would be wonderful if other people could anticipate our needs. And, if circumstances could converge to make our lives easier, that would be helpful too. These are enjoyable fantasies, because when things do not happen as we hoped they would, it is harder to think clearly and to feel at ease. This is stress - and stress has effects, or reactions. Our hearing and thinking might be influenced. The sensations in our bodies might change. Even our vision might be influenced. When events don't happen as we want them to, it can seem as though we have been pushed off balance - physically, mentally, and emotionally. From that moment, the things we do to restore balance and clarity are called coping strategies.

Stress is anything, positive or negative, that throws us off balance.

Coping is what we do to restore balance.

Coping has many facets. There is skillful coping (e.g., anticipating challenging events, noticing them when they happen, using them as a reminder to take care of ourselves, deciding what to do, advocating for a desired outcome). There is also unskillful coping (e.g., yelling, throwing things, drinking, shutting down, hurting ourselves). Unskillful coping is like being caught on film with a caption that reads, "when I thought about what I wanted to do, I had already done something else."

It takes effort to cope skillfully while trying to be an advocate. We have to learn to be aware of ourselves and others. We have to distinguish between what we need and what we want. We have to decide which things are most important. We have to let the right people know what those things are in ways that they understand. And sometimes, we have to negotiate and adjust



to disappointment. A high school principal told me that he wanted to put one of life's big lessons on a message board in the front of his building that said, "This isn't Burger King, you can't always have it your way."

Balance is a critical factor in social interaction and advocacy. People will say and do things we don't like. We might not like the message (i.e., the substance) or the way a message is delivered (i.e., the style). Long term advocates learn not to react to every unwelcome detail. This too, takes some effort. We have to learn how to take care of ourselves in order to be strong and effective advocates. We can actually use the events we don't like to cultivate balance and improve our coping strategies.

**Step 1:        Name the events that you wish would not happen.**

Think about the sources of conflict, the events, that throw you off balance. "Events" are the things that you wish you would not see or hear again. They don't have to be the biggest or most dramatic events, just the ones that have a significant effect on you. "Off balance" refers to those situations in which your anger or sadness or frustration goes from a zero to a ten and you find yourself agitated or shut down. Make a list of these events that you wish would not happen. Or, finish the following sentences.

- I don't like it when I hear... \_\_\_\_\_
- I don't like it when I see... \_\_\_\_\_
- I don't like it when I feel... \_\_\_\_\_

Or, more generally, name the situations that you wish would not happen again.

**Step 2:        Notice the effects - How do you react?**

Stressful and challenging events result in comments like, "I was beside myself" or "I don't remember a thing." In order to communicate and advocate effectively, a person has to be present and attentive. Event > Reaction. Event > Reaction. First one, then the other. Without thought or planning, the reaction follows the event. This is mindless behavior, not conducive to good communication or advocacy. The goal is to respond by choice rather than to react without thought.

Notice what is stressful and how it effects you - the events and your reactions. It is neither indulgent nor selfish to pay attention in this way - it is wise. Passengers on airplanes are

reminded to secure their own oxygen masks, during an emergency, before attempting to help anyone else. If you don't learn to respond more skillfully, you might find that you are not only reacting to events when they happen, but you might be reacting when they don't happen. Maybe you wish that you would never see someone again. Not only do you find yourself having a reaction when you actually see that person, but you start to have the same reactions when you think that you might see the person. You experience the full effects even without the event. This can't be a good thing.

When I first started learning about skillful and unskillful coping, one of the events I wished would not happen, was hearing someone respond to my (great) ideas by saying, "Yes, but...." This seemed like such a small event, I was embarrassed to admit it was having such a significant effect. My reaction was to stop listening. My mind got busy with judgment and then changed to self-doubt. I thought, "You're a jerk. You're not listening. You're not even trying to understand. Maybe I'm not smart enough to explain this." I also noticed changes in my vision. I was not seeing the speaker. I could only see a moving mouth or hair, but I was not seeing the person. I noticed physical sensations too, tightness in my chest and pressure in my head.

Refer to your list. What do you wish would not happen? How do those events affect you?  
When IT happens,

How does it affect your thinking - what are your thoughts?

How does it affect your body - what do you feel and where do you feel it?

How does it affect your vision - what do you see?

If you are not sure how you react to a particular event, make a commitment to notice what happens to you the next time that event occurs. Unfortunately, just because you made a list of the events you wish would not happen, there is still a significant likelihood that they will. We cannot control everything that happens, however, we can learn how to cope with events, as they happen, in more skillful ways.

### **Step 3:        Learn to pause.**

Some people are afraid that if they consider what is said, ask a question, or if they do not react with a loud angry voice, they will be perceived as passive or in agreement. Learning to pause has nothing to do with passivity or agreement. You pause to notice clearly what you heard, how you feel, and what you see, in order to decide how to respond. The goal is to change from reaction to response. Rather than being either swept away or beside yourself - you pause to recover your sense of balance and decide how to represent your interests.

The list of events that you wish would not happen, can serve as signals. They can be reminders to pause. Instead of reacting, when you see or hear that thing that you wish you wouldn't, let it be like a traffic light, an alarm clock, or a tap on the shoulder - let it be a personal message. The message is, "Time to pause and notice yourself. What do you want to say or do next?"

After noticing my aversion and reaction to "Yes, but..." I decided to anticipate it. I wrote the word "but" on the top of my notepad at meetings as a reminder, and then checked it off when it arrived. I acknowledged it. There it is. I let it remind me to exhale, to loosen my shoulders and jaw, to listen carefully to what was said next, and to ask questions. The same events that have, in the past, caused you to be thrown off balance, can remind you to recover your balance and focus your attention. How will you remember to use an event that you have dreaded to help you?

#### **Step 4:        Select a Response - What will you do?**

You probably know how it feels to be reactive. We get caught in a moment and either do too much or not enough, and then wish we had the chance to try again. Although you will not get that moment back, you probably will be in a similar challenging situation.

• How do you want to be perceived? \_\_\_\_\_

\_\_\_\_\_

• How have you noticed people you admire participating in difficult situations? \_\_\_\_\_

\_\_\_\_\_

• How would you like to participate in a difficult situation? \_\_\_\_\_

\_\_\_\_\_

Decide beforehand how you would like to participate.

## **SUMMARY**

**Step 1:        Name the events that you wish would not happen?**

**Step 2:        Notice the effects. How do you react?**

**Step 3:        Learn to pause. What might remind you?**

**Step 4:        Select a response. What will you do?**

## INTERACTION STYLES

Consider the following interactive styles and notice whether you ever participate in one of these ways.



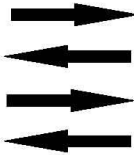
characterized by

two people talking at the same time  
often with raised voices  
often with high intensity



characterized by

one dominant person  
one overwhelmed person



characterized by

two people taking turns  
not listening for content  
waiting to say "that's wrong"

In addition, each of these interaction styles can be characterized by assumptions and a surprising absence of questions. None of them represents a genuine exchange of ideas or a curiosity to better understand one another. How can there be better understanding without questions or discussion? The method in each of these interactive styles is to overwhelm - with intensity, speed, volume, certainty, statements, or dominance - and to win. None of these styles allows for even the possibility of learning from one another or being creative.

Imagine what could happen in any of these arrangements if one of the people decided to pause, consider what was said, and ask a question.

# ADVOCACY SKILLS & STRATEGIES

Effective self-advocacy requires building and practicing skills to help you feel comfortable and confident in reaching your advocacy goals. This section provides you with worksheets and tools to assist you in developing your skills and taking action.

In order to make your self-advocacy efforts effective you need to:

1. identify the problem or issue, and
2. plan your advocacy strategy to get what you want or need.

This planning process takes time. 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.

Sometimes even the best laid plans fail to achieve the identified goal. Developing skills to negotiate a compromise or resolve a conflict that poses an obstacle to achieving your goal are important components to effective self-advocacy. Therefore, problem-solving strategies, action plan development, conflict resolution and negotiating skills are key instruments you can practice and apply to achieve your advocacy objectives. This section provides a wealth of information and worksheets that you can use to build advocacy skills and try out different self-advocacy strategies.

## Problem Solving Strategies

(Adaptation from Teacher's Guide, Freedom Self-Advocacy Curriculum, National Mental Health Consumers' Self-Help Clearinghouse (April 2000 Pilot Version), pp. 9-17.)

With the right attitude, you can be an effective self-advocate, but you also need to develop a plan for handling the obstacles that you encounter. As you learn to surmount these obstacles, you'll find that you develop certain skills that make problem solving easier.

## Educating yourself

A common sentiment among consumers/survivors is that each of us has gotten an education at the "School of Hard Knocks." There's some truth to this, but consumers who make extra efforts to educate themselves can become much more effective self-advocates. Take every opportunity

to educate yourself – don’t wait for a problem to arise. Take advantage of educational programs at consumer-run services and special events.

You should also prepare yourself by creating your own resource library. Ask your doctor, therapist, or health plan for information about diagnoses, treatments, medications; often, they have free informational brochures to give you.

Mary Ellen Copeland says that you must form your own opinions and develop your own goals. “You really need to educate yourself,” she says. “Read every viewpoint from conservative to radical and then decide for yourself what you can or can’t do.”

In addition to building your own resource library, you should prepare a list of contacts so that you’ll know where to go if you ever need help. Later in this section is a worksheet that you can complete to develop your own list of contacts. Useful phone numbers to have on hand might include the protection and advocacy (P&A) organization for Wisconsin – Wisconsin Coalition for Advocacy, the Bureau of Community Mental Health within Wisconsin’s Department of Health and Family Services, consumer groups, drop-in centers, and Social Security offices. (See page 170 in the *Toolbox* for Wisconsin specific resource information.)

Today, the Internet has emerged as a powerful tool for finding information that you need to know. On the worldwide web, you can find the web sites of organizations that provide information, as well as the agencies that you’ll need to contact to achieve your advocacy goals. Using tools such as e-mail lists and newsgroups, you can seek advice from people who have been in the same type of situations that you face. (Internet resource information is available in the *Toolbox* beginning on page 160.)

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 consumer-run organizations now offer both Internet access and training.

## **Identifying your rights**

In the United States, we all have rights as citizens. As consumers, we have often been led to believe that we don’t have rights or should be afraid to exercise them. Mary Ellen Copeland, who has lectured throughout the nation about her own recovery, tells a powerful story about a visit to Mississippi. “I spoke to a group of about 500 people, who were all dressed in matching uniforms depending on the facility that they were from. They had to ask for permission to go to the restroom. I couldn’t believe it.”

As Copeland spoke to the group, she began to spell out the rights that everyone has when he or she is in a psychiatric facility. At first, the crowd seemed to be in disbelief, but then they began to stand and cheer. After being led to believe that they had checked their rights at the hospital door, they realized that they had the right to stand up for themselves. Copeland uses a “Personal Bill of Rights” (see below) in her “Dealing with and Recovering from Psychiatric Symptoms” training sessions.

***“Personal Bill of Rights”***

1. I have the right to ask for what I want.
2. I have the right to say no to requests or demands I can’t meet.
3. I have the right to change my mind.
4. I have the right to make mistakes and not have to be perfect.
5. I have the right to follow my own values and standards.
6. I have the right to express all my feelings, both positive and negative.
7. I have the right to say no to anything when I feel I am not ready, it is unsafe, or it violates my values.
8. I have the right to determine my own priorities.
9. I have the right not to be responsible for others’ behavior, actions, feelings, or problems.
10. I have the right to expect honesty from others.
11. I have the right to be angry at someone I love.
12. I have the right to be uniquely myself.
13. I have the right to feel scared and say, “I’m afraid.”
14. I have the right to say, “I don’t know.”
15. I have the right not to give excuses or reasons for my behavior.
16. I have the right to make decisions based on my own feelings.
17. I have the right to my own needs for personal space and time.
18. I have the right to be playful and frivolous.
19. I have the right to be healthier than those around me.
20. I have the right to be in a non-abusive environment.
21. I have the right to make friends and be comfortable around people.
22. I have the right to change and grow.
23. I have the right to have my needs and wants respected by others.
24. I have the right to be treated with dignity and respect.
25. I have the right to be happy.

This list of rights could perhaps best be classified as “natural rights,” which might or might not be spelled out by any particular law, but nonetheless exist for everyone. “The people who wrote the Declaration of Independence asserted the rights of life, liberty, and the pursuit of happiness,” says Marie Verna, “and on the most basic level, as consumers, we too should assert these rights because they are rights that we have as citizens.”

As a consumer of mental health services, you also have more specific rights spelled out by local and state laws. “Many of your fellow consumers are working to reform the system so that consumers will have more rights and better services,” says Joseph Rogers. “To take advantage of the rights and services that these people have fought for, you must learn to demand them,” he continues.

Many states have a “bill of rights” for consumers, and in some states, each individual facility is required to develop its own bill of rights. Wisconsin’s Bill of Rights, based on Wisconsin law, is located in the *Toolbox* of this *Tool Kit* on page 147. Another good way to educate yourself about the rights you have under local or state law is to contact Wisconsin’s protection and advocacy agency, the Wisconsin Coalition for Advocacy. Contact information is located on the cover of this *Advocacy Tool Kit* and in the *Toolbox*.

You also have many rights under federal law. Some important rights guaranteed by federal laws and regulations include:

- The right to employment without discrimination based on disability, under the Americans with Disabilities Act.
- The right to public services without discrimination based on disability, under the Americans with Disabilities Act.
- The right to seek housing without discrimination based on disability, under the Fair Housing Amendments Act.
- The right to financial support (as determined by various Social Security laws and regulations).
- The right to health care (as determined by Medicaid or Medicare laws and regulations).
- The right to employment supports, under the Rehabilitation Act and the Work Incentives Improvement Act.



The *Toolbox* contains basic information about how to find a law or regulation, including some useful websites. *Rights & Realities II*, a manual summarizing many state and federal laws relating to people with disabilities, is another useful resource. Information about *Rights & Realities II* can be found on the Wisconsin Coalition for Advocacy's website, located at [www.w-c-a.org](http://www.w-c-a.org), and on the order form included on page 186 in the *Toolbox*.

## **Breaking down the problem**

Sometimes, our problems seem overwhelming: Have you ever replied “everything” when someone asked you what was wrong? When you feel overwhelmed by a problem, you should try to break it down into smaller “chunks” so that you can more effectively plan your strategy.

Say, for example, that you have been attending a job training program, but you have been arriving late because you can't wake up on time. The director of the program has told you that if you can't show up on time, you will be kicked out. You have told your doctor that your medication is making you sleepy, but your doctor is unwilling to change your medication.

In that example, you could break down the problem into smaller problems:

- You are sleepy because of the medication;
- You have been arriving late to your training program;
- You have been threatened with being kicked out of the training program; and
- Your doctor won't change your medications.

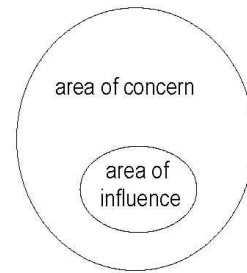
By breaking down a problem into smaller segments, you have greater insight into what steps to take. In the above example, you might find that parts of the problem are easier to deal with than others are. Depending on the circumstances, it might be better to see whether you can transfer to a training program that doesn't begin quite so early; on the other hand, it might be better to think of ways to convince your doctor that you need to switch medications.

By deciding which parts of the problem you can most easily solve, you can save yourself time and effort. “Not all problems can be solved,” says Brian Cooper, director of consumer advocacy at the National Mental Health Association. “You have to ask yourself two questions, ‘Which problems matter most?’ and ‘Which problems have a chance of being solved?’”

Cooper uses an example created by author Stephen Covey: Picture two circles, one inside the other. The inner circle is your “area of influence” and the larger outer circle is your “area of concern.” The point is that you need to analyze whether something that is bothering you is

something that you can do something about. If not, you should concentrate on things that you can change.

*Based on the The Seven Habits of Highly Effective  
People, by Stephen Covey, 1990*



In the job training example, you might decide that both the prospect of being kicked out of the program and your doctor refusing to change your medications are in your area of concern. However, you might find that your area of influence includes your doctor's actions, but not the training program's attendance policies. If so, then you would proceed by working to change your doctor's decision regarding your medications. In other words, says Clearinghouse executive director Joseph Rogers, "You've got to pick your battles."

### **Developing a solution**

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. Nevertheless, by using a systematic approach, you'll do a much better job at finding the solution that fits your problem.

#### Preliminary steps

The first step in developing your desired solution is to determine what you want to happen. While consulting other people is extremely helpful here, you must make up your own mind, rather than relying exclusively on suggested strategies or predicted outcomes. "Ask yourself what you need," says Jo Halberstadter, director of advocacy services for the Mental Health Association of Southeastern Pennsylvania. "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.

In 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. However, 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 determine the course of your self-advocacy efforts. For example, say that at your job, you make a request for an adjustment in working conditions (such as a later starting time).

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.

However, you should keep your eye open for potential allies who might be able to help you with your problem. Don Roberts, a self-advocate from Alaska says, "When I come up to a brick wall, I don't beat my head up against it. There may be allies on the other side of the wall, and even though you might not be able to break through, they might be able to do some damage on the other side of the wall." After realizing that nobody at the local community mental health center was willing to help him, he began looking for allies in the state department of mental health.

### Building your case

Having decided what you want and whom to contact, you can begin building your case. Ask yourself about the strengths of your side of the story: Do you have legal rights that have been violated? Has an established policy or procedure been ignored to your detriment?

You should also 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 assembling all of the documentation that you'll need as you proceed with your self-advocacy efforts. Although the relevant documentation will vary from situation to situation, you should always keep copies of any document 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.

(Additional information about documentation ideas and strategies is discussed later in this section.)

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? Being able to acknowledge 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. As Massachusetts advocate Howard Trachtman says, "In many cases, you'll continue to deal with an agency [regarding other matters], so you can learn the tricks to dealing with them in the future."

### 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. Joseph Rogers recommends that a "reality-check group" can help you plan your strategy. "We all need checks and balances," he says, "or you run the risk of losing perspective. You might think that you have your case well constructed, but talking to others can help you identify and improve upon weaknesses."

Consulting with others can help you plan more effectively. Becky Smith, a consumer who also is an advocate for Tennessee's P&A system, says, "If I'm too emotionally attached, I'll ask for outside help. I might need someone to be more objective."

You should also spend some time reflecting on what you plan to do before you do it. Jo Halberstadter, director of adult advocacy services for the Mental Health Association of Southeastern Pennsylvania, says, “Before you make your first contact, sit back and think. Don’t just act impulsively.”

“Plan how you are going to phrase your words when you talk to someone,” she continues. “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 Action Plan Worksheet follows and can help you develop your action plan for a specific self-advocacy goal you identify. In addition, information about the methods you can use to carry out your problem-solving strategies is discussed later in this section.

# ADVOCACY SKILLS & STRATEGIES

## 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 facts do you know?**

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

**How would 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?**

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

# ADVOCACY SKILLS & STRATEGIES

*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 \_\_\_\_\_.**

**Documentation that I will need:**

**Other people who can help me:**

**What I expect the other side to do:**

**Strategies for what's next:**

**Debriefing: who will I call or how will I take care of myself following this encounter?**

## 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.)

These tips address problems of treatment, denial of basic rights, or such crises as loss of benefits.

1. Try not to be intimidated by authority; learn to question responses with which you do not agree.
2. Find out what the authority is for the agency's decision. 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. Better yet, order a copy of the regulations for your library. Ask the worker what regulation her/his decision is based on.
3. 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."
4. Use your imagination to come up with solutions to problems. If, for example, you can not locate a document you need, think of alternate ways to prove the fact. Use a declaration (sworn statement) or an affidavit (sworn, notarized statement).
5. 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.
6. 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.
7. 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.
8. 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.

9. Use all available methods for increasing your legitimacy as an advocate.
10. 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 contributes 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 case notes of all conversations (phone and in-person) that you have regarding the situation beginning with the initial contact. You may want to use an initial contact sheet to collect information from the person and you may also want to utilize a case/situation contact sheet to track all of the players involved. (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:
  1. Date;
  2. Time;
  3. Full name of the person(s) you contacted;
  4. Person's title;
  5. Agency name;

6. Agency telephone number; and
7. A description of what was discussed.

- If there is a question of accuracy about the 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. 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 low-level 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. 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, says Brian Cooper, but one alternative is to "call them once a day until they realize that you won't stop calling until they resolve the situation." 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 discussed assertiveness generally in *Attitudes necessary for self-advocacy* in the *Communication Skills* section of this *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. 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	
<u>Statement</u>	<u>Assertive Response</u>
<i>Insurance company customer service representative:</i> "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."
<i>Social Security representative:</i> "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."
<i>MCO executive assistant:</i> "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?"
<i>MCO customer service representative:</i> "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." Advocate Howard Trachtman says that he recommends the "judicious" use of appeals to supervisors, especially in cases when it's your first point of contact with an agency. 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. The *Telephone Log* is located on page 62 of this *Tool Kit*.

## 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.



# ADVOCACY SKILLS & STRATEGIES

## My Contact List

Name & Organization	Telephone & Fax Numbers	Email

# ADVOCACY SKILLS & STRATEGIES

## Telephone Log

### Outgoing Phone Log

**Date:**

**Person called:**

**Telephone Number:**

**Referred by:**

**Was call answered?**

**Left message?**

**Person spoken with:**

**Title of person you spoke with:**

**Fax number:**

**Summary of conversation:**

**Action suggested:**

**Action agreed upon?**

**Deadline:**

### Incoming Phone Log

**Date:**

**Person calling:**

**Telephone Number:**

**Title of person you spoke with:**

**Fax number:**

**Summary of conversation:**

**Action suggested:**

**Action agreed upon?**

**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* 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. Says Janet Paleo, "When you're writing a letter to someone, 'cc' it to someone who is that person's boss or peer, because if you send a letter that's not cc'd to someone, then it's easier for the person to put your letter aside. If it is cc'd to someone important, then the recipient will give it a lot more credence."

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. Says Jo Halberstadter, "When you cc someone right off the bat, it shows anger. You have to decide whether expressing anger at such an early stage will end up hurting you."

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 she was probably angry at the insurance company's broken promise, she is not rude or insulting. She 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. "Having someone else to be supportive and objective can help make the letter less antagonistic," says Brian Cooper, director of consumer advocacy at the National Mental Health Association.

## Sample Letter A

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

January 2, 2005

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, 2005

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, 2001. 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, 2001 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, 2001.

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 self-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. "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 Cooper, "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. (See the *Toolbox*, page 157 for information on how to locate laws and regulations.)

## **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 Cooper 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. 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 guns.* 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 guns 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 Cooper 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 self-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.

## **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 community-based mental health services 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.

### **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 consumers can't attend.
- Holding meetings in places which are difficult to reach or where consumers 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.

### **Reconciliation: A Brief Conflict Resolution Study Guide**

(Reconciliation: A Brief Conflict Resolution Study Guide. Peace and Social Concerns Committee, Madison Friends Meeting (Madison, WI 1988 and 1999). Permission to make and distribute copies of this study guide, permission to copy is given provided you make no changes.)

Conflict is a part of life. At times, the media seem to imply it is the major part. Conflict captures our attention, but it is only a tear torn in the vast fabric of life. We may experience it as discomfort, antagonism or physical violence. We may find it at home, in the community, at



work or among governments. We respond to it as individuals, organizations and nations. We may create conflict with our assumptions, attitudes, language and actions.

We need to make a distinction between conflict and violence. Some conflict, in the sense of being in disputes or even discord, may be inevitable in our lives. Violence, in the sense of injurious action or force, need not be part of our lives. Conflict can be injurious or malicious without being physically violent. We are concerned with preventing both psychological and physical violence.

Usually, we don't like conflict, but sometimes it serves a useful purpose when it arises in the pursuit of justice, creativity, integrity, or freedom. People in conflict sometimes threaten or use violence to gain advantage. When this happens, the damage can subvert any intended good purpose.

In this booklet you can read about a way of reconciling conflict without the use or threat of violence. We want to introduce you to some positive responses to conflict. You will find:

- Alternatives to the threat or use of violence
- Alternatives to the winner/loser outcome of conflict
- Principles that may enable all parties in a conflict to meet their needs.

To use these alternatives, most people will need more than reading this brief introduction, but this is a place to start. Further reading and practice will help. We have included suggestions on books that are major sources of information on nonviolent conflict resolution. Among the books we suggest for further study are these three:

- *Getting Past No: Negotiating Your Way from Confrontation to Cooperation* by William Ury
- *People Skills: How to Assert Yourself, Listen to Others, and Resolve Conflicts* by Robert Bolton
- *Mediator's Handbook* by Jennifer Beer, a publication of Friends Conflict Resolution Programs. 3rd Edition 1997.

We will describe 7 steps of nonviolent conflict reconciliation. They apply whether you are a party to a conflict and are, yourself, negotiating with the other parties, or you are a neutral 3rd party mediator invited in by the disputants. However, the emphasis here is on negotiation since everyone negotiates sometimes, and the opportunity to serve as mediator is more restricted.

The 7 steps are, in reality, an arbitrary division for convenience in teaching and learning. We could have used 3 steps or 21. The 7 steps outline a process with a beginning, a middle and an end, but roadblocks and unforeseen events often require application of a variety of methods to move the process forward.

- |                           |                                 |
|---------------------------|---------------------------------|
| 1. Awareness of conflict; | 5. Agree on an alternative;     |
| 2. Prepare;               | 6. Do what you have agreed; and |
| 3. Identify the Problem;  | 7. Celebrate.                   |
| 4. Problem Solving;       |                                 |

Read: *Getting Past No*, pages 3-14; *Mediator's Handbook*, pages 3-9.

### **Example of reconciliation in a marriage**

**Situation:** Joan and Dave both worked. They tried to plan a vacation, but couldn't agree on how to use their vacation time.

#### **1. Awareness of Conflict**

When Dave and Joan try to discuss their vacation plans, they didn't seem to be getting anywhere. Something was wrong, and it was not immediately obvious.

#### **2. Prepare**

Joan hoped that they could get away for a nice vacation, so she decided to ask Dave to set aside an evening to discuss nothing else. Dave agreed. They turned off the t.v. and did focus on the issue one night.

#### **3. Identify the Problem**

Joan said: "When you avoid the subject of our vacation plans, it makes me feel annoyed as if you didn't care. I think it's important for us to get away from the rat race and enjoy ourselves a little." They went on with their discussion and found that Joan wanted to travel. She had never been to Europe, but Dave had been to Europe before their marriage, and he traveled a lot in his work. He just wanted to relax at home.

#### **4. Brainstorming**

They explored their options and came up with 6 alternatives.

- a. Both stay at home.

- b. Both travel in Europe.
- c. Joan could travel in Europe with her friend Donna and Dave could stay home.
- d. They could both stay home this summer and go to Europe next summer.
- e. They could both go to Europe, but spend at least one week at a quiet Mediterranean resort instead of traveling extensively.
- f. Joan could take her entire 3 week vacation in Europe. Dave could stay home for half of the time, and join her in Europe for the last half of the time.

#### 5. **Select Alternative**

They felt good about the options they had developed and agreed to find one that met both of their needs. They settled on the 5th option.

#### 6. **Do What Was Agreed**

They did take the 5th option, and it worked out well.

#### 7. **Celebration**

The vacation itself was the celebration of their conflict resolution.

\* Adapted from Charlotte Whitney's book "Win-Win Negotiations for Couples: A Personal Guide to Joint Decision Making." Para Research, Gloucester, MA 1986.

### **Definitions of some key words:**

- *Conciliation*: the process of overcoming the hostility or suspicion of others, or securing their friendship.
- *Reconciliation*: 1) the process of bringing back to friendship after estrangement, 2) the act of settling a conflict.
- *Resolution*: 1) the act of resolving or reducing to a simpler or clearer form, 2) the act of reaching an agreement between persons in conflict.
- *Conflict*: 1) a struggle between opposing forces, 2) a condition of opposition and discord: mutual antagonism.
- *Conflict Resolution*: Another term with essentially the same meaning as reconciliation.

- *Arbitration:* A process in which an impartial third party makes a final, usually binding, decision. (Mediator's Handbook)
- *Mediation:* A process in which an impartial third party helps disputing parties work out an agreement. The disputants, not the mediator, decide the terms of this agreement. Mediation usually focuses on future rather than past behavior. (Mediator's Handbook)
- *Negotiation:* Refers to a process of back-and-forth communication aimed at reaching agreement with others when some of your interests are shared and some are opposed. (William Ury) It is done by the parties directly involved in the dispute.
- *Conflict Management:* A general term for a wide variety of methods to manage, control or resolve conflict. The methods range from the use or threat of force, including police and the judicial system, to nonviolent methods including arbitration, negotiation and mediation.

## 1. Awareness of Conflict

Some conflicts we can see ahead of time. We can go into the situation prepared to some degree, but more often, in our day to day lives, we sometimes discover, when we least expect it and at an awkward or inconvenient moment, that someone seems to cause a problem for us or the other way around. We may be surprised to discover that someone is angry about something we did or did not do. Often we first deny, then discover those conflicts late in the game. Earlier awareness would have enabled us to take corrective action when the problem was smaller and more manageable.

You, as a potential mediator or negotiator in a conflict, may find people practicing power games or trying to manipulate you by playing the victim, crying, pouting, or blaming you. You may find threats made by persons on each side of an issue. The conflict, if not reconciled, can increase in a downward spiral leading to violence: psychological or physical or both. Recognition of the existence of a conflict is the first step toward reconciliation.

Read: *Mediator's Handbook*, pages 10-13.

## 2. Preparation

*"Most negotiations are won or lost even before the talking begins."* (William Ury)

*"Separate the people from the problem."* (Roger Fisher and William Ury)

In approaching a conflict in which you are involved, remember that you have two types of interest: the issue and your relationship with the people involved. Some of the parties to the conflict may not be immediately obvious. Check to find out who is actually involved. Listen actively to what they say. Let them express their feelings. Listen until you can grasp the feelings involved. Show that you understand their feelings. Listen until you understand their concern. Talk about how each party sees the situation. Develop a relationship in which you and the other party can face the problem. If you are trying to negotiate a solution without a mediator, you may need to explain the process of collaborative problem solving to gain their consent to try this approach to reconciliation. They may need to be assured that there will be no agreement unless each party agrees with it.

If they won't talk with you at all, try communicating through neutral parties they trust. Find out why they won't negotiate. If mediation and other channels available don't seem to work, you may need to use direct action.

One form of direct action calls for little steps, not big ones. Make small positive actions that invite other parties to respond with similar positive actions, but you don't suggest what they should do in return. The steps are initiatives because you take the first step on your own. You don't need to have a good relationship with the other parties. You select actions that will reduce the tension between you and the others. The reduction in tension may create opportunities for communication and starting negotiation.

Non-cooperation, another form of direct action, may be indicated when the other party won't negotiate. Gandhi and Martin Luther King have given us examples that apply on the community level. In the home, family members have gone on strike to open up blocked communication. When the direct action opens up communication, you are back at step three of the process. Not every effort to reconcile conflict reaches that goal. Sometimes, within the limits of the time, energy and skill you can devote, those with whom you have a conflict may not start to communicate. They may not participate in reconciliation. This is where forgiveness comes in. This is where you may have to make peace with yourself. You may have a loss to admit and grieve. You may need to manage the stress of the loss, then move on toward other goals, or you may be able to persist with love and wisdom, and find a way, given time and application of what you know, to, in fact, achieve reconciliation. No one said it would be easy.

Preparation includes becoming clear on your underlying interests in the situation, and also knowing your "Best Alternative To A Negotiated Agreement" (Your BATNA). Having your BATNA clearly in mind will help you know your options if the negotiation turns difficult.

The goal at this step is to do the preparation and start talking in an environment conducive to developing communication and understanding. You are trying to build or repair relationships so the rest of the process can proceed.

Read: *Getting Past No*, pages 15-28, *Mediator's Handbook*, pages 14-30, 67-102, and 133-148.

#### Obstacles, Power Games & Tactics

*"Talking about interests, options, and standards may be a wise, efficient, and amicable game, but what if the other side won't play?"* Roger Fisher and William Ury

The 7 steps outline a process that moves from discovery of the problem through defining the interests and generating alternative solutions to reaching an agreement that is enacted. Between the start and conclusion of that process many obstacles can get in the way. William Ury's book, *Getting Past No*, describes about 2 dozen methods for overcoming or working around those obstacles. Those methods are valuable additions to the reconciliation process. They do not fit into a sequence, but might be used, as needed and appropriate, at any stage of the process.

Those methods include:

1. Handling your own emotional reactions.
2. Getting outside the problem or taking time out.
3. Asking questions that clarify or change the perspective from which issues are viewed.
4. Negotiating on the process itself.
5. Listening Actively and acknowledging the concerns and feeling of the others.

The methods can be applied to obstacles like stonewalling, attacking and tricks.

Read: *Getting Past No*, page 31-51, and pages 130-156.  
*Mediator's Handbook*, page 127-130.

### 3. Identify the problem

*"When someone is violating my space, I want THAT behavior changed."* (Robert Bolton)

Imagine that you are involved in a conflict. You have a dispute with someone. You must tell him or her about the nature of your grievance. Your message will be delivered most effectively as an assertion message with three parts.

The first part describes the specific behavior of the other party that concerns you. It should be a factual, nonjudgmental description.

#### 1. BEHAVIOR

"When you left the kitchen all messed up. . . .

The second part is an "I" message. It states clearly your genuine feelings about the problem behavior.

## 2. FEELINGS ABOUT IT

I felt upset. . . .

The third part tells the effect the behavior is having on your life.

## 3. EFFECTS OF IT ON YOU

Because I didn't have the time to clean it up and I had guests coming."

The assertion message should be brief and clear. Until you are skilled at phrasing the assertion, you may need to write it out before talking to the other party. By giving thought to it, you can be sure you focus on the real issue and describe specific objective behavior. You should avoid judgments. Make your assertion to the person with whom you have the conflict, not someone else who may be easier to reach. Listen actively to the thoughts and feelings of the other party. You can expect some defensiveness to your assertion. Re-assert if needed. Move the discussion toward defining the problem and jointly seeking a solution.

Awareness of the same 3 assertion elements: behavior, feelings, and effects, can also be helpful in understanding the concerns of a person who is upset with you, but is not communicating clearly to you what you have done that they find upsetting. Listen actively or ask questions to find out what specifically you did that upset them, how they felt about it and what effects your behavior had for them. Summarize for them what you perceive to be their concerns, feelings, and the effect on them. If you don't have it quite right, they will correct you.

The exchange at this stage is likely to be in terms of what each person feels to be his or her position in the dispute. You, as a participant in the dispute, need to know your own underlying interests or needs: what needs you hope to satisfy in the outcome. Becoming clear about your underlying interests was part of your preparation. Your task now is to help the other parties bring out into the discussion their own underlying interests which may be different from their stated position at the start.

*"Behind opposed positions lie shared and compatible interests, as well as conflicting ones."*  
(Roger Fisher and William Ury)

Your goal here is to develop a statement of the needs or a definition of the problems to be solved, a definition agreeable to all parties to the conflict. Often, the solutions they advocate are in conflict, but the underlying needs are not. Active listening may enable you to understand those needs. A need is a discrepancy between what is and what should be. Move the discussion toward identifying those underlying interests or needs. If the other party has taken a firm

position advocating a favorite solution, ask why he or she takes that position. The answer may lead to a statement of needs. If you are a party to the conflict and have not previously defined your own underlying interests, you should ask yourself the same question. By looking at the whole situation, you may discover that all parties involved have more interests that are compatible than those in conflict.

The conflicts that lead most readily to win-win outcomes are those based on conflicting positions but non-conflicting underlying needs. Other types of conflict you may find include conflicts over values or emotional upsets, resource scarcities, and competitive games. Resource scarcities often call for compromise solutions, but even here an analysis of needs may lead to a win-win outcome. The competitive game is really not a conflict, if it is really a game, and no one is getting hurt. However, sometimes a game masks a real conflict that needs to be resolved so the game can be enjoyed. If the same pattern of conflict is repeated in an organization or community, the problem may be structural rather than individual. If it is structural, the source of the conflict in rules or policies must be discovered and changed through a problem solving process. A conflict may consist of several parts each of a different type. Then, each different part should be defined so problem solving can start.

Read: *Getting Past No*, pages 52-104 or *People Skills*, chapters 8--11 or *Mediator's Handbook*, pages 31-49, 105-119.

#### **4. Problem Solving**

Generate alternative solutions that enable all sides to meet their needs.

*"Many a seemingly insoluble problem has been constructively solved through the use of (brainstorming)." (Robert Bolton)*

Brainstorming is only one of many methods that can be used to generate alternative resolutions. Other methods include the nominal group process, divergent thinking and incubation. Mediators often use the brainstorming method to generate options. Bring together all parties to the conflict. Resource persons with a fresh point of view may be a helpful addition. Select an environment that will encourage relaxation. Ask someone with experience in brainstorming to facilitate the session. Be sure the definition of the problem, purpose of the meeting and ground rules are clear. Brainstorm by getting the group to generate as many ideas for solving the problem as possible. Record all ideas on a chalkboard or large newsprint sheets. Don't judge the ideas while the brainstorm is running. Each suggestion makes an important contribution to the process. The goal here is to list all the alternatives for solving the problem.



Read: *Getting Past No*, pages 105-129 or *People Skills*, pages 243-245 or *Mediator's Handbook*, pages 120-130.

## **5. Agree on an alternative**

Use agreed upon criteria to evaluate alternative solutions.

*"...commit yourself to reaching a solution based on principle, not pressure...."* (Robert Fisher and William Ury)

Now you have a list of alternative solutions. Before selecting from the list, participants should decide on the criteria they will use to make judgments. The criteria should be relevant to the problem. The criteria should be independent of the will of participants. Such criteria will help each party agree that a solution is fair. To enable all sides to win, the solution should be the one that best meets the needs of all sides. The search for criteria should be a joint search. Consensus decision making can apply both to the selection of criteria and the application of those criteria in choosing the solution. When you have a consensus, write the agreement. Specify who is to do what when.

Read: *Getting Past No*, pages 119-156 or *People Skills*, pages 245-246 or *Mediator's Handbook*, pages 53-60 and 123-126.

## **6. Do what you have agreed**

*"Sometimes people are so elated at arriving at a decision that meets everyone's diverse needs that they celebrate prematurely rather than work out the nitty gritty of how the solution will be implemented."* (Robert Bolton)

The agreement should include the steps needed to do what was agreed. Decide who will do what. Do what you agreed and check to see that the others did their part. At a later time, evaluate the whole collaborative problem solving process and see how the solution is working out. If the problem is not really solved, or new concerns appear, start the process again. If things are going fine, go on to the final step.

Read: *People Skills*, pages 246-248.

## **7. Celebrate your accomplishment**

With all the problems in the world, we too quickly forget our accomplishments. Take a little time to celebrate. Arrange a little appropriate reward and recognition for all parties to the conflict. You may need to work together again.

### **What Can You Do with This Information?**

You may learn enough from just reading this booklet to make an important difference in your life. You can make that critical difference in at least four ways:

1. Apply the principles described here.
2. Study one or more of the books we have listed and participate in a course designed to teach the skills of reconciliation.
3. Simply learn from this booklet that an alternative exists to the threat or use of violence in the management of conflict. Knowing about the alternative, you may have confidence to call upon a counselor or mediator trained in reconciliation when needed.
4. Support the development of services to provide mediation and training in negotiation and mediation at all levels from the elementary school to the international world.

### **Resources for Study**

- Barnett, Robin and others. *A Manual for Resolving Large Group Conflicts*, The Community Board Center, San Francisco, CA, 1986 to be revised 1999. Phone 415-552-1250. Mediators attempting to work with neighborhood, organization and community conflicts will find this how-to-do-it manual a valuable guide to planning their approach.
- Beer, Jennifer. *Mediator's Handbook, Friends Conflict Resolution Programs*, 3rd Edition, 1997. Friends General Conference, phone 215-561-1700. Designed for practicing mediators, it reviews key procedures at each step of the mediation process both formal and informal. It includes suggestions on how to organize a community mediation program, and how to work with antagonists who are reluctant to mediate. The Friends Conflict Resolution Program is a laboratory for discovering and applying Quaker insights to resolve disputes.
- Brinkman, Rick and Kirschner, Rick. *Dealing with People You Can't Stand: How to Bring Out the Best in People at Their Worst*, McGraw-Hill, 1994. Brinkman and Kirschner identify ten common problem behaviors and give ideas on how to use communication skills to deal with those behaviors. The methods presented address problems that often block or sidetrack the reconciliation process.

- Bolton, Robert. *People Skills: How to Assert Yourself, Listen to Others, and Resolve Conflicts*, Englewood Cliffs, NJ, Prentice-Hall, 1979. With a major emphasis on developing listening skills, psychologist Robert Bolton provides a systematic guide to conflict resolution.
- Bondurant, Joan V. *Conquest of Violence: The Gandhian Philosophy of Conflict*, Berkeley, Univ. of California Press, 1969. Political Scientist Bondurant analyzes the techniques, history and philosophy of non-violent direct action. Her description of the steps of direct action would be helpful to a concerned person considering this option as a way to open up an impasse.
- Bower, Sharon and Gordon. *Asserting Yourself: A Practical Guide for Positive Change*, Addison-Wesley, New York, 1991. Focusing on skills for the 3rd step: identifying the problem, the Bowers devote their 244 page book to building understanding and skills for assertive communication, one aspect of the reconciliation process.
- Covey, Stephen. *The 7 Habits of Highly Effective People*, Simon and Schuster Fireside Book, Paperback, New York, 1990. A popular best-seller not presented as a conflict resolution work, nonetheless, Stephen Covey has orchestrated an integrated sequence of personal and social growth based on being proactive, setting goals, prioritizing one's use of time, finding win-win solutions, understanding others before trying to be understood, building synergy and continual self-improvement. The win-win emphasis is close to the heart of reconciliation. The other elements of his 7 "habits" form a personal context for developing and applying reconciliation, not as an add-on, but as a central element of one's life.
- Crum, Thomas. *The Magic of Conflict: How To Turn Your Life Of Work Into A Work Of Art*, Career Track Publications, 4 VHS Videotapes, 1996. Thomas Crum applies the principles of Aikido to show principles of body-mind integration that enable one to remain "centered" in the face of conflict and move creatively in response to challenge. These tapes illuminate a side of reconciliation not often presented. He also has a book by the same title.
- Fisher, Roger and Ury, William. *Getting To Yes: Negotiating Agreement Without Giving In*, New York, Penguin, 1981. Fisher and Ury of the Harvard Negotiation project provide a basic introduction. This slender paperback may be the most concise single source on win-win conflict resolution.
- Fisher, Roger and Brown, Scott. *Getting Together: Building A Relationship That Gets To Yes*, Boston, Houghton Mifflin, 1988. Roger Fisher expands on a critical step given only brief treatment in *Getting To Yes*. It applies to any relationship including personal and international.
- Gordon, Thomas. *Parent Effectiveness Training*, (P.E.T.) New York, Wyden, 1970.

- Gordon, Thomas. *P.E.T. in Action*, (1976) New York, Bantam paperback, 1978.
- Gordon, Thomas. *Teacher Effectiveness Training*, (T.E.T.) New York, Wyden, 1974.
- Gordon, Thomas. *Leader Effectiveness Training*, New York, Wyden, 1977.

Psychologist Thomas Gordon's four books describe his no-lose method of conflict resolution applied, as the titles indicate, to critical roles where conflicts are part of daily life. He is a pioneer in development of the win-win approach to conflict resolution. His methods for this are widely taught to parents and teachers seeking to be more effective. His T.E.T. gives a penetrating analysis of the traditional school discipline approach, vital insights for teachers.

- Kraybill, Ronald S. *Repairing The Breach: Ministering in Community Conflict*, Scottsdale, PA, Herald Press, 1981. This is a rich source of ideas for reconciliation and mediation between groups in the community and within organizations. Prepared by the Peace Section of the Mennonite Central Committee, it demonstrates the role of churches in reconciliation.
- Kreidler, William J. *Creative Conflict Resolution: More Than 200 Activities for Keeping Peace in the Classroom K-6*, Scott, Foresman & Co., Glenview, IL, 1984. Teachers in elementary schools will find this a valuable handbook for resolving student-student and teacher-student conflicts. It shows how to integrate peace studies in the curriculum.
- Robert, Marc. *Managing Conflict From the Inside Out*, San Diego, University Associates, 1982. Educational psychologist and management consultant Marc Robert focuses on the interpersonal level of conflict. He includes a self-test to enable students to become aware of their own style of handling conflict. His rich collection of alternative strategies includes suggestions for handling threatened violence.
- Mindell, Arnold. *The Leader As Martial Artist: An Introduction to Deep Democracy*, Harper, San Francisco, 1992. Jungian Psychotherapist Arnold Mindell presents techniques and strategies for resolving conflict and creating community. Drawing on insights from Taoism and Zen Buddhism, Mindell helps us tune in to our intuitive sensing of flows of energy beneath the surface of conflicted relationships. *Deep Democracy* aims at helping the world become whole.
- Rhode, Helga. *Dealing With Conflict and Confrontation*, Video cassettes or Audio cassettes and workbook, Career Track, Boulder CO, 1993. While psychologist Helga Rhode's basic approach to conflict resolution is consistent with the ideas outlined in this study guide, her analysis of the several levels of conflict makes this a valuable contribution to the resources for learning. Using examples

from work and family settings, she describes both the positive and negative aspects of conflict. She does this in a way that can appeal to those who rationalize power plays and the threat or use of force. Then, when she reminds us of the cost of win-lose strategies, her audience may be motivated to take seriously the value of the win-win process.

- Ury, William. *Getting Past No: Negotiating Your Way From Confrontation To Cooperation*, Bantam Books, 1991, paperback 1993. William Ury was co-author, with Roger Fisher, of *Getting To Yes*. Both were with the Harvard Law School Program on Negotiation. This more recent work expands on the brief treatment in *Getting to Yes* on how to handle barriers, dirty tricks and plain refusal to talk. It lists more than two dozen methods that can be used at any stage in the reconciliation process to reach a win-win outcome.
- Whitney, Charlotte. *Win-win Negotiations for Couples: A personal Guide to Joint Decision Making*, Gloucester MA, Para Research, 1986. Counselor and teacher Charlotte Whitney does for couples what Thomas Gordon does for parents, teachers and leaders. Working with the win-win model of reconciliation found in most of these books, she features examples that can help couples work out their problems in living together.

## **Negotiation: 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 confrontative. 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 consumer 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 dissensus 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 psychiatrists 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 minimum 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.

# EMOTIONAL SELF-CARE

An important and often overlooked component of self-advocacy is emotional self-care. Remember, self-advocacy means representing and advancing your own interests. Although self-advocacy relies on you, you do not have to experience this process in isolation. In order to effectively speak and advocate for yourself, think about the people, information and resources you might want or need to achieve your advocacy goal:

- who you can share strategies and ideas with,
- what resources might assist you in gaining the confidence and experience you want or need to be effective, and
- what would assist you to prepare for and debrief following a self-advocacy experience?

The following articles and exercises will assist you in identifying some tools you might want or need as you build and enhance your skills and initiate actions on your own behalf. The initial focus of this section includes articles and exercises to assist you in identifying ways to promote emotional self-care. Next, this section focuses on the importance of sustaining yourself as you encounter success and resistance along the way.

Self-advocacy is not always a benign process: it can be tiring, frustrating, and sometimes risky – depending on the situation. This section will assist you to acknowledge and identify concrete ideas and steps that you can take to help you stay emotionally well or feel better through any advocacy situation you might encounter.

## Developing a Wellness Toolbox

(Excerpts from Copeland, Mary Ellen. Developing a Wellness Toolbox (© 1995-1999). Reprinted with permission.)

[The next several pages of this Tool Kit focus on Mary Ellen Copeland's *Wellness Recovery Action Plan*. For more in-depth information and resources by Mary Ellen Copeland, please check the *Resources* section of the *Toolbox*, page 182.]

The first step in developing your own Wellness Recovery Action Plan (WRAP) 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.

Complete the *Wellness Toolbox Worksheet* on the following page. List on this worksheet 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 and other resources.

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. Extra rest.
12. Take time off from home or work responsibilities.
13. Hot packs or cold packs.
14. Take medications, vitamins, minerals, herbal supplements.
15. Attend a support group.
16. See your counselor.
17. Do something “normal” like washing your hair, shaving or going to work.
18. Get a medication check.
19. Get a second opinion.
20. Call a warm or hot line.
21. Surround yourself with people who are positive, affirming and loving.
22. Wear something that makes you feel good.
23. Look through old pictures, scrapbooks and photo albums.
24. Make a list of your accomplishments.
25. Spend ten minutes writing down everything good you can think of about yourself.
26. Do something that makes you laugh.

27. Do something special for someone else.
28. Get some little things done.
29. Repeat positive affirmations.
30. Focus on and appreciate what is happening right now.
31. Take a warm bath.
32. Listen to music, make music or sing.
33. Spend time with your pet.

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 this list as you develop your Wellness Recovery Action Plan. Information about how to develop this Plan follows the *Wellness Toolbox Worksheet*.

# EMOTIONAL SELF-CARE

## Wellness Toolbox

(Based on Copeland, Mary Ellen. Developing a Wellness Toolbox (© 1995-1999). Reprinted with permission.)

These are the tools that I most commonly use to stay well and help relieve symptoms:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_
6. \_\_\_\_\_
7. \_\_\_\_\_
8. \_\_\_\_\_
9. \_\_\_\_\_
10. \_\_\_\_\_

These are things that I would like to avoid:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_

# Guide to Developing a WRAP: Wellness Recovery Action Plan

(Adaptation from Copeland, Mary Ellen. Developing a Wellness Toolbox (© 1995-1999). Reprinted with permission.)

This is 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.

## 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 paper;
4. A writing instrument of some kind; and
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 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 all right.
- 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.



- On the first page, write down 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 your own ideas from the *Wellness Toolbox Worksheet* as a guide.

### **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 Worksheet* as a guide.

### **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*.
- On the first page of this section, 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 Worksheet* as a guide.

### **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 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 page should include space to write about the following:

- 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; and
- Instructions on when the plan no longer needs to be used.

## **Presents to Give Yourself**

(Adaptation from 81 Presents to Give Yourself. Mental Health Association of Oregon.)

- |  |                                 |
|--|---------------------------------|
| • Walk instead of ride                     | • Sign up for a class           |
| • Give yourself a compliment               | • Enjoy silence                 |
| • Break a bad habit, if just for today     | • Search out a long-lost friend |
| • Read a poem aloud                        | • Look at the stars             |
| • Visit someone who cannot leave the house | • Be thankful                   |
| • Use a new word                           | • Frame a picture               |
| • Walk to the nearest park                 | • Forget an old grudge          |

- Take yourself to lunch
- Try a new food
- Take a risk
- Tell someone you love him or her
- Do something you've always wanted to do
- Contact someone you've been thinking about
- Surprise a child
- Sing in the shower
- Walk in the rain
- Give away something you don't like
- Curl up before an open fire with some cocoa
- Return something you've borrowed
- Organize some small corner of your life
- Draw a picture, even if you can't draw
- Keep a secret
- Go wading
- Smell a flower
- Send a card to someone for no reason
- Take an early morning walk
- Tell a joke
- Walk barefoot
- Visit a lonely person
- Go for a swim
- Build a sandcastle
- Write a poem
- Volunteer some time to a good cause
- Reread your favorite book
- Take a different road to get home
- Let someone do you a favor
- Hide a love note where a loved one will find it
- Go to a fair
- Do something hard to do
- Get up before anyone else
- Hum
- Help a stranger
- Go to the library
- Jump in a pile of leaves
- Take a rainy day nap
- Meditate
- Learn something new
- Hug someone
- List 10 things you do well
- Pay a compliment
- Waste a little time
- Buy a ticket to a special event
- Pop popcorn
- Turn off the TV and talk
- Practice courage in one small way
- Eat with chopsticks
- Bake bread
- Kiss someone
- Clean out your wallet
- Laugh at yourself
- Look at old photos
- Talk to a pet
- Encourage a young person
- Give yourself a present
- Follow an impulse
- Start a new project
- Have breakfast in bed
- Give your dog a bone
- Watch the sun set
- Allow yourself to make a mistake
- Make a surprise gift
- Lie on the grass
- Rearrange a room
- Let someone love you
- Go shopping

# EMOTIONAL SELF-CARE

## What Presents Would You Give Yourself?

List any ideas and activities that you might undertake to give yourself a present:

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

# EMOTIONAL SELF-CARE

## Boundaries

Another aspect of emotional self-care involves recognizing and maintaining healthy boundaries. Whether we are asking for help, breaking down barriers of isolation, or advocating, boundaries play a key role in how we interact with others and they with us. List below some ways that you can maintain healthy boundaries while pursuing your self-advocacy goal.

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

## Patience, Perseverance and Sustenance: Self-Advocacy for the Long Haul

Taking care of ourselves emotionally is critical to the success of self-advocacy strategies; however, all of our effort, skill development and action might not result in success. As the self-advocate, you control only half of the process! The person, agency or entity with whom you are self-advocating has her/his/its own response to your efforts. You have control only over your actions, not theirs. As a result, achieving a self-advocacy goal that you have set is limited in some degree by the other party. That is why it is important for your self-esteem, confidence and focus to be patient with the often-slow wheels of change, to persevere when you meet resistance, and to sustain yourself over time for the long-term solution – not the quick fix.

As you learn or enhance self-advocacy skills, it's most gratifying to experience immediate results. Sometimes the absence of immediate resolution to a situation, despite your best advocacy efforts, can feel disheartening, discouraging and defeating. Because it might take an extended period of time and repeated efforts on your part to achieve your goal, you might feel “stressed out” or “burned out” about the situation.

Refer back to Mary Ellen Copeland's *Wellness Toolbox* information on page 97 to assist you in developing strategies to address these less desirable aspects of being a self-advocate.

# PEER ADVOCACY

## Understanding Your Role as a Peer Advocate

As stated at the beginning of this *Toolkit*, peer advocacy means representing the rights and interests of someone other than yourself. For many individuals, deciding whether and how to speak up or take action in response to a problem can be a scary process to undertake alone. Knowing there is someone available to assist you can provide great comfort throughout the resolution process. This “someone” can be a peer advocate – a friend, family member, co-worker or other person whom you ask to act as a peer advocate.

There are two distinct functions of peer advocates:

1. To work jointly and collaboratively as a knowledgeable supporter of an individual seeking resolution to a problem; or
2. To work at the request of and on someone else’s behalf.

### The “With” Function: Role of Knowledgeable Supporter

The primary responsibility of a peer advocating jointly and collaboratively is **knowledgeable support**. Your role is to assist that individual and be supportive of him/her. In this role, the peer advocate provides support and assists an individual with information regarding the advantages and disadvantages of various options to resolving the problem. Regardless of the circumstances of the situation, the ultimate decision of what to do and how to do it is made by the individual – not the peer advocate. While you need to feel comfortable with your understanding of the situation and your role in its resolution, you should not direct the individual’s decisions about how that resolution should or should not be achieved. Instead, communicate together about the advantages and disadvantages of the various strategies that could be applied. Clarify the goal that the individual has identified, and work together to determine what strategies and actions might best achieve that goal. While a chosen goal or strategy might differ from what you believe is the best course of action, the individual with whom you advocate gets to choose the resolution they will try to achieve as their advocacy goal.

### The “For” Function: Representational Peer Advocacy

While any form of peer advocacy involves working together, advocating on someone else’s behalf combines providing knowledgeable support with actually representing another person’s

interests. When a person has a problem that demands representational peer advocacy, they might be in a state of crisis, or feel that having someone else advocate for them will be more effective. An individual might need and/or want someone to act on their behalf – to advocate for them and in consultation with them.

The key to being an advocate is having an interest in the welfare of the individual, a willingness to become knowledgeable about the situation at hand, as well as about the relevant rights and remedies, and an ability to speak out on behalf of the individual. (Advocacy Training Manual. Wisconsin Coalition for Advocacy (1996).)

Of primary importance in being an advocate for another individual is always remembering that you are the spokesperson for that individual. If the individual has the mental capacity to express her/his own wishes, it is your responsibility to assist her/him to implement those desires whenever possible. You may not always be in total agreement with the person for whom you are advocating, but you must put aside your own opinions and represent those of the individual. You should not continue to act as an advocate for another person if you cannot separate your opinions from those of the individual. Of course, you can discuss your perceptions and ideas with the person you are helping, but the individual ultimately makes the decisions about her/his situation. When you as an advocate meet and talk with other persons regarding the individual you represent, you must present the individual's wishes and opinions, not your own. In many situations, you will have to deal with persons who disagree with the individual's wishes and opinions. This situation can make being an advocate challenging, especially if you also disagree with the person but have agreed to advocate for her/him. (Advocacy Training Manual. Wisconsin Coalition for Advocacy (1996).)

## **Peer Advocacy Blueprint for Success**

Regardless of which peer advocacy function you and another person choose to employ in any given situation, there is a common guide or blueprint that should be followed for success of the relationship.

1. *Have and utilize effective advocacy skills and strategies.* Before undertaking any peer advocacy relationship, learn and practice the skills and strategies contained within the Self-Advocacy portion of this *Tool Kit*.
2. *Ask yourself probing questions* about your involvement in a peer advocacy relationship.
  - What are *my interests and motivations* in this peer advocacy relationship?

- Do I feel comfortable undertaking this role, with this person?
- When and how are my interests and motivations the same as the person I am advocating for or with?
- When and how are they *different*?
- Am I *enabling and empowering the individual* to be her/his own advocate? (Fernandez, Happy Craven. The Child Advocacy Handbook. The Pilgrim Press, New York (© 1980).)

3. *Develop a Peer Advocacy Plan.* Deciding what your function will be as a peer advocate is just as important as talking about advocacy goals and strategies. Will you primarily serve as a supporter or a representative for the person? The peer advocate and the person requesting assistance should meet to decide on a peer advocacy plan. This plan involves jointly figuring out the “ground rules” of the peer advocacy relationship. The next section discusses strategies and steps to take to set up these ground rules.

## Setting the Ground Rules

In order for a peer advocacy relationship to be mutually successful, both individuals involved need to create and then agree to a set of ground rules for how the relationship will operate. While it might feel unnecessary to clarify the issues described below at this early stage of the peer advocacy process, it is better to discuss these issues up front so that everyone is “on the same page.” Clarify answers to the following questions as specifically as possible. The more time and discussion the advocate and individual have about these issues, the less confusion and miscommunication there will be.

### Issues to Consider and Ground Rules to Set

1. What is the person asking you to do – function as a knowledgeable supporter or as a representative on her/his behalf? If both, under what circumstances will you function as a supporter working with the person and when will you actually act as a representative of the individual?

---



---



2. What is the problem needing a peer advocacy response?

---

---

---

3. Does the peer advocate feel clear about and comfortable with the topic?

---

---

---

4. What is the goal or outcome the person would like to achieve?

---

---

---

5. What does the person expect the peer advocate to do? Be specific.

---

---

---

6. What ideas and strategies have the person and advocate mutually agreed upon?

---

---

---

7. In what order will these steps be taken and by what date? Who will decide when strategies should be employed?

---

---

---

8. What if the peer advocate chooses to no longer participate as a peer advocate?

---

---

---

9. What happens if there is a disagreement between the advocate and the person: on strategy, on the goal(s)?

---

---

---

10. If the advocate is representing the person, what process is agreed upon for informing the person of what is happening? How often should that communication take place?

---

---

---

11. Does the representational advocate need to check-in with the person after completing each task before starting another one?

---

---

---

12. Are there any decisions that the advocate should make on her/his own? If so, what if the person changes their mind after an action has been implemented?

---

---

---

13. What documentation should the peer advocate keep? What is the process for providing this documentation to the person?

---

---

---

## **Do's and Don'ts of Peer Advocacy**

(Ideas for this piece originated from How to Organize an Effective Parent/Advocacy Group and Move Bureaucracies. Family Resource Center on Disabilities, Chicago (© 1993).)

Peer advocacy can be a tremendously rewarding experience for the advocate and the person for and with whom they are advocating. Yet, peer advocacy also involves many pitfalls. Care and caution are required in order to make the relationship mutually beneficial. Review the lists below and write down your thoughts about how and why each of the items listed can be helpful and/or harmful – to you and the person for and with whom you are advocating.

### **As a Peer Advocate, it's okay to:**

- Help individuals help themselves;
- Build confidence so individuals are able to practice self-advocacy;
- Provide necessary tools and support to promote informed decision-making;
- Assist individuals to learn about their rights;
- Take action as requested by a person for whom you are advocating;
- Be persistent in advocating on a person's behalf;
- Assist with analyzing a problem and deciding on strategies for resolution;
- State options that might be the most effective for solving a problem;
- State your opinions as long as you are clear that you act on the other person's desires, not your own;
- Decide that the peer advocacy relationship is too stressful or unworkable for whatever reason; and
- Assist individuals to find and use resources available to them.

**As a Peer Advocate, it's not okay to:**

- Take over someone's life or problem and make all of the decisions for them;
- Down play or squelch someone's efforts at self-advocacy;
- Reinforce feelings of dependence and helplessness;
- Keep the person in the dark while doing everything for them;
- Make excuses for your lack of agreed to action;
- Deny the existence of a problem or complaint that the person has communicated to you;
- Speak disparagingly about the person to individuals that you are working with on a person's advocacy goal;
- Share information about the person without their consent;
- Decide for the person what they need and want as a resolution to a problem or situation; and
- Assert your own personal agenda under the guise of acting on someone else's behalf.

**Helping Agent Skills**

(Metro Denver Gang Coalition.)

Another way to think about being a peer advocate is thinking of yourself as a "helping agent." When you perceive cues that the other person is experiencing a problem, and you choose to be a helping agent, there are a variety of communication skills that you can use. They are listed below in order of increasing activity on your part.

**Silence**

Passive listening with accompanying non-verbal behaviors (posture, eye contact, etc.) that communicate interest and concern.

## **Non-Committal Acknowledgement**

Brief expressions that communicate understanding, acceptance, and empathy, such as:

- “Oh”
- “Really”
- “I see”
- “No fooling”
- “Mm-hmm”
- “You did, huh”
- “How about that”
- “Interesting”

## **Door Openers**

Invitations to expand or continue the expressions of thoughts and feelings. Again, the listener is showing interest and involvement. Examples:

- “Tell me about it”
- “I’d like to hear your thinking”
- “Would you like to talk about it”
- “Sounds like you’ve got some feeling about this”
- “I’d be interested in what you’ve got to say”
- “Let’s discuss it”

## **Content Paraphrase**

Putting the factual portion of the message into your own words and sending it back to check your accuracy in understanding. Examples:

- “So you really told your boss off”
- “You’re saying, if your plan works, the problem will be solved”
- “She just keeps going on and on, huh”

## **Active Listening**

Helping the sender to understand both the thoughts and feelings of his/her communication. The listener does this by reflecting or mirroring what he has heard. Examples:

- “You sound upset when he uses your car”
- “You are not pleased with the way your part of the report is coming”
- “You’re stumped about what to do next”

## **Advocacy Oriented Peer-Support Part Two: Moving from Talk to Action**

*(Advocacy Oriented Peer-Support Part Two: Moving from Talk to Action, by Steven Brown. © 1999 ILRU, 2323 S. Shepherd, Suite 1000, Houston, Texas 77019. Voice 713-520-0232; TTY 713-520-5136; Fax 713-520-5785. Available at <http://www.ilru.org/ilnet/files/reading/peer2.html>. Substantial support for development of this publication was provided by the Rehabilitation Services Administration, U.S. Department of Education. The content is the responsibility of ILRU and no official endorsement of the Department of Education should be inferred.)*

**[Tool Kit Editor's Note:** The importance of sharing common experiences with another person can be a powerful motivator. Peer advocacy is one form of peer support. The following article describes the importance and power of peer support, and its application in the independent living movement. The independent living movement, which began in the late 1970's, is defined by consumer choice, autonomy and control. The independent living philosophy holds that individuals with disabilities have the right to live with dignity and with appropriate support in their own homes, fully participate in their communities, and to control and make decisions about their lives. The concept of sharing experiences and working with a peer to solve a problem is what peer advocacy is all about. Many organizations and movements, including the mental health recovery movement, rely on the knowledge and experiences of peers as advocates. This piece helps us to explore and think about how to utilize the strengths of our experiences.]

### **How Does Talk Become Action?**

This is a key question that center for independent living (CIL) staff, consumers and board members may sit and ponder for years. We all know people who talk a lot about change, share wonderful ideas, and have all kinds of theoretical methods to put their rhetoric into motion, but somehow never manage to translate that passion for words into concrete actions. We also know another set of people who may not have much to say, but always show up when there is a need for someone to participate in a legislative action, or a demonstration, or a conference. Like most spectrums, these two groups compose minorities. The vast majority of us neither verbalize our frustrations nor do we act on them. At different times, any one of us might fit into any or all of the three groups described above. At the best of times, we somehow manage to take our concerns from talk to action. The purpose of this paper is to identify some ways that CIL staff might identify when someone is ripe to move from talk to action.

### **Anger**

Anger is generally the most obvious sign that someone is ready to work for change. Since people with disabilities often encounter discrimination, anger is a frequent response. A person may call or come in to your CIL who is exasperated with a bureaucracy, or who has just encountered a barrier of some kind in your community, or who expresses one of a dozen other reasons to be

upset with something that has happened in his or her life. Maybe a person who works with your CIL has been sent to you by Vocational Rehabilitation or another agency to access peer support services.

They join a peer support group and you hope that this will entice them to move from expressing their anger to doing something about it. But instead all they do, and in fact all the group seems to do, is complain. What can you do to advance the process so talk doesn't just continue endlessly and no one does anything?

## **Acknowledgment**

The first, and perhaps most important, reaction you can have is to acknowledge that anger exists. A famous advocate with a disability often tells the story of his younger years when he first began to understand he encountered discrimination and oppression because of his disability. He expressed this belief to some family and friends and they all denied his perception. Years later he decided to see a psychologist who also had a disability. When he proclaimed his frustrations with discrimination and oppression, she did not deny his feelings. In fact, she affirmed them. Yes, she agreed, you do face discrimination and oppression because you have a disability. Now, what are you going to do about it?

Validating someone's feelings of anger is critically important. For a group of people who have been identified for years as in-valid, having emotions of anger denied or minimized is just another slap in the face from an uncaring society. Before someone can act on their anger they must believe it is justifiable. Before CIL staff are likely to be willing to assist someone else in moving their anger from talk to action, they must acknowledge their own feelings of anger as well as those of the person with whom they are working.

## **Support**

Support from CIL personnel many times leads to a way to funnel anger positively. Each CIL possesses knowledge of many situations in your community that need to be changed. CIL staff do not have to be the ones to make all the changes. In fact, if CIL staff are unwilling to share the responsibility of community change with others, then the bulk of the work required is likely to remain undone. There are simply too many items in need of reform.

Once CIL staff recognize and acknowledge the existence of anger they will be challenged to provide support to transform that anger. Individuals coming into CILs often focus solely on what has happened to them. CILs have a responsibility not only to address the individual problem, but to assist people in understanding how their individual problems relate to systemic issues. This



may be the most significant role provided by CIL staff because an individual whose attention is turned toward systemic problems is more likely to become engaged in the necessity of a movement, as opposed to resolving only individual concerns. This, in turn, is one way to move someone from talk toward action.

The willingness of CIL staff is a vital component of this transition. But an eager CIL staff does not necessarily translate into one that is skilled at taking an individual or a group from talk to action. Both CIL personnel and those who seek support from the CIL must be attuned to characteristics of leadership.

## **Leadership**

Leaders exist everywhere: schools, workplaces, institutions, families, organizations. Potential leaders include not only those who work at an independent living center, but also those who serve as volunteers or who receive services from a CIL. All leaders have one thing in common: they are able to move people to accomplish change. Sometimes leaders are people who get tired of hearing other people gripe and do nothing. Some people just seem born to lead. Others get angry and tired and decide they cannot sit around and do nothing and just start acting. Some people lead by example and others lead groups of people. All have an ability to persuade other people that their issues are at the very least worth considering.

There is no set formula to become or recognize a leader. Indeed, there are many formulas and lots of books written and seminars conducted about leadership. For the purposes of an independent living center, everyone the CIL comes into contact with can be considered a leader or a potential leader. That way CILs do not make the same mistake other societal organizations do and exclude someone from leadership because they look different, or walk funny, or drool while they talk, or think more slowly than the peer to whom they might be assigned.

There is another advantage to considering everyone a leader. Initially, some people will rise to the occasion. Others will fall back. But even those who retreat will learn something that will be of benefit to them, and one day they may use that knowledge to assume a leadership position with a CIL or elsewhere.

## **Combining Anger and Leadership**

A CIL can be a perfect setting to offer someone a chance to test their leadership skills. It can also be a place to squash leadership development. What's the difference?

Some CILs are criticized for too much delegation and others for too little, but if CIL staff do not share opportunities to create reform then why should others be interested in working with them?

CILs who foment leaders are ones who are willing to let go of some of the responsibility and work toward making change happen. All CILs have many opportunities for people to try out their leadership skills. These include becoming a peer supporter or counselor, facilitating peer support groups, serving on CIL board committees, writing about their experiences and concerns in CIL newsletters, volunteering for other community organizations, communicating with elected officials, attending rallies, writing letters to editors and opinion columns, and volunteering at the CIL.

Not every individual who tries one or more of these or other possibilities will succeed. Neither will all fail. The same is true of every other demographic group. But if people with disabilities are not encouraged to try and fail (or succeed) with the support of a CIL, where will they find the opportunities they need to test their skills? Possibly nowhere. That's why a CIL is a perfect setting to offer someone a chance. It's a good possibility that one or more of the CIL's current staff got such an opportunity in their past.

Over the years since the first CILs began in the early 1970s, many people with disabilities have combined anger and leadership to effect positive change. Examples abound. The Americans with Disabilities Act resulted from people with disabilities being tired of encountering discrimination in a variety of areas of life and writing a law to forbid this discrimination, then fighting to see that the law was passed. As this is being written, many disabled people are readying themselves to advocate with their state governors and with the federal Supreme Court not to weaken the ADA.

Rallying cries are occurring at this moment for a variety of causes: stopping the attempts of Jack Keivorkian to promote mercy-killing; increasing Social Security benefits and obtaining work incentives to keep people in the workforce; diverting money from nursing homes into maintaining personal assistance services in the community; increasing transportation options; getting the study of disability into college curricula; promoting disability history through events like Initiative 2000, a celebration of the 10th anniversary of the passage of the ADA; and retaining independent living centers as advocacy organizations.

### **What Can Your CIL Do?**

Perhaps the most important supervisory task for CIL management is to encourage staff to pay attention. With all the tasks facing CIL staff on a daily basis there may be a tendency to become immersed in what there is to do rather than who there is to do it. In this way we may lose those

who come to CILs for help before they are ready to become leaders. For some people, assuming a leadership role will come quickly and naturally. For others, it may take years. CILs, as organizational entities, need to remember that sometimes the world is changed one person at a time and that it is just as vital to interact with one consumer for many hours as it is to talk with a legislator. That consumer may be around for years to come; the legislator may be gone before you know it.

Once a CIL feels that it delivers its services as best it can, do not become discouraged by a seeming lack of response. Even though you may not think you are getting through to someone, you could be wrong. Many times, someone will return to a CIL months or even years after their initial contact. Something said in a first CIL encounter might have changed their life or stimulated their thinking. Those in the CIL may be unaware of these transformations. Just because they are not visible to a CIL does not mean they are not happening.

Finally, just as CIL staff appreciate praise, leadership development includes acknowledgment.

Sometimes the only way leaders know that they are leaders is if people tell them how much they appreciate their efforts and that because of their work change has occurred.

Every CIL has the potential to utilize peer support to move people from talk to action, from anger to leadership. Just like individuals, CILs are not all alike. What works for one may not work for another. But it's more likely that a CIL that has identified some techniques of leadership development will be able to share aspects of their success that do work at other CILs. Contact the ILRU/NCIL National Training & Technical Assistance Project to find out who they are. It may be the most important contact your CIL will ever make.

###

*The IL NET is a collaboration of Independent Living Research Utilization (ILRU) Program and the National Council on Independent Living (NCIL), and organizations and individuals involved in independent living nationwide. Now in its second three-year funding cycle, the IL NET is building on its strong foundation to address the spectrum of needs expressed by centers for independent living and statewide independent living councils.*

*For additional copies of this document, contact ILRU at 713.520.0232 (V), 713.520.5136 (TTY), 713.520.5785 (fax) or email at [ilru@ilru.org](mailto:ilru@ilru.org).*

*ILRU is a program of TIRR, a nationally recognized, free-standing rehabilitation facility for persons with physical disabilities. TIRR is part of TIRR Systems, a not-for-profit corporation*

*dedicated to providing a continuum of services to individuals with disabilities. Since 1959, TIRR has provided patient care, education, and research to promote the integration of people with physical and cognitive disabilities into all aspects of community living.*

©1999 ILRU  
2323 S. Shepherd, Suite 1000  
Houston, Texas 77019  
713.520.0232 (v); 520.5136 (TTY); 520.5785 (fax)  
ilru@ilru.org

*Substantial support for development of this publication was provided by the Rehabilitation Services Administration, U.S. Department of Education. The content is the responsibility of ILRU and no official endorsement of the Department of Education should be inferred.*

*ILRU is a program of The Institute for Rehabilitation and Research (TIRR), a nationally recognized, free-standing medical rehabilitation facility for persons with physical and cognitive disabilities. TIRR is part of TIRR Systems, which is a not-for-profit corporation dedicated to providing a continuum of services to individuals with disabilities.*

## **Ways to Resolve a Dispute**

(Adapted from Wisconsin Coalition for Advocacy. Where to Now?: A field guide to resolving complaints within the mental health system, (© 2000). Reprinted with permission.)

Described below is a summary list of ways to resolve a dispute. Although this list is generally organized in order of least aggressive to most aggressive forms of action, how you as a peer advocate and the person for or with whom you are advocating choose to approach resolving a concern or dispute is up to you. It is not necessary that you follow the order listed below.

Learn about the rights, complaint procedures and available resources applicable to the type of situation in which the person for whom you are advocating is involved. (See the Toolbox for information resources on rights and complaint procedures.) This should help you to decide what information you need to gather and whether the facts you obtain indicate that a right has actually been violated.

### **Before You Begin**

The *Peer Advocacy Action Plan Worksheet* should be used to develop a clear plan for addressing a person's problem or situation. (This worksheet follows this piece.) Remember that the

activities you undertake as a peer advocate are on behalf or with someone else. Any communication, whether written or verbal, should be discussed and reviewed with the individual with whom you are advocating. Also, remember to document everything!

- Keep a file of all of your notes, any correspondence you send or receive, and all written records you may obtain. These documents should be reviewed with the person for or with whom you are advocating.
- Make written notes during all meetings and telephone calls.
- When you are meeting in person or speaking on the phone with anyone about a complaint or concern, write down the date of the communication, the name of the person and her/his position (if any), and the facts you obtain from the discussion. During the communication, it may seem easy to remember what was said, but keeping written notes at the time is very important.
- Write letters confirming and summarizing important phone calls and meetings. Always make a copy of any letter you send.

### **Try to resolve the dispute informally**

The majority of disputes are resolved informally. As a peer advocate, think about talking directly to the individual your peer has a dispute with. Trying to resolve issues or disputes directly and informally can often resolve the person's concern quickly, effectively, and without much time.

When discussing a concern or complaint with someone, it is useful to be prepared. Below are some suggestions that may help you when you talk with someone regarding specific concerns.

- *Decide whether you would prefer to address the issue verbally or in a letter.* Depending on your personality, you may feel more comfortable about addressing your concern in writing instead of verbally or vice versa. Use the strategy that works best for you, and talk over your decision with the peer for whom you are advocating.
- *Make an outline of what you want to say.* Often writing down what points you want to make when you meet with someone can assure that you will not forget to mention an item that is important to you. Bringing in a "cheat sheet" with your points outlined will help you to stay on track. Work with your peer to develop this "cheat sheet."

- *Be clear about what you want to accomplish.* Before you address an issue with a provider, be prepared to answer the question, “What do I want to accomplish in this meeting? What is my desired outcome?” Your answer may range from just wanting to get the complaint off your chest, to receiving an apology. Although there is no guarantee that you will get the response you are looking for, being aware of what you want will clarify your role and the purpose of bringing it to their attention.
- *Rehearse what you want to say.* Rehearsing what you want to say will give you an edge in the meeting, particularly if you are nervous about addressing someone about the issue. Some people are more comfortable rehearsing by themselves in front of a mirror, while others prefer to have an audience. The more comfortable you are with what you want to say, the more effective you will be as a peer advocate in conveying your points.
- *Take notes during the meeting.* Make sure you write down the date of the meeting, who was present, and any agreements made during the meeting. Often summarizing what has been decided at the end of the meeting insures both parties are in agreement with the course of action if there is one.

## **Know Your Rights**

Before you consider utilizing a more formal resolution process as a peer advocate, you have to know and understand what rights a person has in the situation that you are addressing. The *Toolbox* at the end of this *Tool Kit* contains information and resources to assist you in learning about and clarifying an individual’s rights. Once you have clarified what rights, if any, are involved, then a grievance procedure or other formal actions can be utilized as a strategy for resolution.

While much of the following information applies primarily to patient rights, many of the tools and strategies discussed below can be applied to all different kinds of situations.

## **What To Do About A Rights Violation**

1. Try to obtain as much information as you can. With the person’s permission and signed informed consent, review the person’s records at the agency or program. Speak with staff to find out their perceptions and opinions regarding the person’s claim of a rights violation.

Do not argue with staff if their version of the facts differs from that of the person. Sometimes staff may seem resistant to your questions. Getting into a shouting match with staff rarely solves anything. If you find that staff will not answer your questions, it may be best to pursue a formal complaint so that others can conduct the investigation. You may also want to request a hearing so that in a more formal setting people can be questioned about what happened.

2. Discuss in detail with the person her/his choices. Explain what the complaint procedures and/or court actions can and can not accomplish. Individuals often think that they can obtain significant amounts of money if their rights have been or are being violated. In actuality, a finding that a rights violation has occurred may only result in the agency or program being told that they should have acted differently and should do so in the future. As an advocate, you must follow the wishes of the person as to what action is taken. In deciding on strategy, you should also consider which route has the most likelihood for success and who has the power to resolve the problems.
3. If the person agrees and the rights violation is an ongoing one that can be resolved, you can try to work out a solution with the staff instead of automatically filing a formal grievance, administrative complaint or court action. Formal legal procedures are frequently time-consuming with no guarantee of positive results. The end result of a lengthy process may be an order from an administrative agency or a court that the agency or program must change the way in which it is treating the individual. It is the unusual case, rather than the typical one, in which the individual is awarded monetary damages. Those cases are most likely to be very complex and require an especially lengthy legal process. Therefore, working out solutions with staff is generally in the best interests of the person. The agency or program often prefers not to become involved in formal administrative or court proceedings, so may show a willingness to work out the problem with the advocate.
4. If the rights violation occurred in the past and is not a continuing problem, there may be no basis for working with the staff to change a current situation. The person and the advocate must decide if the past rights violation warrants the filing of a complaint or court action. Considerations in reaching a decision may include the seriousness of the violation, the likelihood that the person would benefit in some manner from formal administrative or court procedures, and the chance that the rights violation will occur again in the future if action is not taken. The person may benefit just because the staff knows that an advocate is involved with her/him and is aware of how the person is being treated. In dealing with staff one must consider their knowledge of rights issues and the person's complaints. Sometimes you will know considerably more

about a person's rights than the staff will. In these situations, aggressiveness on your part will probably not be helpful. You may need to educate staff in a non-threatening way about a person's rights and what you feel needs to be done to correct the situation.

If an agreement is reached with the staff to either cease a practice which violates a person's rights or to take affirmative steps to grant a right being ignored or poorly implemented, the agreement should be written down in detail. The responsibilities of the various individuals involved must be clearly described. Dates for implementation of any changes to be undertaken should be agreed upon. A time for reviewing the agreement should also be set.

## **File a Patients Rights Grievance**

The State of Wisconsin established a special procedure to resolve patient rights disputes for any individual receiving inpatient or community mental health, drug/alcohol, or developmental disability services.

The grievance procedure was designed to deal specifically with the violations of the rights under section 51.61 of the Wisconsin Statutes. These rights include:

- *Treatment Rights:* the right to prompt and adequate treatment in the least restrictive environment, the right to give informed consent for treatment and medication, and the right to not be unduly subjected to seclusion or restraints.
- *Rights relating to privacy:* confidentiality and access to one's own records.
- *Communication rights:* access to the telephone to make and receive private calls, the ability to meet with visitors, and the right to receive and send sealed mail.
- *Personal rights:* the right to be treated with respect and dignity, the right to be treated in a humane environment, and the right to personal choice regarding religious worship.
- *Financial rights:* being compensated for one's labor, being informed of any charges for treatment, and the right to manage one's own money.

For a complete description of Wisconsin's Bill of Rights, please refer to the *Toolbox* at the end of this *Tool Kit*.



By law, all community and inpatient mental health and drug/alcohol agencies must have a Patient Rights Grievance Procedure in place. In addition, these agencies are required to have a Client Rights Specialist (CRS) on staff. It is the job of the CRS to meet with you and assist you with filing a grievance. In addition, the CRS will investigate your grievance once filed.

A grievance must be filed with a CRS within 45 days of the incident. If, however, you have good cause for not being able to file your complaint within the 45-day time limit, your program manager may extend the time limit. Within 30 days of filing the grievance you will receive a written report by the CRS with a summary of the incident and a determination as to whether a patient rights violation has occurred. If a patient rights violation is found, a set of recommended changes will be given to the agency and/or individual staff to follow. If the ruling is not in your favor, you may decide to appeal the decision.

Below is a brief outline of the appeal levels.

1. If you are not satisfied with the decision handed down by the agency, you have **10 days** to appeal the decision to the county department of community programs or human services. The county department will review your grievance and must provide you with a written report of their decision within 30 days of when you filed the appeal.
2. If the decision handed down by the county department is still not satisfactory, and you wish to appeal their decision, you have **14 days** after you receive their report to file an appeal with the state grievance examiner. The state grievance examiner will review the incident and has 30-60 days to inform you of their decision in the form of a report.
3. If you are not satisfied with the state grievance examiner's decision, and you wish to appeal the decision, you have **14 days** after you learn of the decision to file an appeal with the Administrator of the Division of Supportive Living at the state Department of Health and Family Services. You should ask your program manager to file the appeal. The Division Administrator must review your appeal and make a decision within 30-60 days. The Division Administrator's decision is final and can not be appealed.

If any part of the grievance procedure is inadequate, you can complain to the Grievance Examiner in the Division of Supportive Living of the Department of Health and Family Services by calling (608) 266-2701 or TTY (608) 266-7376.

To **find out more about filing a grievance**, ask to speak to the Client Rights Specialist associated with your program or agency, or contact Wisconsin Coalition for Advocacy (WCA) at

(608) 267-0214 or (800) 928-8778 and request the pamphlet entitled “Wisconsin’s Patient Rights Grievance Procedure.” To find out which Client Rights Specialist to contact, either ask your provider or contact WCA for a listing of Client Rights Specialists in the State of Wisconsin.

### **File an administrative complaint**

A complaint is usually written, and is filed with a governmental agency or professional organization to resolve a dispute or a violation of state law. For example, complaints can be used for disputes other than patient rights. Complaints can be used and filed regarding care in a nursing home or hospital, in a landlord/tenant dispute, a discrimination violation against your employer, an automobile dealership, etc.

One can choose to file a complaint rather than a grievance regarding a rights issue if preferred. A complaint can also be filed in addition to a grievance. Therefore, depending on your dispute, the complaint process and the grievance procedure can be separate forums for addressing the same issue. For example, in a case involving a rights violation in a hospital you could file a grievance with the hospital or a complaint with the Bureau of Quality Assurance in the Wisconsin Department of Health and Family Services.

Unlike the grievance procedure which addresses only patient rights issues as defined by Wisconsin law, the complaint process can address a wider variety of disputes which can range from rights violations to ethics and standards of care.

You may file a complaint with either a governmental agency or a professional organization. Each agency and organization has its own set of complaint procedures. There are many ways to file a complaint for a single dispute. It is important to remember, however, that some agencies will not allow you to file a complaint or a grievance on the same dispute concurrently.

The *Toolbox* contains a resources section that lists agencies and professional organizations where you could file a complaint in the State of Wisconsin. A good place to start is the Wisconsin Coalition for Advocacy’s *Rights and Realities II* which is an action guide filled with information about regulation of health care providers, housing, discrimination, Social Security disability benefits, and Medical Assistance as well as the resources you can access if you are interested in filing a complaint. The *Toolbox* contains an order form you can use to this get helpful action guide.

## **Take legal action**

In certain types of cases when you do not believe that filing a complaint or a grievance will resolve the issue, you may want to consider taking some sort of legal action. These cases may involve obtaining money damages from a provider whose actions have injured you or using the criminal law when an action has been particularly serious. Taking legal action is a major step that can be costly emotionally and financially. However, in certain situations when other remedies are not sufficient, it may be appropriate.

There are two major types of legal actions – civil lawsuits and criminal cases. In a civil case the individual retains an attorney to file a lawsuit involving a violation of the individual's rights or an injury sustained by the person. In a criminal case the individual must take the case to the police or district attorney and ask them to take action against the person who is believed to have violated the law. These agencies have discretion about whether or not to proceed. Thus, a criminal case may or may not be filed depending on their assessment of the facts and whether they believe that a violation of the law can be proven.

## **Contact your legislators**

Another advocacy avenue or option to consider involves contacting your state representatives to voice your complaint. According to where you live, you have one state Assembly Representative and one State Senator. You also have one Representative and two Senators at the federal level. You have the right to voice your opinion on various topics to your legislators; however, this is just a forum to inform your legislator about your opinions.

Contacting your legislator should not be considered a “last step.” Legislators, especially at the state and federal levels, have staff available to assist constituents with problems. For example, if you have a complaint or concern with the Social Security Administration (SSA) about your Supplemental Security Income (SSI) benefit, working with your federal legislator to help you solve the dispute might be a really effective course of action. Many times, a legislator's office can help you cut through bureaucratic red tape or give you advice about who to contact at a large agency, such as the Social Security Administration. This information can be invaluable in saving you time and energy.

- You can find out who your **state legislators** are and how to contact them by either calling (800) 362-9472 or looking on the web at <http://www.legis.state.wi.us>.

- To find out who your **federal legislators** are, look on the web at <http://www.thomas.loc.gov/> or check the blue section, the government section, of your telephone book.

## **Conclusion**

When deciding what direction to take to resolve your dispute, it is important to think about what outcome you are looking for, and choose the correct forum accordingly. You do not want to file a grievance or complaint, for example, with an agency that does not have the capacity to render your desired outcome. In addition, being aware of the time limits on filing a complaint, grievance or taking other action to resolve the issue can help you to determine the best course of action.

# PEER ADVOCACY

## Peer Advocacy Action Plan

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

**Problem:**

**How do we want the situation resolved?**

*Go to and complete the "Information Gathering" Worksheet prior to completing this action plan.*

**I/we will call/meet with/write to \_\_\_\_\_**

**by the following date: \_\_\_\_\_.**

**If this person doesn't resolve the situation by the following date \_\_\_\_\_,**

**then I/we will call/meet with/write to \_\_\_\_\_.**

**Documentation that I/we will need:**

**Other people who can help us:**

# PEER ADVOCACY

**What I/we expect the other side to do:**

**Strategies for what's next:**

**Debriefing: who will I call or how will I take care of myself following this encounter?**

**What steps do I need to take to get information about this encounter to the person for whom/with whom I am advocating?**

**1.**

**2.**

**3.**

**I sent/called the person I am advocating for/with about this information on the**

**following date: \_\_\_\_\_ . Comments:**

# PEER ADVOCACY

## Information Gathering Worksheet

Person's Name: \_\_\_\_\_

Peer Advocate's Name (if applicable): \_\_\_\_\_

Date of Incident: \_\_\_\_\_

Summary of the Facts:

What is the person's advocacy goal? (could have more than one)

What have you agreed to do for/with the person?

# PEER ADVOCACY

*Keep in mind that there are many ways to gather information. Are there resources that you might need to review before proceeding? Described below are several ideas to consider as you gather needed information. Don't forget the human resources, too, such as interviews with relevant witnesses and others about a particular situation.*

**What additional information might I need regarding this situation?**

**How can I gather this information?**

**What legal rights might be involved in the situation? Think about:**

- Wisconsin Statutory rights – see Wisconsin's Statutes
- Wisconsin Administrative Regulations – See Wisconsin's Administrative Code
- Federal laws and administrative regulations
- City/County Ordinances – available at your local library. (Many landlord/tenant requirements are found in ordinances.)
- Other: \_\_\_\_\_

**What legal rights, if any, might have been violated in the situation? (write down the statute/administrative code reference number and a brief description of the right violated)**



# PEER ADVOCACY

What **formal** dispute resolution procedures might be available?

- Grievance procedure within the agency/program
- Grievance procedure run by a county department of human services
- Grievance procedure for state institutions
- Request a fair hearing (for federal entitlements, such as Social Security, Medicaid or Medical Assistance, etc.)
- Complaint with a government oversight agency (such as the Bureau of Quality Assurance, the Department of Agriculture (consumer complaints, etc.)
- Mediation project within your community
- State Courts
- Other: \_\_\_\_\_

What **informal** problem-solving options might be available? Be specific.

Based on the information gathered about the situation/problem, what different advocacy strategies have you and/or the peer advocate chosen to try to achieve the advocacy goal?

# PEER ADVOCACY

**What are the barriers to achieving this goal?**

**Who are the key decision-makers in resolving the situation/problem?**

**Any additional information/thoughts that would be helpful to resolve this person's situation/problem?**

# PEER ADVOCACY

## Telephone Log

### Outgoing Phone Log

Date:

Person called:

Telephone Number:

Referred by:

Was call answered?

Left message?

Person spoken with:

Title of person you spoke with:

Fax number:

Summary of conversation:

Action suggested:

Action agreed upon?

Deadline:

### Incoming Phone Log

Date:

Person calling:

Telephone Number:

Title of person you spoke with:

Fax number:

Summary of conversation:

Action suggested:

Action agreed upon?

Deadline:

Copy to person advocating for/with: \_\_\_\_\_ (date).

# PEER ADVOCACY

## Peer Advocate's Contact List

Name & Organization	Telephone & Fax Numbers	Email

# TOOLBOX

## Scenarios to Practice Self- and Peer Advocacy Skills

Effective self-advocacy or peer advocacy requires building and practicing skills to help you feel comfortable and confident in reaching identified advocacy goals. This section provides you with opportunities to practice applying some of the skills that you have learned to some real-life scenarios.

Below are several brief vignettes of common complaints. The first four scenarios include a summary of different actions one could take to resolve the issue. Please be aware that more formal actions, such as filing a complaint or a grievance, do not guarantee you will achieve your desired outcome. For example, in Scenario 1, Jacob may decide to file a complaint with the Department of Regulation and Licensing with the desire to have the psychiatrist's license taken away; however, the Medical Examining Board may decide instead to issue a written warning to the psychiatrist.

### Note to Peer Advocates:

The strategies employed to assist an individual in the scenarios described below might differ in a peer advocacy role. Therefore, it will be most useful to understand those differences by first reviewing the scenarios from a self-advocate's perspective. Write down your thoughts and responses. Then, go through the scenarios again and review each situation and develop responses from a peer advocate's perspective. Go back through and compare how the strategies and/or information vary between being a self-advocate and a peer advocate.

### Scenario 1: Confidentiality

Jacob is looking for information on what action, if any, he could take against his previous psychiatrist whom he had seen as an adult, but who shared confidential information about him with his parents and his wife without obtaining his written consent. He was not able to file a grievance under the Patient Rights Grievance procedure because the incidents had occurred several years ago.

*Pretend you are Jacob*

*Think about:*

- What additional information do you need?
- Where can you get more information?
- What outcome(s) do you want to achieve?
- What rules govern this situation?
- Who are some of the key decision-makers?
- What strategies could you use to achieve the desired outcome(s)?
- What barriers might you encounter/have to overcome?

*Possible Actions:*

- Jacob could write a letter to the psychiatrist.
- Jacob could contact the Medical Examining Board in the Wisconsin Department of Regulation and Licensing (DORL) which would be able to investigate the psychiatrist's breach of confidentiality which is in direct violation of the state mandated Administrative Code all psychiatrists must follow as licensed practitioners.
- Jacob could also contact either the State Medical Society or the Wisconsin Psychiatric Association. These professional organizations might be able to assist him in confronting the doctor in an informal meeting, or they might write a letter reprimanding the psychiatrist for not respecting a patient's right to confidentiality that is a violation of the professional code of ethics.
- If the psychiatrist is an employee of a clinic or hospital, Jacob could file a complaint with the Bureau of Quality Assurance in the Department of Health and Family Services which has the authority to review confidentiality practices at the clinic or hospital.
- Jacob could contact a lawyer to discuss filing a lawsuit against the psychiatrist for violating his right to confidentiality.

*What else might Jacob try to do in this situation?*

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

### **Scenario 2: Insulting, Disrespectful Comments from Therapist**

Martha believes that the social worker/therapist that she and her daughters were seeing in family therapy made negative, judgmental comments about her and her daughters during the sessions. Instead of working in a supportive, therapeutic way with the family, Martha felt that the therapist was “blaming the victims” who had sought help from her.

*Pretend you are Martha*

*Think about:*

- What additional information do you need?
- Where can you get more information?
- What outcome(s) do you want to achieve?
- What rules govern this situation?
- Who are some of the key decision-makers?
- What strategies could you use to achieve the desired outcome(s)?
- What barriers might you encounter/have to overcome?

*Possible Actions:*

- Martha could decide that meeting with the therapist and discussing her concerns about the therapist’s behavior might be useful.
- Martha could file a patient rights grievance regarding these comments, as a violation of her right to be treated with dignity and respect.

- If the therapist failed to address Martha's grievance she could contact the Grievance Examiner in the Division of Supportive Living of the Wisconsin Department of Health and Family Services who monitors any problems or complaints that can not be resolved because a program's grievance procedure is deficient.
- The Wisconsin Department of Regulation and Licensing could be called to determine if the therapist involved has violated a provision of the Social Work Administrative Code.
- Martha could also call the Wisconsin Chapter of the National Association of Social Workers to file a complaint, or to see if someone could facilitate an informal meeting to resolve the issue.
- If the incident took place in a certified mental health clinic, Martha could contact the Bureau of Quality Assurance to file a complaint against the facility for not following the state mandated grievance procedure or for violating her right to be treated with respect and dignity.

*What else might Martha try to do in this situation?*

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

### **Scenario 3: Landlord/Tenant conflict**

Angela has concerns about the fact that the windows in her first floor apartment don't lock. She didn't notice that the windows didn't lock when she viewed the apartment before signing her one-year lease. She recently talked with her landlord and he promised that her windows would be replaced. Three months have gone by, and still the windows haven't been replaced.



*Pretend you are working with/for Angela as a peer advocate*

*Think about:*

- What additional information do you need?
- Where can you get more information?
- What outcome(s) does Angela want to achieve?
- What rules/ordinances/laws govern this situation?
- Who are some of the key decision-makers?
- What strategies have you and Angela agreed you could use to achieve the desired outcome(s)?
- What barriers might you encounter/have to overcome?

*Possible Actions:*

- Angela could set up a meeting with her landlord, you as the peer advocate, and herself to talk over her concerns.
- You and/or Angela could write a letter to the landlord.
- Angela and/or you could file a complaint with the housing authority and copy the landlord.

*What else might you/Angela try to do in this situation?*

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

#### **Scenario 4: Sexual abuse**

Karen is an incest survivor who was in therapy with a psychologist who told her that he was attracted to her. He told Karen that he needed to “bring that out in the open so that they could move on from there”. Karen got involved with support groups and read books on the subject of sexual abuse. As time passed, she realized how inappropriate it was for her therapist to tell her he was attracted to her. Karen would like to file a complaint even if no action is taken against the psychologist so that at least there is a record for others who may experience the same thing with him.

*Pretend you are Karen*

*Think about:*

- What additional information do you need?
- Where can you get more information?
- What outcome(s) do you want to achieve?
- What rules govern this situation?
- Who are some of the key decision-makers?
- What strategies could you use to achieve the desired outcome(s)?
- What barriers might you encounter/have to overcome?

*Possible Actions:*

- Given Karen’s desire to have a record of her complaint on file, she should contact the Wisconsin Department of Regulation and Licensing, which licenses psychologists.
- If Karen decided to pursue action against her psychologist within 45 days of the incident, she could file a grievance with the agency or business where the psychologist is employed.
- Karen could also contact the Wisconsin Psychological Association to file a formal complaint against her former psychologist for an ethics violation.
- If the incident took place in a state mental health certified clinic, Karen has the option to contact the Bureau of Quality Assurance in the Wisconsin Department of Health and Family Services to file a complaint.

*Karen has stated the outcome she wants to achieve. If she hadn't wanted to file a complaint, what other self-advocacy strategies might Karen try to do in this situation?*

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

### **Scenario 5: Medications**

John talks with you about helping him resolve some concerns he has about his medications. He feels like he's not being listened to. And he wants your help as a peer advocate. John, a CSP client, has been put on a new medication by a psychiatrist, and has been experiencing blurred vision for the last several days. John believes that there is something wrong with his vision and that he may be losing his eyesight. John talks with his physician about his vision on several occasions and is told that his vision is fine. John continues to experience blurred vision and is very concerned about it. When he went to see the psychiatrist about the medication and his vision, the psychiatrist was rushed and did not have time to discuss John's concerns. He doesn't know what to do and hope that you, as the peer advocate, can help him out.

*Pretend you are John's peer advocate*

*Think about:*

- What additional information do you need?
- Where can you get more information?
- What outcome(s) does John want to achieve?
- What rules/ordinances/laws govern this situation?
- Who are some of the key decision-makers?
- What strategies could you use to achieve the desired outcome(s)?
- What barriers might you encounter/have to overcome?

*List Possible Actions:*

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

### **Scenario 6: Overwhelmed**

Mahalia has been in the hospital for the last two weeks. She was living in a shelter prior to her hospitalization because she lost her apartment due to not being able to pay her rent. Mahalia's immediate plans are to stay with her sister upon discharge, but she can't stay with her long. She needs a longer-term housing solution. Mahalia would like assistance in finding housing and also would like to receive a referral to an outpatient AODA program, information on employment opportunities and emergency income assistance. She feels overwhelmed with all of the issues that she feels need to be addressed. She doesn't know where to begin or where to go. She asks you to assist her as a peer advocate.

*Pretend you are Mahalia's peer advocate*

*Think about:*

- What additional information do you need?
- Where can you get more information?
- What outcome(s) does Mahalia want to achieve?
- What rules govern this situation?
- Who are some of the key decision-makers?
- What strategies could you use to achieve the desired outcome(s)?
- What barriers might you encounter/have to overcome?

*List Possible Actions:*

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

### **Scenario 7: Gaining Independence**

Irma has had an agency-based payee for the last three years. During this time, the agency staff that Irma had started working with left the agency, so she's been working with a new staff person for about nine months. Irma wants to be more actively involved in the budgeting of her finances and has told the staff person about her desire to move to a different apartment. The staff person/payee states that Irma's apartment is fine and that there is no need for her to move. The payee also states that Irma doesn't need to be more involved with her own financial concerns, since it's the payee's job. What strategies might Irma and you try in this situation?

*Pretend you are Irma's peer advocate*

*Think about:*

- What additional information do you need?
- Where can you get more information?
- What outcome(s) does Irma want to achieve?
- What rules govern this situation?
- Who are some of the key decision-makers?
- What strategies could you use to achieve the desired outcome(s)?
- What barriers might you encounter/have to overcome?

*List Possible Actions:*

- \_\_\_\_\_
- \_\_\_\_\_

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

### **Scenario 8: A Friend**

Jessie is 17 years old. She was admitted to a Child Caring Institution six weeks ago under a court order as a child in need of supervision. A teacher at the Institution called you because Jessie continually comes to class wearing outdated, ill-fitting clothing. Jessie's self-image was poor from the start and the teacher believes that the clothing has made matters worse. The only person Jessie says she cares about is you.

*Pretend you are Jessie's friend who has been contacted by the teacher*

*Think about:*

- As a Peer Advocate, who is the person for whom you are advocating?
- What additional information do you need?
- Where can you get more information?
- What outcome(s) do you want to achieve?
- What outcome(s) does Jessie want to achieve?
- What outcome(s) does the teacher want to achieve?
- What rules govern this situation?
- Who are some of the key decision-makers?
- What strategies could you use to achieve the desired outcome(s)?
- What barriers might you encounter/have to overcome?

*List Possible Actions:*

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

## **Rights for Consumers of Disability Related Services**

When you receive any type of service for mental health, alcoholism, drug abuse, or a developmental disability you have the following rights under Wisconsin law (section 51.61, Wis. Stats. and HFS 94, Wis. Admin. Code):

### **TREATMENT AND RELATED RIGHTS**

- You must be provided *prompt and adequate treatment* appropriate for you, subject to certain funding limitations.
- You must be in the *least restrictive setting* necessary, subject to certain funding limitations.
- You must be allowed to *participate in the planning* of your treatment and care.
- Staff must *inform you* of your treatment and care, including alternatives and possible side effects of medications.
- *No treatment or medication* may be given to you *without your informed consent*, unless it is needed in an emergency to prevent serious physical harm to you or others, or a court orders it. [If you have a guardian, however, the *guardian* will make those decisions for you.]
- You must not be given *unnecessary or excessive medication*.

### **RECORD PRIVACY AND ACCESS**

- Staff must keep your treatment information *private* (confidential).
- Staff *cannot release your records* without your consent, unless the law specifically allows them to do so.
- You can ask to *see your records*. Staff must show you any records about your physical health or medications. Staff may limit how much you can see of the rest of your records while you are in treatment. They have to give you reasons for any such limits. You can challenge those reasons in the grievance process. After discharge, you can see your entire record if you ask to do so.

- If you believe something in your records is *wrong*, you can *challenge its accuracy, completeness, timeliness, or relevance*. If staff will not change the part of your record you have challenged, you can put your own version in your record.

## COMMUNICATION RIGHTS

- You may use the *telephone* daily. \*
- You may see (or refuse to see) *visitors* daily. \*
- You may *send and receive private mail*. [Staff cannot read your mail unless you or your guardian asks them to do so. Staff may check your mail for contraband. They can only do so if you are watching.]
- You can *call or write to public officials* or your *lawyer advocate*.

## PERSONAL RIGHTS

- Everyone must treat you with *dignity and respect*, free of any verbal or physical abuse.
- Staff must make *fair and reasonable decisions* about your treatment and care.
- You cannot be *filmed or taped* unless you agree to it.
- You can *make your own decisions* about things like getting married, voting, and writing a will.
- *No one may treat you differently* because of your race, national origin, sex, age, religion, disability, or sexual orientation.
- You can decide whether you want to participate in *religious services*.

## FINANCIAL RIGHTS

- Staff *cannot make you work* except to clean up after yourself in your room or in common areas. If you agree to do other work, you must be *paid*.



- You must be *informed of any costs* of your care and treatment that you or your relatives may have to pay.
- You may *use your own money* as you choose within some limits.

## **RIGHTS RELEVANT TO IN-PATIENT TREATMENT FACILITIES**

- Staff may *restrain* you or place you in a *locked room* (seclusion) only in an emergency if it is necessary to prevent physical harm to you or to others or when part of a treatment program.
- You cannot be subject to any *drastic treatment measures, electro-convulsive treatment, or experimental research* without your *informed consent*.
- The environment in the facility must be *psychologically and physically humane*.
- Your surroundings must be kept *safe, clean, and comfortable*.
- You must be given the chance to *exercise and go outside for fresh air* regularly and frequently.
- You must have *privacy* when you are in the *bathroom*. \*
- You can *wear your own clothing*. \*
- Staff must arrange for you to have your *clothes washed*. \*
- You can keep and use your own *belongings*. \*
- You must be given a reasonable amount of *secure storage space*. \*

## **DENIALS OR LIMITATIONS OF RIGHTS**

*Staff may limit or deny some of your rights for treatment or safety reasons.* [See the rights with a \* after them.] Staff will decide if this is necessary. However, your wishes and the wishes of your guardian should be considered. If staff limit or deny any of your rights, they must give you reasons for doing so. You may ask to talk with them about it. You may also file a grievance about any limits of your rights.

## **GRIEVANCE RESOLUTION PROCESS**

- If you feel your rights have been violated, you may file a grievance.
- You cannot be threatened or penalized in any way for filing grievances.
- The service provider or facility must inform you of your rights and how to use the grievance process; the program's Client Rights Specialist must be available to help you with your grievance.
- You may, at the end of the grievance process, or any time during it, choose to take the matter to court.

## **WHAT INFORMED CONSENT IS**

1. The individual must be given specific, complete, and accurate information and the time to study the information or to seek additional information.
2. Information must be given about:
  - a. Benefits of proposed treatment and services.
  - b. The way treatment is to be administered and the services are to be provided.
  - c. Expected treatment side effects or risks of side effects which are a reasonable possibility, including side effects or risks of side effects from medications.
  - d. Alternative treatment modes and services.
  - e. Probable consequences of not receiving the proposed treatment and services.
  - f. Time period for which the consent is effective, which shall be no longer than 15 months from the time the consent is given.
  - g. The right to withdraw the consent at any time, in writing.
3. The individual must be competent, i.e., substantially able to understand all significant information which has been explained in easily understandable language.

4. No retaliation may be threatened or carried out for refusing to give consent or for withdrawing it.
5. The individual must be given a copy of the consent document, upon request.

HSS 94.03, Wis. Administrative Code.

## **Legal Basics**

(Excerpts from Arbetman, Lee P., M.Ed., J.D. and O'Brien, Edward L., J.D. Street Law: A Course in Practical Law, 6th ed., West Educational Publishing Co. © 1999. Reprinted with permission.)

### **What is Law?**

The question “what is law?” has troubled people for many years. An entire field of study known as jurisprudence (the study of law and legal philosophy) is devoted to answering this question. Many definitions of law exist. For our purposes, however, law can be defined as the rules and regulations made and enforced by government that regulate the conduct the people within a society.

As a child, you learned about rules first at home and later at school. At home, adults made and enforced rules concerning issues like chores and bedtimes. Rules made and enforced by the government are called laws. The government makes laws that affect almost every aspect of daily life.

One thing is certain: Every society that has ever existed has recognized the need for laws. These laws may have been unwritten, but even preindustrial societies had rules to regulate people’s conduct. Without laws, there would be confusion and disorder. This does not mean that all laws are fair or even good, but imagine how people might take advantage of one another without a set of rules.

A democratic system of government cannot function effectively unless its laws are respected. In other words, society must be based on the “rule of law.” This means that all members of society – average citizens and government officials such as senators, judges and even the president – are required to support the legal system and obey its laws. No one is above the law.

## **Human Rights**

Human rights are the rights all people have just because they are human beings. We violate human rights when we treat people as though they were not human beings. To advocate human rights is to demand that the dignity of all people be respected. Both government and private individuals can violate human rights. Human rights apply in people's homes, schools, and workplaces. In fact, they apply everywhere. We have our human rights from the moment we are born until the moment we die.

## **Balancing Rights with Responsibilities**

The emphasis on rights in the United States has led some people to criticize America for being too concerned with citizens' rights, while neglecting their responsibilities. Some say that "with every right there goes a responsibility" and urge citizens to act more responsibly toward one another, their families, and their communities.

Critics cite America's emphasis on individual rights as evidence of "radical individualism," which has resulted self-centered focus and the loss of a sense of community. While individual rights are important, they must be matched by social responsibilities, these critics say. For example, if people wish to be tried by juries of their peers, they must be willing to serve on such juries. If they want to be governed by elected officials who respond to their values and needs, they must not only vote, but also get involved in other ways: attend election forums, work for candidates, and run for positions on school boards, county councils, and community associations.

Americans justifiably have great respect for laws extending rights to citizens, including women, minorities, and persons with disabilities who were previously excluded from full participation in society. Many laws, however, also require citizens to act responsibly. Parents must provide their children adequate food, shelter, and clothing; drivers must obey traffic laws; and all workers must pay taxes.

Rights also imply responsibilities. For example, it is the responsibility of everyone not to violate the human rights of others. This means that people need to understand what human rights are, and then treat others with the dignity every human being deserves.

Other critics of the emphasis on rights in America point out that just "because you have a legal right to do (or not to do) something does not mean it is the right thing to do." For example, the First Amendment guarantee of freedom of speech sometimes gives people the right to say hateful and abusive things to others, but it does not make such speech "right." Summarizing the situation, one critic said, "Rights do not automatically make for rightness."

## **Kinds of Laws**

Laws fall into two major groups: criminal and civil. Criminal laws regulate public conduct and set out duties owed to society. A criminal case is a legal action brought by the government against a person charged with committing a crime. Criminal laws have penalties, and offenders are imprisoned, fined, placed under supervision, or punished in some other way. Criminal offenses are divided into felonies and misdemeanors. The penalty for a felony is a term of more than one year in prison. For a misdemeanor the penalty is a prison term of one year or less. Felonies are more serious crimes such as murder or robbery. Misdemeanors are less serious crimes such as simple assault or minor theft.

Civil laws regulate relations between individuals or groups of individuals. A civil action (lawsuit) can be brought by a person who feels wronged or injured by another person. Courts may award the injured person money for the loss, or they may order the person who committed the wrong to make amends in some other way. An example of a civil action is a lawsuit for recovery of damages suffered in an automobile accident. Civil laws regulate many everyday situations such as marriage, divorce, contracts, real estate, insurance, consumer protection, and negligence.

Sometimes behavior can violate both civil and criminal laws and can result in two court cases. A criminal case is brought by the government against a defendant, the person accused of committing the crime. A civil case is brought by the plaintiff (the person or company harmed) against the defendant (the alleged wrongdoer).

## **Our Constitutional Framework**

The U.S. Constitution is the highest law of the land. Drafted over two hundred years ago, this remarkable document is the longest-lasting written constitution in the world. It sets forth the basic framework of our government. It also lists the government's powers, the limits on those powers, and the people's freedoms that cannot be taken away by the government.

Integral to the Constitution is the principle of limited government. Before the U.S. Constitution was written and ratified, the individual states were reluctant to give up power to the national government. After all, a revolution had just been fought against the government of the king of England to preserve individual liberty and the freedom to govern without interference. As a result, the Constitution created a national government of limited powers, with authority to pass laws only in the areas specifically listed in Article I of the Constitution. Those who criticize the

power and reach of the federal government today often cite these historic reasons for limiting its power.

Perhaps nothing is more important in the Constitution than the division of lawmaking power among the three branches of government: the executive (the president and federal agencies), the legislative (Congress), and the judiciary (the courts). This division is known as the separation of powers.

## **Lawmaking**

The laws that U.S. citizens are expected to obey come from many sources. Constitutions set forth laws and also establish the structure of government. Legislatures, of course, make laws. In some situations, voters can act directly as lawmakers. Administrative agencies make many laws. Finally, laws are sometimes made by courts when they decide appeals.

## **Legislatures**

As you have seen, the U.S. Constitution divides the power to make laws between the federal government and the state governments. At both the federal and state levels, legislatures are the primary lawmaking bodies. The U.S. Congress – the federal legislature -- is made up of two houses: the Senate (100 members, two from each state) and the House of Representatives (435 members, each state represented according to the size of its population). The U.S. Constitution gives Congress the power to pass laws that are binding on the people in every state. States have the power to pass laws that apply within their boundaries.

The lawmaking authority of Congress is exercised through the passage of laws known as federal statutes. When Congress passes a federal statute, it affects people in every state. Federal statutes deal with issues of national impact, such as environmental quality, national defense, labor relations, veterans affairs, public health, civil rights, economic development, postal services, and federal taxes.

The states' lawmaking powers are vested in their legislatures, which pass laws called state statutes. Except for Nebraska, every state has a two-house legislature. Most states' legislatures meet on an annual basis; in a few states, the legislatures meet every two years. States pass laws with statewide impact in such areas as education, traffic, state taxes (including how they will be spent), marriage and divorce, most criminal laws, and the powers and duties of state government officials. Although tribal governments of Native Americans vary a great deal, many place legislative authority – and sometimes executive authority as well – in a body known as the tribal council.

In addition to the U.S. Congress and state legislatures, cities, towns, and counties have lawmaking bodies. These are called county or city councils, boards of aldermen, local boards of education, or other names. Local governments pass laws known as ordinances or regulations. Legislative issues that concern local governments include land use, parking, schools, and regulation of local business. Laws passed by local governments apply only to a county, city, or town. The local lawmaking body has been given the power to enact ordinances by the state. Many of the laws most important to us in our daily lives are passed by local governments.

Legislatures and other lawmaking bodies try to respond to the needs of the citizens they represent by introducing legislation in the form of bills. Bills are used to enact new laws or amend or repeal old laws. Ideas for bills can come from legislators, the executive branch, individual citizens, or citizens' groups. The courts also sometimes identify problems that legislatures need to address. If a bill is passed by the legislature and not vetoed by the executive, it becomes law.

### **Agencies**

Many of the laws that affect you are made by government agencies. Legislative bodies usually deal with problems only in a general way. They authorize administrative agencies to develop rules and regulations to make laws more specific. These regulations influence almost every aspect of our daily lives and have the force of law.

The administrative agencies with the greatest impact on your daily life are those at the state and local levels. For example, a zoning commission and other local agencies where you live may have developed a plan that determines what kind of buildings can be located in specific parts of your town. A local agency may hold public hearings to determine whether a new restaurant can serve alcohol and feature live music.

### **Courts**

Law is also made by courts. [T]hink about courtroom scenes you have watched on television. These courts were conducting trials. The person who loses a trial can sometimes ask a higher court to review and change the result of the trial. These higher courts are called appeals or appellate courts. When an appeals court decides a case, it issues a written opinion that sets a precedent for similar cases in the future. All lower courts in the place where the precedent was issued must follow it. For example, if a state's supreme court ruled that the state's constitution required that school funding be equalized throughout the state – richer and poor school districts

would each have to spend the same amount per student – then all lower courts in that state would have to follow that precedent.

## **Methods for Solving Disputes**

Among the most common methods for solving disputes out of court are negotiation, arbitration, and mediation.

*Negotiation* is the process by which people involved in a dispute talk to each other about their problem and try to reach a solution acceptable to all. This informal means of settling disputes should be familiar to about everyone. You negotiate when you have a disagreement with your parents, your friends, or your teacher, and you work out an agreement. The informality of negotiation makes it ideal for many types of problems. Sometimes people hire attorneys to negotiate for them. For example, people involved in auto accidents sometimes hire attorneys to negotiate with the insurance company over payments for injuries or damages to their cars. Even if you use an attorney to negotiate, you must approve any agreement before it becomes final. Attorneys sometimes file a case in court and then attempt to work out a settlement (agreement) before the case goes to trial. A large number of civil cases are settled this way, saving both time and money.

In *arbitration*, both parties to a dispute agree to have another person listen to their arguments and make a decision for them. The arbitrator is like a judge, but the process is less formal than a trial. Arbitrators, like judges, have the authority to make the final decision, and the parties must follow it (except in what is called nonbinding arbitration). Arbitration is common in contract and labor-management disputes and in some international law cases. Agreements between labor unions and employers include arbitration clauses. This means that the union and the employer agree in advance to submit certain disputes to arbitration and to be bound by the arbitrator's decision.

*Mediation* is another method of alternative dispute resolution. It takes place when a third person helps the disputing parties talk about their problem and settle their differences. Unlike arbitrators, mediators do not impose a decision on the parties. The agreement is the result of the parties' willingness to listen carefully to each other and come up with a reasonable settlement.. The mediator acts as a neutral third party by listening carefully to both sides and trying to help the parties understand each other's positions and find ways to resolve the dispute. Mediation is voluntary; therefore, the mediator has no power to impose a decision on the parties. Mediation allows the disputants to air their feelings, avoids placing blame, and concentrates on the future relationship between the parties.



## **Law Books – The Basics**

This piece describes the major sources of statutes and administrative policy. All the following works are available at the University of Wisconsin and Marquette University Law Libraries and the State Law Library. Most of the state and local volumes also are available at the Legislative Reference Bureau Library in Madison, your local public library, and county law libraries. State and federal laws and regulations and many court decisions also are available through the Internet. Sites are listed at the end of this section.

### **Federal**

#### *United States Code:*

This work contains a consolidation and codification of all the general and permanent laws of the United States. It is arranged by title, e.g. Agriculture, Food and Drugs, Labor, Public Health and Welfare. There is an index of acts cited by popular names, as well as a general index.

#### *United States Code Annotated:*

Like the U. S. Code, this work contains all the general and permanent laws of the United States. In addition, the annotated edition adds the interpretation which the courts have placed upon these laws. Historical data are also given, showing the antecedents of the particular acts or sections, with comments on the sources and the character of the changes. It is arranged by title; also there's a general index and a popular name (of the statute) index.

#### *Code of Federal Regulations:*

The Code of Federal Regulations (CFR) is a codification of the general and permanent rules published in the Federal Register by the Executive departments and agencies of the Federal Government. The Code is divided into fifty titles (like the U. S. Code and the U. S. Code Annotated) which represent the broad areas subject to federal regulations. Each title is divided into chapters which usually bear the name of the issuing agency. Each chapter is further subdivided into parts covering specific regulatory areas. Each volume of the Code is revised at least once each calendar year.

The CFR is kept up to date by the individual issues of the Federal Register. These two publications must be used together to determine the latest version of any given rule. To determine whether there have been any amendments since the revision date of the CFR volume, the following two lists must be consulted: (1) cumulative "List of CFR Sections Affected,"

issued monthly, and (2) “Cumulative List of Parts Affected,” appearing daily in the Federal Register. These two lists will refer the user to the Federal Register pages where he or she may find the latest amendment of any given rule. The subject index to the Code, which is revised annually and supplemented periodically, is contained in a separate volume entitled “General Index.”

## **State**

### *Wisconsin Statutes:*

This work contains all general statutes in force in Wisconsin. A new edition is prepared after the end of each general session of the legislature. You can generally find what you are looking for by using the table of contents in the front of the book or the index in the back.

### *Wisconsin Statutes Annotated:*

This work is the state counterpart of the U. S. Code Annotated. Wisconsin Statutes Annotated (W.S.A.) contains the general and permanent laws of Wisconsin along with the court cases interpreting them. The Titles, Chapters, and Sections conform to the official text, numbering and arrangement of the Wisconsin Statutes. In addition to the Notes of Decisions covering judicial interpretation and the administrative rulings of the Attorney General, W.S.A. incorporates other annotative materials such as source notes and explanations of legislative amendments, library references, and citations to the Wisconsin Administrative Code. A General Index to the text of the Constitution and the text of the Statutes is published in separate volumes.

### *Wisconsin Administrative Code:*

The Wisconsin Administrative Code contains all rules issued by state administrative agencies. The code is published in loose-leaf volumes and kept current by means of new and replacement pages. The pages are issued monthly, together with notices of hearings on proposed rules, emergency rules, and new rules. This monthly service is called the Wisconsin Administrative Register, and is issued shortly after the 25th of each month. There's a general index in the last volume. Sale of the Code: Department of Administration, Document Sales and Distribution, 202 S. Thornton Avenue, Madison, WI 53702.

## **City/County**

### *City/County Ordinances:*

Check your local public library for the city and/or county ordinances applicable to your locale. You also will find many counties, and some cities and villages, in Wisconsin have their code of ordinances available through their website. For county websites in Wisconsin, type in [http://www.co.\(name of county\).wi.us](http://www.co.(name of county).wi.us).

## **How to Find Statutory Law**

### *Federal Laws*

1. Use index to United States Code or United States Code Annotated
2. Use table of contents
3. Popular Name Table
4. For recently enacted laws which have not yet been incorporated into bound volumes, use United States Code Congressional and Administrative News (U.S. Cong. and Admin. News)

### *Wisconsin Laws*

1. Use index to Wisconsin Statutes or Wisconsin Statutes Annotated
2. Use table of contents
3. Popular Name Table
4. For recently enacted laws which have not yet been incorporated into bound volumes, use Wisconsin Legislative Service

## **How to Find Regulations**

### *Federal Regulations*

1. Use index to Code of Federal Regulations
2. Check titles (they are parallel to U.S.C. titles)
3. Check statute which is authority for the regulations in U.S.C.A.
4. Use index to Federal Register for recently adopted regulations
5. To find if regulation in C.F.R. has been amended, use "List of CFR Sections Affected," which is issued monthly in the Federal Register

### *Wisconsin Regulations*

1. Use index to Wisconsin Administrative Code
2. Check table of contents (it is organized by agency)
3. Check statute which is authority for the regulations in Wis. Stat. Ann.
4. For very recent regulations, check Wisconsin Administrative Register or call agency or revisor of statutes.

### *City/County Regulations*

1. Use index to your city's/county's Code of Ordinances
2. Check table of contents (it is organized usually by title or issue area)

## **Internet Web Sites for Access to Laws, Regulations and Court Decisions**

- **Wisconsin Legislature: Info Bases**  
<http://folio.legis.state.wi.us/>
- **Wisconsin State Bar**  
<http://www.wisbar.org>
- **Wisconsin Revisor of Statutes Bureau**  
<http://www.legis.state.wi.us/rsb/states.htm> or  
<http://www.legis.state.wi.us/rsb/index.htm>
- **Federal Legislation provided by the Library of Congress**  
<http://thomas.loc.gov>
- **Federal Statutes and Regulations**  
[fedlaw.gsa.gov/intro2.htm](http://fedlaw.gsa.gov/intro2.htm)
- **Cornell University Law School's Legal Information Institute**  
<http://www.law.cornell.edu>
- **Legal Resources: FindLaw**  
<http://www.findlaw.com>

## **GLOSSARY**

*The following definitions were retrieved from public documents.*

### **Adult family home (3-4 residents)**

The term “adult family home” is defined as a place that meets the definition for community-based residential facility (CBRF) but serves 3 or 4 adults; must be licensed under HFS 82, Wis. Admin. Code.

### **Advocacy**

Speaking and acting on behalf of oneself or others; pleading a cause.

### **Access**

The extent to which an individual who needs care and services is able to receive them. It is more than having insurance coverage or the ability to pay for services. Access also is determined by the availability of services, acceptability of services, cultural appropriateness, locations, hours of operation, transportation needs and cost.

### **Accreditation**

An official decision made by a recognized organization that a health care plan, network, or other delivery system complies with applicable standards.

### **AODA**

Alcohol or Other Drug Abuse.

### **Autonomy**

Not being controlled by others; independence; being self-directed.

### **BadgerCare**

BadgerCare offers the same health care coverage as Medicaid to low-income families without access to health insurance whose income exceeds the MA guidelines, but is below 185% of the federal poverty level. There is no asset test.

### **Barriers**

An obstacle; something that separates or keeps away.

### **Behavioral healthcare**

A continuum of services for individuals at risk of or experiencing mental, addictive, or other behavioral health disorders or conditions.

**BRC**

Blue Ribbon Commission. Download a copy of the Wisconsin Governor's Blue Ribbon Commission on Mental Health Report at the following web address:

[http://www.dhfs.state.wi.us/MH\\_BCMH/bluerib.htm](http://www.dhfs.state.wi.us/MH_BCMH/bluerib.htm)

**BSAS**

Bureau of Substance Abuse Services in the Wisconsin Department of Health and Family Services.

**Centers for Medicaid and Medicare Services (CMS)**

A federal agency formerly known as the Health Care Financing Administration (HCFA), its name recently changed to the Centers for Medicaid and Medicare Services. It oversees the federal Medicaid and Medicare programs.

**Chronic**

Lasting for a long period of time; continuing.

**Client Rights Specialist**

Mental health, developmental disability, and substance abuse programs must have a Client Rights Specialist (CRS) to work with consumers who file grievances. It is the job of the CRS to meet with the consumer to assist him/her with filing a grievance. The CRS must investigate the grievance by meeting with the consumer and any parties involved in the grieved incident, reviewing records and other materials and taking other needed actions. A Client's Rights Specialist cannot have any involvement in the incident which the client is complaining about.

**Community-Based Residential Facilities (CBRF's)**

With some exceptions, a CBRF is a place where 5 or more adults, who are not related to the operator, reside and in which care, treatment or services above the level of room and board but not including ongoing nursing care are provided as a primary function of the facility. Typically, ongoing nursing care would have to be provided from an outside source not connected to the facility operator. CBRF's are licensed under HFS 83, Wis. Admin. Code.

**Community Options Program (COP)**

The Community Options Program (COP) is a state-funded, county-operated program, available in all Wisconsin counties, which makes available long term supports, services, and funds to eligible individuals. COP is designed to divert or relocate individuals of target groups from nursing homes or other institutions. COP helps eligible people get the long-term supports they need to live in the community instead of an institution. The eligible target groups include people with permanent or chronic disabilities in need of long term care or support who are elderly, have physical disabilities, developmental disabilities, chronic mental illness and/or chemical dependencies.

**Community Support Program (CSP)**

A Community Support Program or CSP is a coordinated care and treatment program which provides a range of treatment, rehabilitation, and support services through an identified treatment program and staff to ensure ongoing therapeutic involvement, individualized treatment, rehabilitation, and support services in the community for persons with severe and persistent mental illness.

**Complaint**

A complaint is filed with a governmental agency or professional organization to resolve a dispute or a violation of state law.

**Complainant**

A complainant is the individual who is filing the complaint. The complainant usually is the user of the services; however, others such as family members, friends, or other professionals may file a complaint on behalf of someone else.

**Conflict Resolution**

Strategies and efforts to address and resolve disputes; might also involve negotiation and/or mediation.

**Consumer**

Any individual who does, could or has received health care or services. Includes other more specialized terms, such as beneficiary, client, customer, eligible member, recipient, or patient. Also, consumer might refer to someone who has been diagnosed with a mental illness and has received treatment in some manner. (See “survivor”)

**County Human Services**

The county departments of human services are responsible for developing and implementing programs and services for children and adults with mental illness, substance abuse and developmental disabilities, as well as providing child welfare and other social services in Wisconsin.

**DD**

Usually refers to developmental disability.

**Deductible**

The amount an individual must pay for health care expenses before insurance (or a self-insured company) begins to pay its contract share. Often insurance plans are based on yearly deductible amounts.

**Department of Health and Family Services (DHFS)**

Wisconsin’s Department of Health and Family Services, located on the web at <http://www.dhfs.state.wi.us..>

**Disability Determination Bureau (DDB), Wisconsin Department of Health and Family Services**

The state bureau that determines whether an individual has an illness, injury or condition that meets the legal definition of disability in the Social Security Act. The DDB reviews cases for initial entitlement and medical Continuing Disability Reviews. Individuals determined to have a disability may be eligible for assistance through programs such as SSI, SSDI, Medical Assistance and the Medicaid Purchase Plan. For more information go to <http://www.dhfs.state.wi.us/ddb/index.htm>.

**Division of Vocational Rehabilitation (DVR), Wisconsin Department of Workforce Development**

Located within the Wisconsin Department of Workforce Development, DVR is the agency that administers vocational services created by the Rehabilitation Act of 1973. For information about DVR, go to their web site located at <http://www.dwd.state.wi.us/dvr/>.

**Entitlements**

Any type of benefits guaranteed to be provided to a certain group or groups by the government.

**Fee for Service**

A type of health care plan where health care providers are paid for individual medical services rendered.

**GEP**

Grassroots Empowerment Project, a statewide mental health consumer organization in Wisconsin.

**Grievance Procedure**

A special procedure set up by the State of Wisconsin to resolve patient rights disputes for any individual receiving mental health, drug/alcohol, or developmental disability services. A grievance is filed with a Clients Rights Specialist at the program or facility involved with the dispute.

**Health Care Financing Administration (HCFA)**

A federal agency formerly known as HCFA, its name recently changed to the Centers for Medicaid and Medicare Services. It oversees the federal Medicaid and Medicare programs.

**Health Insurance Portability and Accountability Act (HIPAA)**

A law that requires coverage of pre-existing conditions for people who change employer group health plans.

**Health Insurance Risk Sharing Plan (HIRSP) of Wisconsin**

A plan to provide major medical and Medicare supplement health insurance to Wisconsin residents with mental or physical disabilities. The contents of the insurance plan are established by state statute and administrative rules. All plan participants must pay a premium, annual deductible and some co-payments.



**Health Maintenance Organization (HMO)**

A health plan that also is involved in how your health care is delivered. Managed care refers to health plans coordinating your health care with you and the providers that participate in that health plan.

**Hospital**

A building, structure, institution or place that offers inpatient, overnight care on a 24-hour basis, and is devoted primarily to maintaining and operating facilities for diagnosing, treating and providing medical or surgical care to 3 or more unrelated individuals who have a physical or mental illness, disease, injury, a rehabilitative condition, or are pregnant, and which regularly makes available at least clinical laboratory services, diagnostic x-ray services and treatment facilities for surgery, obstetrical care, or other definitive medical treatment.

**Insurance Claim**

A request by an individual (or her or his provider) to an individual's insurance company for the insurance company to pay for services obtained from a health care professional.

**Legal Advocacy**

Using attorneys and the legal or administrative systems to establish or protect legal rights.

**MCO**

Managed Care Organization.

**Mediation**

A process for resolving disputes and conflicts in which a neutral third party acts as a moderator for the process.

**Medicaid**

A program, also known as Medical Assistance, MA, Title XIX, T-19 and the Wisconsin Medical Assistance Program (WMAP) that provides medical assistance for certain individuals and families with low income and resources. It's a joint federal/state program established to pay for medical services for people with disabilities, people 65 years and older, children and their caretakers, and pregnant women who meet the program's financial requirements. The purpose of Wisconsin Medicaid is to provide reimbursement for and assure the availability of appropriate medical care to persons who meet the criteria for Medicaid.

**Medicaid Purchase Plan (MAPP)**

Many people with disabilities want to work but worry that doing so could jeopardize their vital health and long term care coverage. MAPP offers people with disabilities who are working or interested in work the opportunity to buy their Medicaid coverage. Program benefits include the same benefits as those available through Wisconsin Medicaid, the opportunity to earn more without the risk of losing health care coverage, higher asset and income eligibility levels, and increased personal and financial independence.

**Medical Assistance (MA)**

Wisconsin's name for Medicaid.

**Medicare**

The national health insurance program for all Social Security recipients who are either over age 65 or permanently disabled. Individuals receiving Railroad Retirement benefits and people with end-stage renal disease are also eligible for Medicare coverage. Eligibility is not based on financial need. Procedures should not vary significantly from state to state and coverage is similar to that provided by private insurance companies: it pays a portion of medical costs. Often, deductibles and co-insurance (partial payment of initial and subsequent costs) are required of the beneficiary (person receiving medical services). Medicare Part A is Hospital insurance, and Medicare Part B is Supplemental Medical (outpatient) insurance.

**Medicare for Working People with Disabilities**

When SSDI beneficiaries lose their Medicare entitlement because they have worked past their Extended Period of Medicare Coverage (EPMC), it is possible for them to buy Medicare insurance.

**Medicare Supplement Insurance**

Medicare supplement insurance is also known as Medigap insurance. Although Medicare covers many health care costs, you still have to pay Medicare's coinsurance and deductibles. There also are many medical services that Medicare does not cover. A Medigap policy provides reimbursement for some of the out-of-pocket costs that are not covered by Medicare and which are the beneficiary's share of health care costs.

**MH**

Mental Health.

**Negotiation**

Any time two groups with conflicting interests meet to discuss the issues between them, and seek resolution.

**Nursing Home**

With limited exceptions, any place which provides 24-hour services to 3 or more residents who need more than 7 hours per week of nursing care or personal care. This definition overlaps with that of CBRF; the central distinction is that a CBRF cannot provide nursing care as a "primary function" of the facility. The term "nursing home" includes both nursing facilities licensed under HFS 132, Wis. Admin. Code, and facilities for the developmentally disabled licensed under HFS 134, Wis. Admin. Code. A facility must be licensed in order to be certified for Medical Assistance funding as a skilled nursing facility (SNF) or intermediate care facility (ICF).

**Ombudsman**

A person who is appointed to investigate complaints and/or assist an individual in filing a complaint. An ombudsman also assists in settling disputes.

**Peer Advocacy**

Representing the rights and interests of someone other than yourself.

**Psychiatric Social Workers**

Have an M.S.W. (Master of Social Work) or D.S.W. (Doctor of Social Work) degree and supervised experience in helping people adjust. Many offer psychotherapy, but social workers generally do not use psychological tests and are never allowed to prescribe medical treatments. Like counselors, many specialize in marital or family problems. They are often involved in helping people who are recovering from psychological disorders and may be involved in arranging practical solutions to life problems.

**Psychiatrists**

A licensed physician, who earns a medical degree such as the M.D. (Doctor of Medicine) or D.O. (Doctor of Osteopathy), and then undertakes a psychiatric residency during which time they learn to apply medical skills, such as prescribing drugs, to treating psychological disorders. They may practice psychotherapy. Most psychiatrists rely on interviews for diagnostic purposes but may refer clients to psychologists for psychological testing.

**Psychologists**

Have at least a master's degree, and in most states must have a doctoral degree (Ph.D., Ed.D., Psy.D.), to use the label psychologist. They use interviews, behavioral observations, and psychological tests to diagnose psychological disorders and adjustment problems, and use psychotherapy to treat them. Most psychologists have been trained extensively in research methods, neuroanatomy, statistics and various types of therapeutic techniques. They are more likely than other helping professionals to be critically acquainted with psychological theory.

**Psychotropic**

Having an altering affect on perception or behavior.

**Recovery-Oriented System**

A recovery-oriented mental health system promotes rebuilding full, productive lives of individuals despite being diagnosed and/or living with a psychiatric disability.

**Recurring**

Occurring time after time; happening repeatedly.

**Residential Care Apartment Complex (RCAC)**

A place where 5 or more adults reside that consists of independent apartments, each of which has an individual lockable entrance and exit, a kitchen, and individual bathroom, sleeping and living areas, and that provides, to a person who resides there, not more than 28 hours per week of supportive, personal and nursing services.

**Respondent**

The respondent is the individual or agency against whom a complaint is filed.

**Rights and Reality II**

An Action Guide to the Rights of People with Disabilities published in 2001 that provides a comprehensive guide on all the laws, rights, and services affecting adults and children with disabilities in Wisconsin. Includes practical self- and peer advocacy strategies, and citations to applicable statutes, regulations and case law. Spiral manual: 400 pages - \$30 for consumers and families; \$40 for others; CD-ROM version - key word search capability; increase screen image size to 800%; can be run on Windows or Macintosh platforms; print directly from CD-ROM - \$30 for consumers and families; \$40 for others. Contact Wisconsin Coalition for Advocacy at 608-267-0214 / 800-928-8778 (for consumers and their families), or email WCA at [lorip@w-c-a.org](mailto:lorip@w-c-a.org). You may order this resource online at the following web address: <http://www.w-c-a.org/pages/order.html>

**Section 8**

A federal program for subsidizing the housing of individuals who have low income and few resources. The individual or family usually pays no more than 30% of his/her monthly income in rent. In addition to Section 8 subsidies, there are other programs that subsidize housing costs, but most of them follow the 30% rule.

**Self –Advocacy**

Representing and advancing one's own interests.

**Bureau of Community Mental Health, Wisconsin Department of Health & Family Services**

The designated state mental health authority responsible for the direction of public mental health services in Wisconsin with an emphasis on serving adults with severe and persistent mental illnesses and children with severe emotional disturbance. The Bureau carries out its mission through collaboration with counties, providers, consumers, and their families. More information at: [http://www.dhfs.state.wi.us/MH\\_BCMH/index.htm](http://www.dhfs.state.wi.us/MH_BCMH/index.htm)

**Social Security Disability Insurance (SSDI)**

The federal program that provides benefits to disabled individuals who have earned credits under the Social Security system.

**Supplemental Security Income (SSI)**

A federal and state program based on need that provides benefits for aged, disabled or blind individuals who are low-income.

**Survivor**

Used in this document, someone who has been diagnosed with a mental illness and has been treated for their diagnosed illness in some manner and endured and come through those experiences. (See “consumer”)

**Systems Advocacy**

Influencing social, political, and economic systems to bring about change for groups of people.

**TA**

Technical Assistance.

**TANF (Temporary Assistance to Needy Families)**

TANF is overseen by the Office of Family Assistance (OFA) which is located within the U.S. Department of Health and Human Services, Administration for Children and Families. It was created by the Welfare Reform Law of 1996. TANF became effective July 1, 1997, and replaced what was then commonly known as welfare: Aid to Families with Dependent Children (AFDC) and the Job Opportunities and Basic Skills Training (JOBS) programs. TANF provides assistance and work opportunities to needy families by granting states the federal funds and flexibility to develop and implement their own welfare programs.

**W-2 (Wisconsin Works)**

The public assistance program, that replaced AFDC, for parents who live with their children. It provides work experience, training education, counseling, childcare, transportation and other assistance to parents so they can find and keep a job. (from *W-2: Your Right to Receive Assistance* published by Legal Action of Wisconsin, Inc.)

## RESOURCES

### *Wisconsin Advocacy Resources*

#### **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: [www.arc.org](http://www.arc.org)

(414) 273-1991

(800) 359-9272

Fax: (414) 273-2357

#### **Brain Injury Association of Wisconsin Inc.**

The Brain Injury Association of Wisconsin helps to create a better future through brain injury prevention, research, education, and advocacy.

2900 N. 117th St., Ste. 100

Email: [biaw@execpc.com](mailto:biaw@execpc.com)

Wauwatosa, WI 53222

Website: [www.biaw.org](http://www.biaw.org)

(414) 778-4144 (800) 882-9282

#### **Center for Deaf-Blind Persons**

The Center serves youths and adults with combined hearing-vision impairments by providing support groups, social groups, rehabilitation training, community support, and community education

3195 S Superior St.

Milwaukee, WI 53207

(414) 481-7477 (voice/ TTY/TDD/TeleBraille)

#### **DAWN**

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.

Web site: <http://www.dawninfo.org>

### **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 26516

Wauwatosa, WI 53226

(800) 770-0599

### **Mental Health Association**

Milwaukee County

734 N. 4th Street

Milwaukee, WI 53203

(414)246-3122

Brown County

P.O. Box 1016

Green Bay, WI 54305

(920) 468-6720

Web site: <http://www.nmha.org>

Madison

Shel Gross/MHA Office of Public Policy

133 S. Butler Street

Madison, WI 53703

(608) 250-4368

### **National Alliance for the Mentally Ill 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

(608)268-6000

(800)236-2988

Email: [nami@namiwisconsin.org](mailto:nami@namiwisconsin.org)

Website: [www.namiwisconsin.org](http://www.namiwisconsin.org)

### **National Federation of the Blind - Wisconsin**

The National Federation of the Blind- Wisconsin works to educate the public about people who are blind and helps people who are blind and their families by providing support, advocacy services, referral services, resources, job opportunities, adaptive equipment, and protection of civil rights.

1420 West State St.

Janesville, Wisconsin 53546

(608) 758-4800

Email: [mark-r@nfbwis.org](mailto:mark-r@nfbwis.org)

Website: [www.nfbwis.org](http://www.nfbwis.org)

**National Spinal Cord Injury Association of Wisconsin**

Works with local and national officials and agencies to develop programs and services and act as community advocates for improved access, housing, transportation, employment, and leisure time activities for disabled people.

1545 S Layton Blvd., Room 516

Milwaukee, WI 53215

414-384-4022

800-962-9629

**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.

YWCA Employment and Training Annex

338 W. Lakeside Street

Madison, WI 53715

(608) 268-3284

Email: [npw@chorus.net](mailto:npw@chorus.net)

Web site: <http://www.ywcamadison.org>

**Wisconsin Association for the Deaf**

Works to ensure that a comprehensive and coordinated system of resources is accessible to Wisconsin people who are Deaf and hard of hearing, enabling them to achieve their maximum potential, through independence, productivity, and integration into the community.

2782 N 71st St.

Milwaukee, WI 53210

(414) 607-3297 (TTY)

(414) 649-9734

**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

(608) 255-0539 (voice/TTY)

Email: [wcadv@inxpress.net](mailto:wcadv@inxpress.net)



**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  
(608) 257-1516 (voice/TTY)

Email: [wcasa@wcasa.org](mailto:wcasa@wcasa.org)  
Website: [www.wcasa.org](http://www.wcasa.org)

**Wisconsin Coalition for Advocacy (WCA)**

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

*Madison Office*

16 N. Carroll St., Ste. 400  
Madison, WI 53703  
(608) 267-0214 voice/TTY

Web site: <http://www.w-c-a.org>

Toll-free (800) 928-8778 (Toll free: voice/TTY for consumers and family members only)

*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)

*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)

**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.

106 E. Doty St., Ste. 300

Madison, WI 53703

(608) 251-9151

**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

Madison, Wisconsin 53703

608.284.0580

Fax: 608.284.0583

1442 N. Farwell, Suite 508

Milwaukee, Wisconsin 53202

414.831.8880

Fax: 414.298.9127

Web site: <http://www.wccf.org>

**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

(608) 266-7826

(608) 266-6660 TTY

Fax: 608/267-3906

E-Mail: [wiswccd@dhfs.state.wi.us](mailto:wiswccd@dhfs.state.wi.us)

Website: <http://www.wcdd.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

(608) 267-6888

(800) 422-7145

## ***Wisconsin Government Resources***

### **Bureau of Community Mental Health, Wisconsin Department of Health & Family Services**

The Bureau with the Department of Health and Family Services works to lead the state in fostering healthy self-reliant individuals and families.

P.O. Box 7851

1 W. Wilson St., Room 433

Madison, WI 53707-7851

(608) 266-5427

Fax: (608) 267-7793

### **County Human Services**

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

### **Division of Vocational Rehabilitation, Wisconsin Department of Workforce Development**

A federal/state program designed to help find, retain, and improve the quality of employment for people with disabilities.

2917 International Ln., Ste. 300

P.O. Box 7852

Madison, WI 53707

Website: [www.dwd.state.wi.us](http://www.dwd.state.wi.us)

(608) 243-5600 (voice)

(608) 243-5601 (TTY) (800) 442-3477

### **Social Security Administration in Wisconsin**

Toll-Free: (800) 772-1213

Website: <http://www.ssa.gov>

TDD: (800) 325-0778

### **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)

### **Wisconsin Department of Regulation and Licensing**

The state agency responsible for regulating and monitoring professionals that require a license or certificate, such as nurses, physicians, psychologists, social workers, etc.

P.O. Box 8935

Madison, WI 53708-8935

(608) 266-7482

(608) 266-3736

Website: <http://www.drl.state.wi.us>

### **Wisconsin Medical Assistance Information**

Web site: <http://www.dhfs.state.wi.us/medicaid/index.htm>

### **Wisconsin SSI Supplement Information**

Web site: <http://www.dhfs.state.wi.us/ssi/>

## ***Wisconsin Legal Advocacy and Legal Services Resources***

### **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

(414) 273-1991

(800) 359-9272

Fax: (414) 273-2357

Website: [www.arc.org](http://www.arc.org)

### **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. Each of these counties has at least one Benefit Specialist. The Center also operates the Wisconsin Guardianship Support Center, which is a state-wide clearinghouse for information about guardianships, protective placements, and advance directives. As part of this project, the Center operates a toll-free telephone hotline at 1-800-488-2596. The toll-free line works on a call back system. When you call, a message is taken with your name, phone number and description of your question.

2850 Dairy Drive, Ste. 100

Madison, WI 53718

(800)488-2596 (608)224-0660

Email: [cwag@cwag.org](mailto:cwag@cwag.org)

Website: <http://www.cwag.org>

Guardianship Hotline: (800) 488-2596

**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 -- Kenosha Office**

Provides civil legal services to low income people in Kenosha, Racine, & Walworth Counties.

508 56th Street

Kenosha, WI 53140

(800)242-5840 (262)654-0114

**Legal Action of Wisconsin -- Madison Office**

Provides civil legal services to low income people in Columbia, Dodge, Jefferson, Dane, & Rock Counties.

31 S. Mills Street

ASL, Spanish

PO Box 259686

Madison, WI 53725-9686

(608)256-3304

(800)947-3529 TTY

**Legal Action of Wisconsin -- Milwaukee Office**

Provides civil legal services to low income people in Milwaukee and Waukesha Counties.

230 W. Wells Street

Milwaukee, WI 53203

(414)278-7722

**Legal Aid Society of Milwaukee, Inc.**

Provides legal representation to persons with mental illness and others with civil legal services in Milwaukee County.

229 E. Wisconsin, Ste. 200

Milwaukee, WI 53202

(414)765-0600

**Legal Services of Northeastern Wisconsin -- Green Bay Office**

Provides civil legal services to low income people in Calumet, Outagamie, Brown, Kewaunee, & Door Counties.

201 West Walnut, Ste. 203

Green Bay, WI 54301

(800) 236-1127

(920)432-4645

**Legal Services of Northeastern Wisconsin -- Oshkosh Office**

Provides civil legal services to low income people in Adams, Waushara, Winnebago, Marquette, Green Lake, & Fond du Lac Counties.

404 N. Main Street, Ste. 702

Oshkosh, WI 54901

(800)236-1128

(920)233-6521

**State Bar of Wisconsin**

The State Bar of Wisconsin offers legal technical assistance and information. State statutes, regulations and some court cases are available on their website.

P.O. Box 7158

Website: <http://www.wisbar.org>

Madison, WI 53707-7158

(608) 257-3838

**State Public Defender's Office**

Provides legal representation to low income individuals who are facing criminal charges or who are the subject of civil commitment or protective placement proceedings.

Administrative Unit

314 N. Henry, 2nd Floor

Website: <http://www.spd.state.wi.us>

Madison, WI 53707

(608)266-0087 -- Call this number for information about local offices.

**Western Wisconsin Legal Services -- Dodgeville Office**

Provides civil legal services to low income people in Crawford, Richland, Sauk, Grant, Iowa, & Lafayette Counties.

202 N. Main Street

Dodgeville, WI 53533

(800)873-0928 (608)935-2741

**Western Wisconsin Legal Services -- La Crosse Office**

Provides civil legal services to low income people in Buffalo, Trempealeau, Jackson, LaCrosse, Monroe, Juneau, & Vernon Counties.

205 5th Ave. South, Ste. 300

LaCrosse, WI 54601

(800)873-0927 (608)785-2809

**Wisconsin Coalition for Advocacy (WCA)**

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

*Madison Office*

16 N. Carroll St., Ste. 400

Web site: <http://www.w-c-a.org>

Madison, WI 53703

(608) 267-0214 voice/TTY

Toll-free (800) 928-8778 (Toll free: voice/TTY for consumers and family members only)

*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)

*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)

**Wisconsin Judicare - serving northernmost 33 counties in Wisconsin**

300 3rd Street, Ste., 210

P.O. Box 6100

Email: [info@judicare.org](mailto:info@judicare.org)

Wausau, WI 54402

Website: <http://www.judicar.org>

(800)472-1638 (715)842-1681

## ***National Resources***

### **American Counseling Association**

Ethics Committee

5999 Stevenson Avenue

Alexandria, VA 22304-3300

(800)347-6647 OR (703)823-9800

Fax: (703)823-0252

Website: <http://www.counseling.org>

### **American Nursing Association**

600 Maryland Avenue, SW

Washington, DC 20024

(800)274-4ANA

Website: <http://www.nursingworld.org>

### **American Psychiatric Association**

1400 K Street, N.W.

Washington D.C. 20005

(202)682-6000

Email: [apa@psych.org](mailto:apa@psych.org)

### **American Psychological Association**

750 First Street, N.E.

Washington, DC 20002-0202

(800)374-2721 (202)336-5500

Fax: (202)336-5997

Website: <http://www.apa.org>

### **Bazelon Center for Mental Health Law**

Legal advocacy for the civil rights and human dignity of people with mental disability.

Web site: <http://www.bazelon.org>

### **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. Congress created CMHS to bring new hope to adults who have serious mental illnesses and to children with serious emotional disorders. CMHS was established under the 1992 ADAMHA Reorganization Act, Public Law 102-321, that mandates CMHS' leadership role in delivering mental health services, generating and applying new knowledge, and establishing national mental health policy. 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.

Web site: <http://mentalhealth.org>



### **Center for Psychiatric Rehabilitation 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.

Web site: <http://www.bu.edu/sarpsych>

### **Consumer Organization and Networking Technical Assistance Center**

A national technical assistance center, Contac serves as a resource center for consumers/survivors/expatients and consumer-run organizations across the United States, promoting self-help, recovery and empowerment. Contac was developed utilizing research on ideal consumer self-help programs, successful consumer-run programs, community support service philosophy about service delivery, descriptions of mature mental health systems, and management and leadership skills.

Web site: <http://www.contac.org>

### **DENDRON**

Publication about the relationship between human rights and psychiatry.

Web site: <http://www.mindfreedom.org/DENDRON>

### **DisAbility.gov**

In 2000, the Presidential Task Force on Employment of Adults with Disabilities created this site, [www.disAbility.gov](http://www.disAbility.gov), to provide one-stop online access to resources, services, and information available throughout the Federal government.

Web site: <http://disability.gov>

### **Great Lakes Disability and Business Technical Assistance Center**

Dept. of Disability and Human Development, College of Health and Human Development Sciences. The purpose of the Great Lakes Disability and Business Technical Assistance Center is to provide technical assistance, materials and training on the American Disabilities Act to businesses, people with disabilities, and their care givers.

1640 W. Roosevelt Rd.

Chicago, IL 60608

(800) 949-4232 (voice/TTY)

Website: <http://www.gldbtac.org>

**International Association of Psychosocial Rehabilitation Services**

The purpose of IAPSRS is to help advance the role, scope, and quality of services designed to facilitate the community readjustment of people with psychiatric disabilities. In these times of change and challenge, we in the psychosocial rehabilitation field need a strong and unified voice to achieve the mission and purposes of psychosocial rehabilitation.

Web site: <http://www.iapsrs.org>

**International Center for Clubhouse Development**

The international site for clubhouse information. A clubhouse is based upon a psychosocial rehabilitation model of helping people with psychiatric disabilities get back to work.

Web site: <http://www.iccd.org>

**Mary Ellen Copeland**

Mary Ellen Copeland is a mental health recovery educator and author. Her focus is on self-help. Her teachings and writings include topics like getting a sense of hope, Wellness Tools, Wellness Recovery Action Planning, Relapse Prevention, Crisis Planning, Developing a Strong Support System, Education, Personal Responsibility, Self-Advocacy, Building Self-Esteem, Healing from the Effects of Trauma, and Relieving Loneliness and Worry.

Web site: <http://mentalhealthrecovery.com>

**Mental Help Net**

Online guide to mental health, psychology, and psychiatry.

Web site: <http://www.mentalhelp.net>

**National Alliance for the Mentally Ill**

NAMI's efforts focus on support to persons with serious brain disorders and to their families; advocacy for nondiscriminatory and equitable federal, state, and private-sector policies; research into the causes, symptoms and treatments for brain disorders; and education to eliminate the pervasive stigma surrounding severe mental illness.

Web site: <http://nami.org>

**National Association for Rights Protection and Advocacy**

NARPA, an independent organization, is a unique mix of people who've survived these institutions, advocates, civil rights activists, mental health workers, and lawyers. NARPA exists to expose abuse, to shed light on coercive and dangerous practices, and to promote real alternatives to a mental health system that even professionals agree is a disgrace.

Web site: <http://www.connix.com/~narpa>

**National Association of Social Workers**

750 First Street NE, Suite 700

Washington DC 20002-4241

Phone: (800)638-8799 (202)408-8600

Website: <http://www.naswdc.org>

**National Consumer Supporter Technical Assistance Center**

NCSTAC was established in 1998 by a grant from the Center for Mental Health Services. Our purpose is to strengthen those organizations supporting mental health consumers, survivors and ex-patients by providing technical assistance in the forms of research, informational materials, and financial aid.

Web site: <http://ncstac.org>

**National Council on Disability**

The National Council on Disability (NCD) is an independent federal agency making recommendations to the President and Congress on issues affecting 54 million Americans with disabilities.

NCD's overall purpose is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature of severity of the disability; and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

Web site: <http://www.ncd.gov>

**National Empowerment Center**

Recovery is real and this website is filled with practical information that will help you recover if you have been labeled with a mental illness.

Web site: <http://www.power2u.org>

**National Institute of Mental Health**

NIMH has heightened the priority it gives to four broad areas: (1) fundamental research on brain, behavior and genetics; (2) rapid translation of basic discoveries into research on mental disorders; (3) research that directly impacts the treatment of individuals with mental disorders, including clinical trials and studies of treatment and preventive interventions in "real world" settings; and (4) research on child development and childhood mental disorders.

Web site: <http://nimh.nih.gov>

**National Mental Health Association**

The National Mental Health Association (NMHA) is the country's oldest and largest nonprofit organization addressing all aspects of mental health and mental illness. With more than 340 affiliates nationwide, NMHA works to improve the mental health of all Americans, especially the 54 million individuals with mental disorders, through advocacy, education, research and service.

Web site: <http://www.nmha.org>

**National Mental Health Consumers' Self-Help Clearinghouse**

The National Mental Health Consumers' Self-Help Clearinghouse is a consumer-run national technical assistance center serving the mental health consumer movement. We help connect individuals to self-help and advocacy resources, and we offer expertise to self-help groups and other peer-run services for mental health consumers.

Web site: <http://mhselfhelp.org>

**Policy.com**

Online policy news and information service.

Web site: <http://www.policy.com>

**Protection and Advocacy System**

Federally mandated system in each state and territory which provides protection of the rights of persons with disabilities through legally based advocacy. (See Wisconsin Coalition for Advocacy under State Resources – Wisconsin's protection and advocacy agency.)

Web site: <http://www.protectionandadvocacy.com>

**Sidran Institute**

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.

200 E. Joppa Road, Suite 207

Towson, MD 21286 USA

410-825-8888

Web site: <http://www.sidran.org>

**Substance Abuse and Mental Health Services Administration**

SAMHSA is the Federal agency charged with improving the quality and availability of prevention, treatment, and rehabilitative services in order to reduce illness, death, disability, and cost to society resulting from substance abuse and mental illnesses.

Web site: <http://www.samhsa.gov>

**Trauma Resource Guide**

The Association of Traumatic Stress Specialists' Trauma Resource Guide provides information on resources available that address trauma, healing and stress reduction for caregivers and survivors.

Web site: <http://www.atss-hq.com/pages/resourcepages/rsrccgiversurvivor.html>

**World Federation for Mental Health**

The World Federation for Mental Health is an international non-profit advocacy organization founded in 1948 to advance, among all peoples and nations, the prevention of mental and emotional disorders, the proper treatment and care of those with such disorders, and the promotion of mental health.

Web site: <http://www.wfmh.org>

## RIGHTS & REALITY II

An Action Guide to the Rights of People with Disabilities in Wisconsin

**NEW EXPANDED AND REVISED EDITION!** 46 chapters covering every major program, funding source, and rights issue affecting adults and children with disabilities in Wisconsin. All sections of the original 1986 Rights and Reality guide have been updated. New sections on the Americans with Disabilities Act (3 chapters), Federal Fair Housing Act, Assistive Technology, W-2, Family Care, BadgerCare, Rights of Inmates in Correctional Settings, and Abuse and Neglect of People with Disabilities. Written primarily by attorneys specializing in disability law, the guide includes citations to applicable statutes, regulations, and case law.

----- Rights and Reality II Order Form -----

Name \_\_\_\_\_ Phone \_\_\_\_\_  
Address \_\_\_\_\_ E-mail \_\_\_\_\_  
\_\_\_\_\_ Zip Code \_\_\_\_\_

Please indicate if you are: consumer \_\_\_\_ family member of a person with a disability \_\_\_\_  
attorney \_\_\_\_ human service professional \_\_\_\_ other (please specify) \_\_\_\_\_

**SPIRAL MANUAL** - 400 pages; user-friendly format; detailed Table of Contents; sturdy, long lasting binding and durable cover; lays flat for ease in copying individual sections.

**Consumers & Families: \$20**

**Others: \$30**

**CD-ROM** - can be run on Windows or Macintosh platforms; automatic install feature; search using key words; links from Table of Contents directly to individual chapters; print directly from the CD-ROM; increase size of images on screen to 800%. Help file, free on-line and telephone technical support available.

**Consumers & Families: \$20**

**Others: \$30**

For quantities of 10 or more, contact us for volume price and billing arrangements (608-267-0214). Prices include postage and handling.

\_\_\_\_\_ **TOTAL ENCLOSED**

\_\_\_\_\_ Check enclosed. Make check payable to: Wisconsin Coalition for Advocacy, 16 N. Carroll Street, Suite 400, Madison, WI 53703. Please allow 4-6 weeks for delivery.

\_\_\_\_\_ Agency purchase order enclosed (for quantities of 5 or more)

\_\_\_\_\_ Charge my \_\_\_\_ MC \_\_\_\_ Visa Card # \_\_\_\_\_ Exp. \_\_\_\_\_