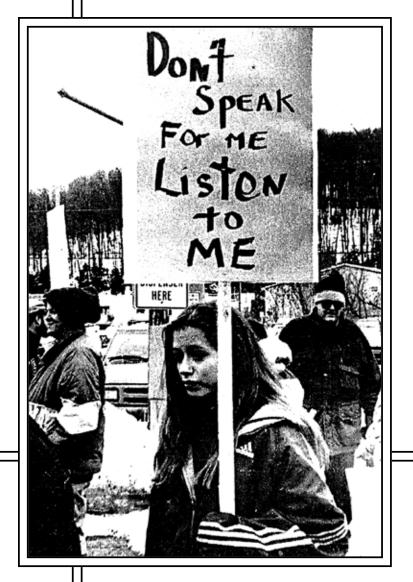
Taking Charge



Tools and Tips from the self-help & psychiatric survivor movement in Vermont

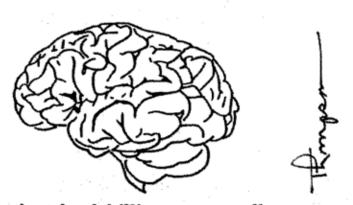
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One hundred billion nerve cells, one hundred trillion connections, an unknown number of chemicals, an infinite number of chemical strengths, it's continually shaped by its environment, and no one knows what's hard-wired.

WHAT'S "NORMAL"?

Table of Contents

Introduction	1
Making a Movement & Keeping it Going	5
Advocating for Yourself: Tips & Tricks	11
Parenting: In Good and Bad Times	22
Finding & Keeping Decent Housing	28
Making Employment Work	39
Institutionalization & Alternatives	53
The Path to Recovery	68
Final Thoughts: Moving Forward	82
My Resources	84

Introduction

Almost ten years ago, with the inspiration and support of psychiatric survivors, VP&A first published this resource book. Since then there are fewer drop-in centers, more recovery groups, new pushes for involuntary civil commitment, more of our peers in prisons and traumatized soldiers returning from war in the Middle East. There is widespread acknowledgement that the Vermont State Hospital needs to close, federal support for the principles of recovery in mental health treatment, erosion of state support for outpatient service options, realization of the role of trauma in the lives of people with mental health labels and in some ways "plus ça change plus ç'èst la même chose" – the more things change, the more they remain the same.

Special Thanks

Uur thanks to many whose voices, ideas and art helped shape these pages. They are:

Linda Corey

Anne Donahue

Paul (Dorfner) Engels

Natalie Frost

Mark Joy

Bob Loomis (in Memory of)

Kate Quinn

Jean Thompson

Boyd Tracy

Xenia Williams

The following professionals contributed expertise, knowledge and historical information to the project: Susan Besio, Liz Manfredi, Brian Smith, Randy Collier, Joe Reinert and Jim Pontbriand. Thanks are also extended to writer Ann Holmblad, who compiled the resource listings and transcribed numerous taped interviews. What hasn't changed is the fundamental truth that the most important changes in the lives of people with labels of mental illness or psychiatric disabilities will occur by the actions of those survivors themselves.

That is why VP&A offers this new edition of "Taking Charge" updated in its details but not in its fundamental message, best expressed in its original introduction:

This book was conceived, dreamed up, and nagged into being by a group of psychiatric survivors who wanted Vermont Protection and Advocacy (P&A) to create a self help and survival guide for individuals with psychiatric disabilities. It took a long time to be born.

When I first explored what these dreamers wanted, I was told this: "Don't make it a legal text book. We don't want a rights handbook. We want a practical guide, shaped by the experiences we have had as survivors. We want to celebrate what is possible, give hope to people fighting to find their own way through mental illness, labels, stigma, as well as the helpful, and sometimes abusive, treatments and systems out there for people labeled psychiatrically disabled. Give people some voices and support from others regarding the signposts and road maps that may help them."

They told me that surviving mental illness (or other people's prejudices about it) meant redefining the world and going beyond the basic assumptions to find what worked for each individual. It meant expecting success and holding on through hard times. It meant surviving the wrong treatments when they happened, and moving on to demand something else.

With that challenge, I had only one choice. To go to the people who had the stories, the experiences, and the real authority to lead others to self-help; people who have survived the stereotypes to find their own ways to healing, recovery and hard won independence.

Everyone's journey was different. Because of this, people's ways of defining their experiences, the labels they were comfortable with, and the ones they found offensive, varied. Some people saw themselves as mentally ill, others as psychiatric survivors; others as people who had experienced a disability and recovered, or experienced a system, survived and moved on. People defined their experiences and how they understood the causes differently, too. What worked for one, oppressed another.

Each of the individuals with whom I spoke highlighted the healing value of being treated with respect, of having their rights and interests recognized and protected, and of being able to make an informed choice about the services they received or chose not to use.

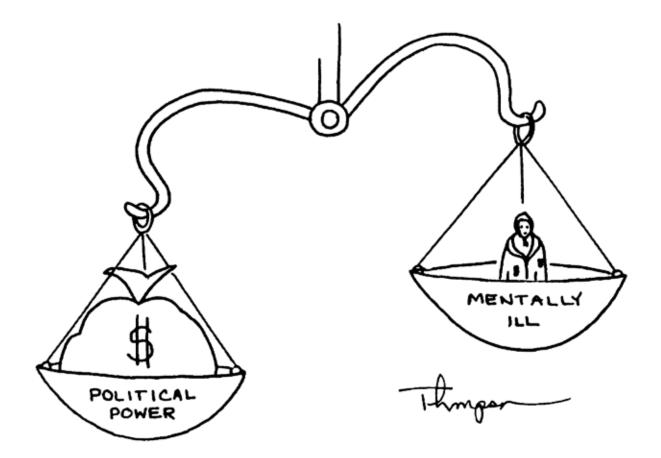
The purpose of this guide is not to take positions on mental health treatment, but to affirm each individual's right to respect, dignity and choice in the care received; and informed choice in managing his or her own life and health. The wide range of people's experiences and positions on this issue speaks to the need for finding ways to work with people that respect and honor diverse needs, interests, and preferences while remaining committed to the sanctity of, and respect for, human life and selfdirection.

Countless individuals shared their stories through personal interviews. These people's words and spirit graced my life during the months I worked on this project and continue to inspire me. In addition, past issues of *Counterpoint* and *The Independent* gave me the voices of many other individuals whose voices contribute to this book.

I also visited or was given information and quotes from other consumer publications and websites. Commissioner Susan Besio shared her research on the early history of Vermont's psychiatric survivors' movement. Finally, the artwork on the cover and some of the images throughout this book come from a few of the artists in this human rights movement, including Anne Donahue's photographs and Jean Thompson's compelling drawings.

Thanks to the people who dreamed this project up. Thanks to Vermont P&A for listening and sponsoring this project, and thanks to all of you who waited through it's longer than expected conception and birth. ..

— Deborah Lisi-Baker



Making a Movement & Keeping it Going

Bob Loomis said these words many years ago in an interview with Susan Besio, who was in the process of writing about the early days of the Vermont's expatient, psychiatric survivors' movement. This movement is still alive and well: a sometimes contentious and almost always fierce radical edge made up of people with very diverse points of view, whose opinions and voices come from a hard fought struggle. The battle to change mental health treatment and laws and protect the basic civil rights of citizens with mental illness, a history of mental illness, or who are believed to be mentally ill, continues. In Vermont and around the country this struggle is a minority group's effort to be recognized as citizens and valued as individuals, with identities that include, but are not defined by, their experiences with psychiatric disabilities. Brave are the people who shake off the ignorance and labels associated with these experiences among the general public and experts.

For many, this fight is a life and death struggle: it is their own lives they are trying to regain, return to, or preserve. The struggle of the most outspoken or determined advocates lead to real changes in the treatment and rights of people labeled mentally ill. Institutions and community services are beginning to change slowly for the better. People are becoming empowered to make their own treatment decisions, regardless of what they might be, rather than simply having their options defined by professionals.

"We are on the verge of the next civil rights movement in this country, and that is civil rights and equality for the mentally ill."

Robert Loomis (1943-1994)

This life and death struggle began in the early 1970s and was part of a national awakening. People became aware of the coercive and demeaning treatment inflicted upon thousands of patients at psychiatric hospitals. With growing public awareness, many courageous individuals

spoke out about their experiences. At first, institutions and experts resisted change — and many still do — but over time practices were altered, and the rights of individuals began to be considered.

We owe a lot to the individuals who have participated in this civil rights struggle. Before this movement began, the power of mental health professionals was

Timeline of Events

The following is a timeline of events which involve the Vermont State Hospital and other laws and services relating to mental health treatment. Much of this information came from a historical book about the Vermont State Hospital, <u>Empty Beds</u>, by Marsha R. Kincheloe and Herbert G. Hunt, Jr.

- **1891** On August 8, 25 male patients were transferred to the Vermont State Asylum for the Insane.
- **1945** Electric shock treatments first used.
- **1949** A state health department was created and responsibility for mental and medical health was included.
- **1952** After a request, the American Psychiatric Association inspected the hospital and found it had 473 beds over its rated capacity.
- **1963** The Department of Mental Health was created by the Legislature.

The children's ward opened.

- **1966** The Fair Labor Standards Act was passed, requiring patient labor to be paid.
- **1968** Mental Health Law No. 305 allowed voluntary admissions regardless of ability to pay.
- **1970** There were 1,350 admissions. This marks the first time that admissions exceeded the daily population of the hospital.
- **1978** Paul Dorfner begins closed-circuit TV project at VSH. As a result, a small network of then current VSH patients formed to discuss treatment.
- **1982** First ex-patient and consumer- run programs funded by state. Total

considerable and difficult to challenge. As one ex-patient recalled of his threemonth stay at the Vermont State Hospital in 1972, "I had the impression then that they had unlimited power to go further than anybody else could go. That they had basically ways of breaking people that were beyond whatever it was that you could push or handle. And then there was the security; solitary confinement, the drugs, or the maximum-security unit. That they could hold you, basically, until you recanted any previous remarks you may have made of an untoward nature."

That power has weakened, but today the stigma of mental illness remains. The Vermont State Hospital (VSH) is no longer used in the same capacity it once was. Stays are shorter, treatment models have changed and much of this is thanks to tireless self- advocates and ex-patients. They put a human face on the experience of mental illness; spoke out with a moral force for more humane and respectful treatments and services. These early advocates stayed the course and were not discouraged with each setback, but used those losses as ways to improve their future efforts. This same moral force established an extensive network of consumer and ex-patient run support groups, drop-in centers and advocacy groups throughout the state - organizations that were never thought possible just thirty years ago.

Still, memories remain intact. As one peer advocate said, "These rooms are full of ghosts. Today, I go to meetings about public policy in rooms where I was once locked up and force treated."

(Continued)

amount: \$15,000.

- **1985** A special task force recommends funding a statewide network of support groups, advocacy work and outreach primarily run by ex-patients and consumers.
- **1986** Paul Carling study released, advocating the closure of the state hospital and developing a regional community mental health system.
- **1987** Vermont Advocacy Network (VAN) established and funded to assist those labeled mentally ill with complaints about treatment.
- **1988** Census at 150.
- **1994** VAN is disbanded and Vermont Protection and Advocacy, Inc, the designated P&A system for Vermont, assumed responsibility for all protection and advocacy for people with disabilities.
- **1995** State engages effort to transfer all but the forensic functions of VSH to the community.
- **2000** Dale unit closed, renovated to house female prisoners.
- **2001** Legislature directs the executive branch to develop a proposal to close the Vermont State Hospital.
- **2002** Vermont Supreme Court uphold Act 114, governing the use of nonemergency involuntary treatment.
- 2002 Medical staff at VSH write a memo to the Governing Board outlining concerns related to patient care, staffing and physical plant.
- 2003 Within a month of each other, two patients at VSH commit suicide.

VP&A releases investigations of both deaths which identify numerous deficiencies in treatment, physical plant and staffing.

The Ex-Patient Movement Begins

In 1978, Paul Dorfner, an ex-patient, began a closed-circuit television project at VSH. This project first brought together VSH patients to discuss treatment and service issues. In 1980, Dorfner and two other Vermont ex-patients formed the Vermont Liberation Organization (VLO). At this time, the state Department of Mental Health was starting to develop a five-year plan for mental health services. In 1982, the department funded six consumer and peer-run projects including Uptight, a mutual-support group in Rutland.

In 1984, consumers, ex-patients, and family members became politically active. They testified at the legislative hearings and VLO submitted a proposal for a mutual support and advocacy network to the state Board of Mental Health. A task force was developed, with five of the fifteen members being consumers or ex-patients, and in 1985 the Task Force Report recommended the development of a statewide advocacy system to be operated primarily by ex-patients. In 1986, funding for these programs, advocacy activities and mutual support groups were submitted as part of the state Department of Mental Health's annual budget request from the Legislature.

This consumer and public pressure not only helped to establish advocacy and support groups directed by ex-patients,

(Continued)

- 2004 The administration submits a report to the Legislature titled: The Vermont State Hospital Futures Project
- **2004** VSH loses its accreditation and funding from the Centers for Medicare and Medicaid Services (CMS). (VSH was recertified briefly and decertified again in 2005).
- **2004** The United States Department of Justice (DOJ) announces it is initiating an investigation into the conditions at VSH.
- **2005** The administration submits another report to the Legislature outlining how it plans to address closure of VSH and dispersal of mental health services into the community
- **2005** DOJ report is issued, citing numerous deficiencies in treatment, physical plant, overuse of seclusion and restraint and staffing problems.
- **2005** Seven months into 2005, the legislative Mental Health Oversight Committee criticizes the administration for lack of movement towards closure of VSH.
- 2006 The administration announces a settlement with the DOJ to avoid litigation. The settlement terms were reached behind closed doors with no consumer or advocate input.
- **2007** Second Spring opens in Williamstown as an intensive residential alternative to transition VSH clients to community settings.
- **2007** Planning continues in replacing the functions of VSH in other settings. As of this writing there are more questions than answers as to what those settings may be.

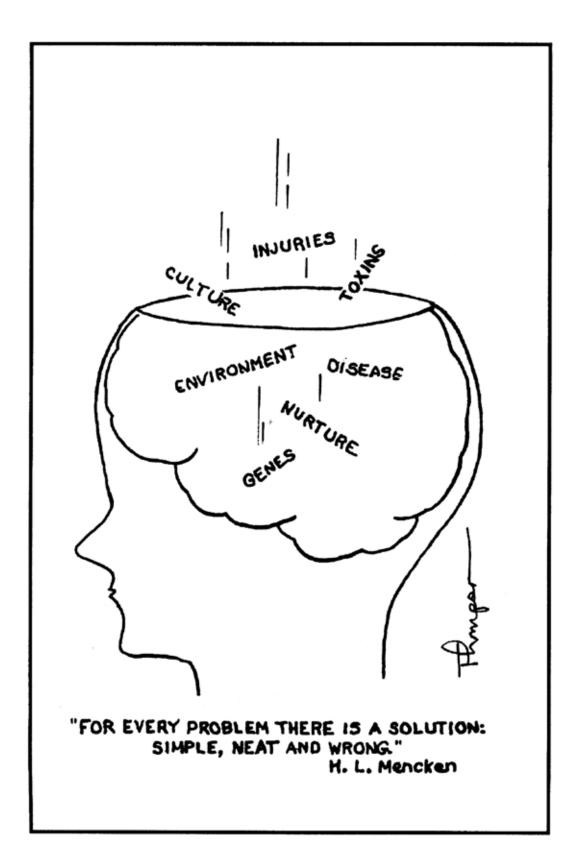
but it helped to de-emphasize use of the State Hospital and institute a more regional approach to treating people during times of incapacitation. Consumer and public pressure during the '98 debate over involuntary non-emergency drugging forced the issue moved from AHS hearing review to family court. Opposition to the idea of involuntary treatment led to two challenges that delayed the law's implementation. One unsuccessfully challenged the legislature's right to set aside the consent decree on which the old system was set up. The second successfully reinforced the idea that it was unconstitutional to set aside an advance directive of an individual with a mental health related disability.

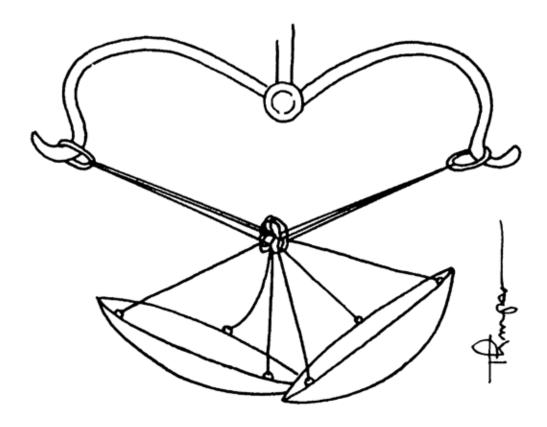
Our society is far from being a place where people are respected and valued for who they are, rather than separated and isolated for what they are not. Homelessness, joblessness and hopelessness are pervasive, and the remedies often come from a need to help the powerless rather than a commitment to help empower people to keep their self respect and control over their own lives.

For some, ex-patients are just another minority group. The goal of psychiatric survivors is to do away with the label of differences. As one ex-patient exclaims, "We are absolutely ordinary people like anyone else who happen to be arbitrarily oppressed in this way. If the oppression were gone, then the identity would be gone, too. After the oppression is gone, then there will just be people who will be indistinguishable from anyone else."

In the end, what it takes is people listening.

But, without people speaking up, no one is ever heard.





PSYCHIATRY & THE SCALES OF JUSTICE

Advocating for Yourself: Tips & Tricks

As with most things in life, the more you prepare for something the more control you can exert on a situation's outcome. The same holds true for times when a person becomes incapacitated, or needs to navigate the mental health or social services system.

Assuring ahead of time what works best for you is the most important step in self-advocacy, as well as being able to recognize when outside help is needed. Outside help can take the form of a family member or friend, a professional advocate or attorney, or another self-advocate. Even good advocates need help in their lives when issues become too emotional. If you don't believe this, just ask someone.

"It's so heart wrenching to be rejected over and over. That means compared to other systems, you may have to do extra advocacy and resist persistent brushoffs"

Spelling out how your life is to be handled by a friend, family member or advocate during a time of need is the best protection to make sure your wishes are followed. If not, you may find yourself like too many people - scrambling while in a crisis situation to find people with the right expertise to help.

There are some very specific steps for self-advocacy that need to be done in advance of any therapy, medication or other form of treatment - if that falls within areas you wish to self-advocate. In fact, one of the first steps toward "treatment" - no matter how one defines this term - is recognizing that there may be times when you are unable to make immediate decisions for your well-being. This does not simply include the use, or refusal to use, medication or forced drugging. You can also make it clear to whom you would give temporary custody of your children, an elderly parent

You & Your Advance Directive

An Advance Directive is an important legal document that allows a person to appoint his or her own agent to make health decisions for him or her if he or she is declared "incompetent," as well as give other advance instructions.

Once you have chosen your agent - remember to choose carefully discuss your preferences with him or her. When you sit down to discuss and write out your Advance Directive, making either a video or audio tape of the proceedings is a good idea. An Advance Directive can include advance instruction on a wide range of issues, from medication preferences to whom to assign temporary guardianship of your children.

Here is a practical Advance Directive checklist developed by one self-advocate:

- Medication Preferences: What you will agree to take, plus any medication you specifically do not want. Also include here any feelings about forced medication or what, if any, medication you are willing to have given to you against your will.
- Where to Go: What facilities you will agree to go to in a psychiatric crisis, and any you don't. List preferences in case of involuntary commitment, too.
- **Conditions of the Facility:** Provide examples of what you need that

in need of care or a support animal or companion. This document, called an Advance Directive, holds a lot of sway in the courts.

Medication: Yes or No

When spelling out medications you would approve to use, or not approve to use, it is important to do the necessary research to give examples of negative side effects of certain drugs. There are ways to research this information on the Internet, as well as through many local libraries. Many advocacy groups such as Vermont Psychiatric Survivors and the Vermont Center for Independent Living and others have access to this type of information. It also helps to have your physician or psychiatrist explain to you the side effects of any proposed medication or treatment.

Another tool is the Wellness Recovery Action Plan (WRAP), which you can utilize to make sure your path toward recovery outside of a crisis situation revolves around vour wishes and not that of a single doctor or institution. A WRAP, developed by counselor Mary Ellen Copeland, can also spell out in detail what type of treatment options you will pursue and who will stay by your side to see you through the good times and the rough spots. A separate crisis plan can be developed that parallels the wishes in your Advance Directive, and serves as additional support in any legal action or medical intervention. It is important to remember that a WRAP is

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will be helpful to your recovery. This could include adequate phone and visiting access, a private room, favorite beverages, being allowed to sleep during the day, going to therapy or groups only when you find them helpful, the ability to smoke whenever you want, and others.

- Visitation: A list of people you do and don't want to visit you.
- Emergency Conditions: If a psychiatric ward considers you to be in an "emergency" situation, do you prefer to be put in mechanical restraints or forcibly medicated?
- **Preferred Treatment Plan:** This one needs to be as detailed as

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possible.

- Special Diets or Religious Requirements: Include not only dietary restrictions (being a vegetarian, Muslim, etc.) but comfort foods which improve your mental health and recovery.
- Child Care Arrangements: Arrange for your children to be placed temporarily in a safe, nurturing environment in a friend or relative's home. Same goes for pets.
- Who to Notify?: Other than your personal advocate, list family and friends, or preferred mental health providers, you would want notified, and list those you don't want notified.

not a legally-binding document, and will not hold up in court.

Putting Power into Your Hands

Self-advocacy may be difficult or less effective when you are working with certain agencies or persons. When you are faced with a system that wields a substantial amount of power and control over an area of your life you may want the support and assistance of an advocate. An advocate could attend important meetings or hearings with you; it is important that your advocate clearly understands your wishes and is able to help you get the results you want. It is easy to become discouraged by the administrative processes in state and federal agencies, so it is important to prepare yourself for delays, complications and temporary setbacks. It is helpful if you and your advocate review your rights, options, goals and preferences before going to a meeting about treatment, services, parental rights, or other issues. It is easier to do this before a crisis rather than during one.

If you choose to seek help from a professional or peer advocate, remember just because an advocate might seem a bit distant or not involved in your case emotionally does not mean that he or she is not on your side. The advocate's job is to not get too emotionally attached. An advocate working on your behalf needs to remain focused on the process; the key is to make sure the process works in your favor. There will be

(Continued)

- Enforcement: Specify that you want your agent to get help, including legal help if necessary, to insist that your previously stated preferences are honored. Remember, crisis plans are not legally- binding documents but Advance Directives are, and you need to make sure you grant the OK to have it enforced.
- **Distribution:** Give a copy to anyone who might remotely need to know that you have done an Advance Directive for Health care. This includes mental health agencies and facilities, friends, family, medical doctors, police, your client file, etc. Keep extra copies for yourself. Hospitals sometimes lose things. Register your Advance Directive with the Vermont Advance Directive Registry.

time for friendships later. This demeanor holds true for self-advocates, too. While it is hard to separate your own personal feelings from a case that involves you or a family member, especially a child, you will be more effective if you remain focused on the facts of the case.

No matter how skilled an advocate you are, it is important to know when not to go alone. As one advocate puts it, "I'm a very skilled advocate and could go in and try to act on my son's behalf, but I know that I'll be thrust into that role of mother, where I can speak until I'm blue in the face. That would not be as effective as calling one of my buddies and saying, 'You need to act in a professional capacity on my behalf. Would you do that?'"

It is also good to remember that a whole system needs to be changed in order for the wishes of some to get heard and realized. Self-advocates may become discouraged because the system has told them they have "lost" during a hearing or

process. However, it may not be a loss. Before you give up, find out about possible next steps, appeal rights, or possible gains in an apparent loss. It is easy to give up without realizing that you still have rights and options. During these times, it is always good to have someone you can turn to help put your efforts in context. Selfadvocates often say it is easy for pride to keep them from compromising during any given process, but the focus needs to be placed on the outcome. Keep your most important goals in mind.

For example, during a divorce proceeding when your parental rights are being threatened because of a perceived mental incapacitation, it is easy to respond in anger and frustration, but this won't help you establish your ability to parent. In this situation it is in your best interest to focus on keeping your parental rights, even if these sometimes start with partial successes such as gaining visitation rights. Compromise on process rather than jeopardize losing all visitation rights.

Another tip many self-advocates offer is to make good on promises or agreements you make in any plan you negotiate with a provider, a court system, a support network,

A Crisis Plan

In addition to an Advance Directive, it is advised to put a "crisis plan" in writing to bolster any potential legal action.

Like an Advance Directive, a crisis plan lets others know how to care for you when you are not well, which keeps you in control even when it seems like things are out of control.

A crisis plan should include all of the items previously listed in the Advance Directive checklist in this chapter, including what medications/facilities you prefer or want to avoid, as well as clear instructions for who will take care of you in case you need at-home care.

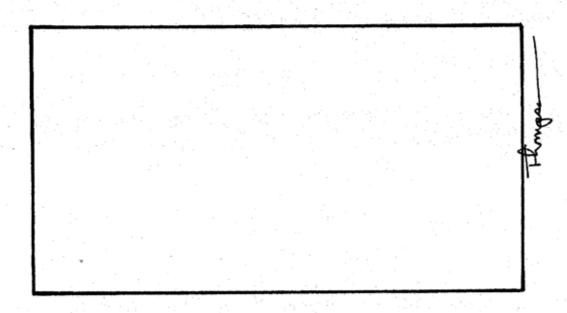
There are a number of formal and informal methods of creating a crisis plan, and you should discuss which of these options best suit your needs either with a patient advocate, Vermont Protection & Advocacy, the Mental Health Law Project of Vermont Legal Aid or other ex-patients. or yourself. This might mean keeping in touch with your support person during a crisis, keeping up on financial payments, or going to a peer support group. Taking responsibility for the success of your selfadvocacy goes beyond providing what the system wants. It gets to the heart of recovery, which is to regain control and be able to put your focus on making connections with other people successful and rewarding for yourself and others who matter to you. It is also a way to make alternative support work when traditional services are not what you want.

If you have a bad experience with a particular agency or administrative process, such as commitment hearings, review your WRAP or Advance Directive to see what might be modified to avoid those obstacles in the future. Or perhaps there is someone you could turn to during those times for help.

If you have had bad experiences with a certain provider or with the system it is easy to act in anger, but as one advocate said, "If you approach somebody with a hostile, raging attitude, that person is

going to react the same way. They're going to become very defensive, very closed, and they're not going to hear what you have to say or what you want because they're going to get caught up in their own anger. If you could take an approach that radiates the following attitude: There are no bad guys and good guys, just you and I working together. If you can see the people that you're approaching as somebody who gets up in the morning and puts on two socks, just like you, it makes a big difference."

Self-advocates also stress the need to follow the golden rule of advocacy: Never give up. "People give up very easily because it's so heart wrenching to be rejected over and over. That means that compared to other systems, you may have to do extra advocacy and resist extra persistent brush-offs," said one advocate and ex-patient. "That means you have to persist, persist, persist. Or, as the departed but not dead said, 'Time and pressure make a rock."



PROTECTIONS AFFORDED BY "GUIDELINES" AND "VOLUNTARY SELF-REGULATION"

self-advocacy resources

Assistive Services

VERMONT INTERPRETER REFERRAL SERVICE

130 Austine Drive Brattleboro, VT 05301 (802) 254-3920 (V/TTY) (800) 639-1519 (V/TTY) Website: www.virs.org Interpreters for the deaf.

VERMONT TELECOMMUNICATIONS RELAY SERVICE

147 Knight Lane
Williston, VT 05495
711 or (800) 253-0191 (TTY)
(800) 253-0195 (Voice)
Website: www.vermontrelay.com
TDD communication service

Information and Referral Services

CLIENT ASSISTANT PROGRAM - RUTLAND

57 North Main Street Rutland, VT 05701 (802) 775-0021 (800) 769-7459 Website: www.dad.state.vt.us/DVR/cap Information and referral

GOVERNOR'S INFORMATION AND REFERRAL

(800) 649-6825 Governor's Office, 109 State Street, Montpelier, VT 05602 Website: www.vermont.gov Information and referral.

HEADREST

1-800-639-6095
(603) 448-4400
14 Church Street, P0 Box 247, Lebanon, NH 03766
Website: www.headrest.org
Information center and crisis hotline.

OFFICE OF HEALTH CARE OMBUDSMAN

(800) 917-7787PO Box 1367Burlington, VT 05401Website: www.vtlegalaid.org/hcoHealth insurance problem assistance.

VERMONT BANKING, INSURANCE, SECURITIES (BISHCA)

(800) 631-7788Health Care Administration, 89 Main St., Drawer 20,Montpelier, VT 05620-3601Website: www. bishca.state.vt.usHealth care insurance consumer assistance.

VT SECRETARY OF STATE'S OFFICE

(800) 439-8683

26 Terrace St, Montpelier, VT 05602 Website: www.sec.state.vt.us Complaints against professionals.

Legal Assistance

SOUTH ROYALTON LEGAL CLINIC

(802) 831-1500 159 Chelsea St., So Royalton, VT 05068 Legal services

VERMONT LEGAL AID, INC

(800) 265-0660Mental Health Law Project, 121 South Main Street, P0Box 540, Waterbury, VT 05676Website: www.vtlegalaid.orgLegal services for the mentally ill.

VERMONT PROTECTION AND ADVOCACY

(800) 834-7890141 Main Street, Suite 7, Montpelier, VT 05602Website: www.vtpa.orgMental health advocacy.

Peer Support Resources

VERMONT CENTER FOR INDEPENDENT LIVING

(800) 639-1522 11 East State Street, Montpelier, VT 05602 Website: www.vcil.org Peer advocacy counseling program.

VERMONT PSYCHIATRIC SURVIVORS, INC.

(800) 564-2106
1 Scale Avenue, Suite 52, Rutland, VT 05701
Website: www.sover.net/~vpsinc/
Mental health advocacy and support.

Life Issues:



parenting, housing, & work

Parenting: In Good and Bad Times

Individuals who have experienced mental illness hold down jobs, do volunteer work, raise families and have successful personal lives. However, no group of people in this country face more personal and legal threats to their rights than do those of us who live with the reality and stigma of mental illness. Attitudinal barriers, lack of support, and misunderstanding threaten one of the experiences many of us value and most of us take for granted: parenting.

There are times when any parent finds it difficult, or even impossible to care for a child or children. Illness, accidents, work responsibilities, and personal and family emergencies happen to everyone, not just individuals with psychiatric disabilities. And all parents can find themselves occasionally overwhelmed and unable to cope with the balancing act of raising children in today's world. Living with a disability — and the social and legal stigma our society places on people who have been labeled "mentally ill"— makes these struggles harder, and the threat to parental rights greater.

Vermonters who have been labeled mentally ill can suddenly find their parental rights and their ability to serve as responsible, active, and caring parents challenged by their spouses, state agencies, and the court system. Nothing is more painful.

Survivors talk about the struggle. They speak about the need to be aware of how their disability affects their ability to parent, the challenge of finding a life-style and

"The hardest thing was advocating for custody of my daughter ... because of the stigma." the right supports to stay well and be a parent. They speak about the importance of recognizing when they need to ask for help for themselves and their children, and taking on the legal challenges to their rights as parents. They describe having the label used against them by former

spouses and the court system. The threats and challenges to parental rights are real, whether the experience of mental illness is a one-time event or episodic.

Sometimes family life itself triggers a psychiatric crisis that later may be used as a reason to deny a mother or father their rights to parent their children. One mother explains, "I had a lot to juggle; I was running a house with three young kids and a husband. In 1999, one child needed extra support - dealing with that and trying to teach the school how to work with him was difficult. I was taking a college course, and I was raising 90 percent of our vegetables. We had built a new house; I don't know what happened, but I ended up in the hospital for five weeks, and I guess my husband decided he didn't need me anymore. And the main reason I didn't get the kids was because of the mental illness label. As soon as a judge sees that, it's a red flag. They don't see beyond that."

Stress triggers many of the behaviors and conditions that medical professionals call mental illness. Parenting, family life, and divorce, all cause emotional, economic, and physical stress. It is no wonder that parents sometimes are unable cope. But when stress makes it difficult to take care of your children, it is important to know what supports are available and how best to protect the rights of your child and yourself. Knowing what helps you cope well, recognizing when you are unable to cope, and



"Because of the stigma involved in mental illness, I had to go to court several times just to get what I was entitled to: my visitation rights." having the resources and support available when you and your family need them, can turn a potential loss of control and authority into an example of successful coping.

Support groups, crisis planning, and creating a lifestyle that promotes wellness are each strategies that work for many people, with and without disabilities. Couples and older children often work out schedules and family ground rules that help everyone balanced. Other stay people find that therapy, exercise or the right mental health counseling and services can help to prevent a crisis. One couple talked about traveling across the state to see the psychiatrist who had taken the time to work out a treatment program that helped the wife manage her bipolar condition without taking away her energy and sense of self.

Several self-advocates first learned their advocacy skills while advocating for a child who needed special services at school. One parent found herself needing to use

Planned parenting

If your children are taken from you, it doesn't mean they will remain in foster care for good, or be treated in ways that you do not approve.

There are ways to demonstrate your ability as a parent — even in times of crisis. They include:

Write a crisis plan for when you do become incapacitated, anticipating some of the needs your children will have and being very detailed about how to meet those needs.

Get help from skilled advocates who know how to get through complicated bureaucratic processes such as those which govern DCF in order to make sure your rights are honored and your wishes heard.

Demand your rights from DCF and other officials in regards to what they can and cannot do with your children without your written permission. And, require that they explain your rights in a clear and comprehensible format. these same skills to advocate for herself and her son when she experienced a psychiatric episode. When local officials came to place her children in protective custody, she found her rights to parent her own children being challenged by the state. She had to get some help, deal with her children being in foster care, and do what she could to demonstrate her own ability to take care of her children when the crisis was over. She said, "Sometimes you can't cope. There are times when you need to let someone else take care of your child, while you get help for yourself. That doesn't mean that your competence or right to be a parent is gone; but you may have a fight on your hands trying to prove this to local officials and the state."

Crisis Planning & Crisis Prevention

A crisis plan makes sense for any parent, and can be particularly important for

a parent with either an ongoing or episodic condition. Talk to your friends, family, advocates, and other advisors about how you want your children to be cared for if you are not able to do it. Coming back from a crisis requires many of the same supports. As one mother says, "If you had some other illness, like a virus, people would be cooking meals and coming around to help. That's not always available when we need it, and sometimes we forget to give that kind of help to each other."

Sometimes, a label of having been mentally ill can be used as a reason to deny a mother or father the rights and opportunities of parenting. When this happens, even a strong self-advocate may need to ask for some help from another advocate. A supportive partner, a support group, a friend, a peer advocate or a lawyer can each offer support.

Don t be afraid to say, "I can t do this alone."

Many parents have found that planning ahead and the right support can make

You Have the Right...

...to be represented when foster care is being considered. When a child is placed in foster care, a parent has the right to:

- Be treated courteously by the court, state agency staff, and the people working with them;
- Be part of planning their child's care and know what they must do before their child can return home;
- Receive timely information and be able to speak to someone immediately in emergencies;
- Receive the help they need to parent children at home; and
- Be represented and challenge a decision that they believe is not right.

all the difference. One advocate suggests, "The DPOA, the Durable Power of Attorney [Advance Directive], can be such an invaluable instrument to people because it provides people, not only with an opportunity to make their medical choices or life-sustaining measures, but you can also include in that, or in a crisis plan, your preferences as to what happens to your children if something happens to you." Just because you are temporarily unable to provide this care, doesn't mean that your rights, responsibilities and interest in your child's life shouldn't be honored. Even when children are placed in foster care or other alternative situations, a parent can still be part of their lives and help decide how that care is provided.

This same advocate talked about how hard it can be to acknowledge what we need to do differently to take care of

ourselves and our children, and at the same time give ourselves credit for the love and support we know how to give our kids.

The keys, she says, are personal responsibility, honesty, self-respect, and a willingness to take on systems when they deny legitimate rights. "Don't try to do it alone. There's a lot to be said for self-advocacy but I think the reality is that when you're dealing with a powerful system like DCF the level of respect and attention increases substantially when there's an advocate involved."

"Sometimes you can't cope. There are times when you need to let someone else take care of your child, while you get help for yourself. That doesn't mean that your competence or right to be a parent is gone; but you may have a fight on your hands trying to prove this to local officials and the state."

parenting resources

ALLIANCE FOR THE MENTALLY ILL (NAMI-VT)

(800) 639-6480
(802) 244-1396
Website: www.namivt.org
132 So. Main St., Waterbury, VT 05676
Families of mentally ill — support.

PARENT-TO-PARENT OF VERMONT

(802) 764-5290
(800) 800-4005
600 Blair Park Road Suite #240
Williston, VT 05495-7549
Website: www.partoparvt.org
Children with disabilities support.

VERMONT 211

211 Website: www.vermont211.org Phone counseling and referrals.

PREVENT CHILD ABUSE VERMONT

(800) 244-5373 or 1 (800) -CHILDREN94 Main Street, P0 Box 829, Montpelier, VT 05601-0829Website: www.pcavt.orgSupport groups for Parents.

VERMONT FEDERATION OF FAMILIES

(800) 639-6071 **26** (802) 434-6757P0 Box 507, Waterbury, VT 05676Website: www.vffcmh.orgParents of kids with emotional/behavioral disorders.

VERMONT PARENT INFORMATION CENTER

(802) 876-5315
(800) 639-7170
600 Blair Park Road, Suite 301, Williston, VT 05495-7589
Special education and advocacy.

Finding & Keeping Decent Housing

Finding decent and affordable housing in Vermont is one of the biggest challenges that many people, including psychiatric survivors, face. People seeking affordable rental housing have a particularly difficult time right now: there just is not enough affordable rental housing to go around. With so many Vermonters waiting for the opportunity to rent an apartment, house, or condominium, it can be hard for individuals

You Have the Right...

(to know your rights)

It is against the law for a landlord to refuse to allow a person with a disability to make reasonable modifications to an apartment, at the expense of the tenant, or to make reasonable accommodations in rules, practices, or services when needed for the full enjoyment of the premises by a tenant with a disability.

Unlawful discrimination can take the form of a refusal to rent or show an apartment, harassment of a tenant, intimidation, or threats of retaliation if you exercise your fair housing rights. Vermont's law also applies to the rental of mobile homes or mobile home lots.

After you have lived in a motel or similar accommodation for at least 30 consecutive days, a landlord-tenant relationship comes into effect, and Vermont law can be applied. and families living on fixed incomes and small budgets not to feel particularly frustrated in their efforts to find a place they can afford. Affordable apartments may be in bad condition and many lowincome tenants are hesitant about asking a landlord to make improvements.

It is easy to wonder how to get help with housing questions and concerns: if the place you rent is cold, the wiring dangerous, or lacks fire alarms; are you responsible? If you need accessibility features, are you responsible, or does your landlord or mental health agency bear some responsibility? How much privacy can you have and what kind of behavior is not OK? If you complain today will you be thrown out on the streets tomorrow? If you get your housing through a service agency, will your decision to ask for alternative providers or not to use treatment affect your access to housing funds? Federal and state laws offer some protections in many of these situations, but the housing situation in Vermont adds its own challenges.

Many of the people we talked to did

(Continued)

Tenant protections include:

Late Fees: Under Vermont law, landlords may charge a fee if rent is not paid on time. If a landlord tries to charge a late fee, you should insist on first seeing documentation that the late fee is equal to the landlord's expenses. If the landlord cannot, or will not, show this documentation you may refuse to pay the late fee.

Retaliation: It is illegal for a landlord to retaliate against you because you complained to a governmental agency regarding possible discrimination or health safety matters.

Privacy and Access: A landlord may enter a residence with your permission at any time that is agreed upon. A landlord may also enter without your permission, but only after no less that 48 hours notice and then only enter your residence between 9 a.m. and 9 p.m. A landlord can only enter for the following reasons:

- to inspect the premises.
- to make repairs, alterations or improvements.
- to supply agreed-upon services.
- to show an apartment.

Rent Increases: Landlords must give you written notice of a rent increase at least 60 days before the increase starts. Lease provisions usually disallow rent increases during the term of the lease.

If you live in subsidized housing where

not have solutions to the current housing shortage, but they did share some good information on how different housing subsidy and service programs worked, and offered tips for understanding your housing options and rights. This chapter highlights three housing strategies: knowing your rights and responsibilities, understand government-sponsored programs, housing including some housing services, and thinking about what you need to do to make your housing situation work for you. Contact information for various housing resources and advocacy groups are listed at the end of this chapter.

Know Your Housing Rights

Vermont law clearly defines the rights and responsibilities of both landlords and tenants. A lease agreement cannot limit or take away the rights, responsibilities, and protections spelled out under that law. The handbook *Renting in Vermont* explains that a "land lord cannot enforce a lease provision that takes away any rights the tenant has under the law, even if the tenant agrees to the provision by signing the lease. Clauses, for example, which give the landlord the right to physically put a tenant out on the street or shut off the utilities because of unpaid rent are forbidden by law and are void."

These protections do not mean that it is easy to find the housing you need, but

(Continued)

a change in your rent results from an annual or semi-annual determination of family income, you may not have a right to 60 days' notice.

Vermont's law does **not apply** to buildings with three or fewer apartments (only if the owner or a member of the owner's immediate family lives in one of the apartments); rental units which would be too small for the family desiring to live there, based on applicable occupancy standards.

Vermont Tenants, Inc. 800-287-7971

they can protect you from an unfair lease, being evicted without due process, and from neglect, exploitation, or other illegal action by landlords.

Fair Housing Law protects people from being discriminated against in housing solely because of a disability. It is illegal to refuse housing or a mortgage to you because you have, or someone close to you has, a disability. Owners are also expected to make accommodations for people with psychiatric disabilities. Though people sometimes think of accommodations in terms of ramps, or other physical changes, legal service programs have been able to help individuals with psychiatric disabilities whose pets help them cope to get a waiver from a "no pets" policy. The Vermont

Human Rights Commission investigates suspected Fair Housing violations, and other legal services like Law Line can provide guidance on whether a complaint falls under Fair Housing laws. Vermont Tenants, Inc. is also a statewide resource for renters to determine whether an action violates state and federal law.

Finding Housing Funds and Subsidies

Sometimes people just need a break in their housing costs. Housing funds that serve the needs of people with psychiatric disabilities are primarily channeled in two directions: one is to agencies such as public housing authorities and nonprofit housing developers, and the other is to those agencies that contract with the state to provide regional mental health services. These funds include subsidies to make housing more affordable for low-income individuals, including people with disabilities; and other programs that provide specialized housing and service money to individuals served by local mental health programs.

Public housing agencies offer subsidized housing (without support services) in two ways: through housing projects where the rent subsidy goes with the apartment, or through certificates or vouchers that allow you to take the subsidy and use it to help partially cover the cost of another apartment. Unfortunately, the high cost of rental

Is It Discrimination When...?

When you're in crisis, you may or may not be able to be a good tenant. It can be hard enough just to get through the night.

The housing issues that can come up when you are not able to cope can sometimes threaten someone's housing situation, and be frightening to deal with. Successful coping sometimes requires some advance planning.

Sometimes it's hard to figure out whether the Fair Housing Law or other tenant / landlord law covers a housing problem.

The law covers not all problems and not all solutions are found in court. It is very hard to say, "I'm losing it" and ask for help; but sometimes that's what it takes. Sometimes people's housing situation gets bad because they have too little support when they reach a crisis point.

It helps to be honest about the support you may need if you go into crisis and to get a few people you trust to sit down with the landlord or a mental health agency to make sure there is help, support, and understanding during a crisis.

If you can do this while you're not in crisis, and have someone available who will help coordinate your supports when you can't, often the hard times won't be so hard and your housing situation can be preserved. housing in many areas of the state makes it hard for tenants with vouchers to find affordable rentals. Local peer support groups, drop-in centers, and service organizations often keep information on available rentals, and know which landlords rent safe and affordable housing.

Any individual with а disability can apply for a subsidy by filling out an application with their local public housing authority, or by applying with the Vermont State Housing Authority (see the resource directory at the end of this chapter for phone numbers). In addition, there are many other nonprofit housing developers throughout the state-such as community land trusts-who are in the business of creating affordable housing, You can apply for housing through these agencies as well. Ask your local public housing authority for the phone number. You can also call the Vermont Center for Independent Living, 1-800-639-1522, and ask the information specialist to look in the directory of housing published by the state Department of Housing and Community Affairs. Or you can call the Department yourself, 1-802-828-3211, and ask for the directory that lists all affordable (and accessible) public housing available in Vermont.

In applying for a rent subsidy, it is important to apply as early as possible because there are often long waiting lists, up to two years or more. While it may seem useless to get on the list because of the current rental costs and long wait, it still makes sense to apply. Sometimes an affordable apartment

Making a House a Home

Many people living with mental illness, a psychiatric disability, or having been labeled mentally ill say the same thing: Take stock of what you want and need in your housing situation and find ways to make it happen.

This can help you choose the right place and build the kinds of space and lifestyle you need to live will and take care of yourself.

Whatever works for you is worth building into your home life. It might be a pet, a quiet space, a light box, writing poetry, having someone you know you can call during a long dark night, or time for a bike ride, close friends, or a good book. will become available. Also housing priorities sometimes shift and you can suddenly be moved up to the top of the list. If you feel you need an advocate to help you with this process, contact either Vermont Psychiatric Survivors, Inc., 1-800-564-2106, or the Vermont Center for Independent Living, 1-800-639-1522.

Housing Funds and Services Available through Mental Health Programs

Community mental health agencies receive federal and state funds for housing from a variety of sources, usually

channeled through the Department of Developmental and Mental Health Services. Funds include Housing Contingency Funds, HUD Shelter plus Care, HUD Transitional Housing, ESD funds (formerly PATH), HUD Safe Haven, and funds to support group homes.

The Community mental health agencies vary in the amount of monies they receive from each source. Consequently, the number of "beds" or slots they have available to serve individuals with psychiatric disabilities also varies. Advocates and users of these programs highlight how important it is to know what these funds pay for and what participating in these programs requires, or does not require.

Sometimes people don't understand that they have certain rights and that they have a right to ask for these types of housing and service funds, even when they don't want to use traditional mental health services. When this happens it helps to have an advocate, someone you trust to help you challenge this. The advocate can make sure you're listened to and that you retain control of your housing situation and understand the requirements of different housing programs. It can be a knowledgeable friend, a peer advocate, or another person you trust to help you get good information, and help make sure your needs, interests and rights are respected.

One advocate says, "There are situations when people are basically told if they're

not going to comply with treatment, then they will lose their housing contingency funds [money given to people on a monthly basis to help pay for the rent]. [They're told] 'you do treatment or else we're taking this basic support piece away.'" When she confronts the issue with a designated agency, it's usually denied. She then sits down with the person she's helping and staff of the agencies involved to make sure the person's need for housing wasn't used to force them into treatment or services they didn't want.

Not everyone is lucky enough to have a knowledgeable advocate in their corner. The following summary of special housing programs may make it easier for you to sort through your options, understand your rights, and know whether a certain program will work for you.

Day by Day

One married couple, both of whom have different psychiatric disabilities, talked about what it is like to raise their kids and take care of their own home. For starters, it meant doing things differently to avoid the chaos they experienced growing up.

"We need to be pretty open with each other and with our kids about how our disabilities affect us and what we need to do to manage. It helps to plan ahead and to be honest with each other, and ourselves, about what we need to do to keep crisis from happening in the first place. We try to support each other and be clear and up front with each other about what works."

Housing Contingency Funds

Housing Contingency Funds are monies given to community mental health agencies that help people with psychiatric disabilities who are waiting for Section 8 or similar housing subsidies. HCF monies can be used to pay up to 50 percent of the rent, if needed, for individuals eligible for a subsidy. Priority is typically given to people at risk of returning to the Vermont State Hospital or a regional hospital psychiatric unit, although this is at the discretion of the local community mental health agency. If an individual does not want to work with the community mental health agency, and they are eligible for the subsidy, they can work through an intermediary agency to meet their needs.

Shelter plus Care

Shelter plus Care funds are HUD (Housing Urban Development) monies targeted

for homeless individuals who are either substance abusers or who are identified as having a "severe and persistent mental illness." These programs fund an arrangement between the public housing authority and the local mental health agency that provide services to the individual. Sometimes people think they have to use these services to stay in housing. They don't. In this program, the housing subsidy may stay with individual, or may be tied to a particular residence with some agencies. Shelter plus Care provides permanent housing and is currently available through the community mental health agencies serving Addison, Rutland, Franklin/Grand Isle, Chittenden, and Windham/Windsor counties.

Transitional Housing

Funds for transitional housing are HUD-based and can be used to enable an individual to live in a supportive environment for up to 24 months.

A supportive environment may include a group home, a licensed community care home, a single residential occupancy home (where everyone has their own bedroom but shares kitchen and living facilities), or a therapeutic community such as Spring Lake Ranch or Birch House. ESD funds (Economic Services Division - formerly PATH) are monies targeted for people who are homeless who need transitional services as they move out of local shelters.

Safe Haven

Safe Haven is a peer-run collaboration between Vermont Psychiatric Survivors and the Clara Martin Center. Safe Haven is an innovative shelter in Randolph, Vermont serving homeless, labeled mentally ill people in the counties of Washington, Orange and Upper Windsor. Safe Haven was liscensed as a Therapeutic Community Residence on March 2, 1998. For information on current capacity at Safe Haven call (802) 728-5233.

The length of stay permitted in Safe Haven programs varies with each project.

housing resources

BARRE HOUSING AUTHORITY

(802) 476-3185 4 Humbert St. Barre, VT 05641 Subsidized housing.

BENNINGTON HOUSING AUTHORITY

(802) 442-800022 Willow Brook Dr., Bennington, VT 05201Subsidized housing.

BRATTLEBORO HOUSING AUTHORITY

(802) 254-6071 PO Box 2275, Brattleboro, VT 05303 Subsidized housing.

BURLINGTON HOUSING AUTHORITY

(802) 864-053865 Main St., Burlington, VT 05401Subsidized housing.

HARTFORD HOUSING AUTHORITY

(802) 295-5047 Municipal Building, 171 Bridge Street, White River Jct., VT 05001 Subsidized housing.

MONTPELIER HOUSING AUTHORITY

(802) 229-9232155 Main Street, Montpelier, VT 05602Subsidized housing.

RUTLAND HOUSING AUTHORITY

(802) 775-2926 5 Tremont Street, Rutland, VT 05701 Subsidized housing.

SPRINGFIELD HOUSING AUTHORITY

(802) 885-490580 Main Street, Springfield, VT 05156Subsidized housing.

ST. ALBANS HOUSING AUTHORITY

(802) 527-1490 13 Lake St., St. Albans, VT 05478 Subsidized housing.

SAFE HAVEN

(802) 728-5233 4 Highland Ave. Randolph, VT 05060

LEGAL AID - BURLINGTON

(800) 747-5022 264 North Winooski Ave., P0 Box 1367, Burlington, VT05402 Legal assistance.

LEGAL AID - MONTPELIER

(800) 789-41957 Court Street, 2nd Floor, P0 Box 606, Montpelier, VT 05601Legal assistance.

LEGAL AID - RUTLAND

(800) 769-745957 North Main Street, Rutland, VT 05701Legal assistance.

LEGAL AID - SPRINGFIELD

(800) 769-9164 Suite 301, 56 Main Street, Springfield, VT 05156 Legal assistance.

LEGAL AID - ST JOHNSBURY

(800) 769-6728177 Western Avenue, Suite 1, St Johnsbury, VT 05819Legal assistance.

VERMONT LEGAL AID, INC

(800) 265-0660Mental Health Law Project, 121 South Main Street,P0 Box 540, Waterbury, VT 05676Legal services for the mentally ill.

VERMONT STATE HOUSING AUTHORITY

(800) 820-5119
(802) 828-3295
1 Prospect Street, Montpelier, VT 05602-3556

Website: www.vsha.org Subsidized housing.

VERMONT PROTECTION AND ADVOCACY

(800) 834-7890 141 Main Street, Suite 7, Montpelier, VT 05602 Mental health advocacy.

VERMONT PSYCHIATRIC SURVIVORS, INC.

(800) 564-2106
1 Scale Avenue, Suite 52, Rutland, VT 05701
Website: www.sover.net/~vpsinc/
Mental health advocacy and support.

VERMONT TENANTS, INC.

(800) 287-7971294 N. Winooski Avenue, Burlington, VT 05401Website: www.cvoeo.orgInformation on tenants' rights.

WINOOSKI HOUSING AUTHORITY

(802) 655-2360 83 Barlow Street, Winooski, VT 05404 Subsidized housing.

Making Employment Work

Work. It's that dirty little four letter word that has come to define who we are as individuals in our society; we are often judged and compared in relation to the work we do, and how well we do it. However, entering the work force can be both difficult and challenging for psychiatric survivors. Episodic conditions can often limit a person's ability to perform a task or maintain a steady workload.

For many people, work — in whatever capacity and level is most appropriate and fulfilling — is a way to connect with other people, expand their knowledge and be involved in something they truly love. When any person has a talent he or she can share with the community, the entire community is better for it — no matter how small or insignificant a person feels about a particular set of skills.

For some people, the idea of holding down a 40-hour-a-week job isn't an option, but that's the case for a lot of people in today's society. There are plenty of people who choose to balance life, family, time for themselves and a hobby in ways that were unheard of even a decade ago. Today, many people choose to live a simpler, less complicated life and work less.

Once you decide to join the work force, it is important to assess what kind of work your skills are best suited for, how much you want to work, and when you want to work. Job counselors through the state Vocational Rehabilitation Program can help assess how much money you can earn and keep your benefits, and what resources are available to help you find a job, get an interview and, if you get the job, receive on-the-job training and adaptive assistance, if necessary.

One psychiatric survivor, who is now working 40 hours a week, suggests first looking for part-time or volunteer positions before trying to work a full week. Once you volunteer time to a local nonprofit, public or charity organization you might then move on to working part-time in an office or at home. However, some workers continue to volunteer time as a way to enrich their own lives and keep a connection to people in the community "I still deliver books [from the Montpelier library] to elderly women who

"It's nice to have supports to help you ... go back to work and feel good about it."

are homebound. I've been doing that for a very long time. It's a wonderful thing. I enjoy the company when I stop by and deliver them. They really, really appreciate it," adds one worker.

Accommodations Employers Can Make On the Job

There are a number of accommodations that can be used on the job. The following examples are a partial list of what an employer can do to help employees.

- Restructure jobs: Reassigning jobs and duties to other employees as needed.
- Adjust work schedules: Allow employees to take time off for therapy appointments, or allow later starting time because of morning drowsiness due to medications.
- Flexible leave: The use of sick leave for mental health reasons, or extended leave without pay due to hospitalization.
- Provide assistive devices and equipment: For example, the use of e-mail to deliver daily instructions.
- Modify work sites: The installation of wall partitions around a workstation to minimize distractions.
- Provide special transportation: Assigned parking space closer to building to manage panic condition.
- Provide human assistance: Instead of readers and interpreters, provide a job coach or mentor.

For one Central Vermont worker, ongoing anxiety attacks make it difficult to maintain a consistent work schedule, but he has learned to find a routine that works for him. "Sometimes the medication just doesn't stop them or prevent them, sometimes they just come right out. I have learned strategies, though. If I work day to day instead of a day and then two days without work and then work again it's better. [When you work with days off in between] it's hard because you have to get used to the crowd again, and the noise and everything else."

During his workday, this employee has found ways to quell anxiety attacks through other techniques. "I have a couple of aquariums running right now, and if I talk about something I'm interested in and do that for like five or ten minutes sometimes that alleviates the anxiety. Then I can continue doing work without having the anxiety bother me because I have my mind on my interest and not on my anxiety," he says.

Being able to understand your own limitations at work and being honest about them to an employer is an important first step. It is also good to know what is expected of you in terms of daily or weekly duties from your employer. In all, however, being professional in all situations will help guarantee long-term success as it creates a mutual bond between you and your employer.

"Your demeanor is very important when you're dealing with employers. I think it's reasonable to expect anybody,

for example, to show up on time. It's also reasonable to ask for a reasonable accommodation so that you can go for an appointment. But, there has to be that

Is it Job Discrimination?

Below is a list of typical examples of job discrimination:

- An employer refuses to make a reasonable accommodation, such as creating a flexible work schedule or providing you with partitions or walls to minimize distractions.
- Disciplining the employee for misconduct that is unrelated to the performance of his or her job.
- An employer discloses to other employees the nature of your disability.
- An employer requests to monitor your medication.
- A prospective employer asks if you need an accommodation or have a disability. Likewise, an employer can not demand to see your therapists' notes to prove your need for an accommodation, but can ask for reasonable verification of your disability.

equivalency there," says one advocate.

When a person decides to work, there are plenty of programs which offer assistance to find work as well as the necessary support to keep a job. Several different laws apply to people with disabilities and require employers and educators to provide reasonable accommodations. They are:

- All employers with 15 or more employees, including for-profit and nonprofit businesses, state and local governments, religious entities and the United States Congress, must comply with the Americans with Disabilities Act (ADA).
- Federal agencies of the executive branch, federal government contractors and those who receive federal financial assistance must comply with the Rehabilitation Act of 1973.

• Although not specifically requiring accommodations, the Family Medical Leave Act provides for 12 weeks of unpaid employee leave in the event of illness, which may be used by an employee with a disability as an accommodation. This law does not apply to businesses with fewer than 50 employees.

Americans with Disabilities Act (ADA)

The ADA defines "disability" as an impairment that "substantially limits one or more of the major life activities." The ADA requires that reasonable accommodation be provided, if necessary, for all impairments that meet the definition of "disability," whether hidden or visible. Reasonable accommodations must be determined on a case-by-case basis to ensure effective accommodations that will meet the needs

Your Ticket to Work

In order to address a significant problem in the United States, the U.S. Congress, under the leadership of U.S. Sen. James Jeffords, passed The Work Incentives Improvement Act of 1999. The so-called "Ticket to Work" program offers more flexible benefits for people with disabilities to return to work while maintaining health care and other benefits.

While the program does not guarantee that you will find a job, this voucher does grant you a number of benefits that current programs do not. Those benefits include:

- An option to buy Medicaid coverage if you are working and receiving SSDI (especially if your earnings would have otherwise disqualified you).
- An up to 93 month extension of Medicare if you receive SSDI. This means you will not have to reapply for benefits during that period.
- A five-year grace period for regaining SSDI benefits if you need them.
- An end to the SSDI practice of basing disability status on wages in disability reviews.
- Work incentive counselors in each state (in Vermont, this role will be assumed by the Vocational Rehabilitation program in conjunction with Vermont Center for Independent Living Benefits

of the employee and the employer. Two Supreme Court rulings have altered the use of mitigating measures (such as medication) to complete a major life activity. This means that if a person has little or no difficulty performing any major life activity because she or he uses a mitigating measure, then that person will not meet the ADA's first definition of "disability." This simply means, however, that a person's "disability" will be measured after weighing both the positive and negatives of any mitigating measure. For example, a person who takes medication because he or she cannot sleep at night because of an episodic condition could still have greater difficulty performing "normal" job tasks due to medication and therefore meet the ADA's first definition.

Job coaches can be essential for many survivors who return to work, even part-time. One survivor who experiences episodic conditions of anxiety has a job counselor who offers feedback and reassurances to dissipate anxiety over situations at work. This survivor works about 20 to 30 hours a week, and is allowed less if he needs to take a day off due to anxiety attacks. His employer, a department store in Montpelier, willingly makes these accommodations.

Social Security Income and Social Security Disability Income

(Continued)

- to Work Counselors) to help you determine your work and support needs.
- A Ticket to Work voucher given by the Social Security Administration to you allowing you to seek the jobsupport service provider of your choice.



Social Security Income (SSI) and Social Security Disability Income (SSDI) are significant programs that offer people with psychiatric disabilities a sense of economic security to pay their bills and live their lives. However, it is also a daunting system to navigate and challenge.

One of the most important facts to remember is that the Social Security Administration (SSA) denies nearly 80 percent of initial disability claims, and the approval rate of appeals is not much better. SSA offers two types of disability benefits. Both eventually require you to qualify medically. But first, SSA will determine which program you are eligible for by considering non-medical factors such as work history and income.

After the initial denial, which is highly likely, you need to file a Request for Reconsideration using a form provided by your local SSA office. The most important part of it is a booklet asking you if your

medical condition has changed, which doctors you have been seeing and what medications you are taking; it also provides space for you to make any comments. This is a good time to add information that you didn't include on the initial application, or correct any errors.

Be willing to stick it out, and remember that the SSA was created to help people in need. It may take up to a year in some instances before a case is resolved, however the money is there for your benefit and you deserve access to it.

At any time during the hearing process, you can seek legal assistance if you are feeling over whelmed by the process. A legal resources list is provided at the end of this chapter.

Common ADA Questions

What is a disability?

Under the ADA, the term "disability" means: "(a) A physical or mental impairment that substantially limits one or more of the major life activities of an individual; (b) a record of such an impairment; or (c) being regarded as having such an impairment."

What major life activities are limited by mental impairments?

The major life activities limited by mental impairments differ from person to person. There is no exhaustive list of major life activities. For some people mental impairments restrict major life activities such as learning, thinking, concentrating, interacting with others, caring for oneself, speaking, performing manual tasks, or working

Can the corrective effects of medication be used against me?

Though some courts have disagreed, the Equal Employment Opportunity Commission has said that the corrective effects of medication should not be considered when determining eligibility for an accommodation.

What about if my disability is episodic — it comes and goes?

Ticket to Work

Federal law is allowing states to offer more potential benefits for workers with psychiatric disabilities. The Ticket to Work program, which was conceived and promoted by former U.S. Sen. James Jeffords, R-VT, is designed to address problems faced by beneficiaries as they work to obtain or retain employment.

Only about 12 to 15 percent of the people labeled to have a serious mental illness work, which is by far the lowest employment rate of any disability group. In Vermont, the unemployment rate is near 40 percent for all people who are disabled, compared to a 4 percent unemployment rate for the remaining population. (U.S Census Bureau, Vermont 2000)

Many disabled individuals tend to stay on SSI / SSDI because previous rules made it difficult to maintain a secure level of support income and health care services after a person decided to enter the work force, even part-time. The theory of Ticket to Work is that people will seek out work and keep those jobs longer if they are able to retain the security of social security and related health insurance benefits while determining if they are able to maintain employment.

The Ticket to Work program provides Employment financial incentives to Networks work (ENs) that with beneficiaries successfully obtain to stable employment. These ENs can get paid by Social Security when they can demonstrate that a beneficiary has

(Continued)

Even if a disability is not currently active, an employee who needs an accommodation to continue controlling symptoms can be covered by the ADA. The EEOC mentions bipolar disorder, major depression or schizophrenia as examples of disabilities that can be episodic during the course of months or years.

Do I have to make an official request for an accommodation?

No. You can ask for assistance in "plain English" without mentioning the word "accommodation.". obtained and maintained employment to the extent that the beneficiary is no longer eligible for Social Security benefits. Beneficiaries who are using their Ticket can choose between several ENs doing business in Vermont. VR caseworkers in Vermont are well versed in the links that need to be established between mental health and employment support services.

Kev changes because of this legislation affect everyone who receives SSI or SSDI. The most significant change is that work activity will not immediately trigger either benefit or disability review. Also, the Ticket to Work Act provides for accelerated reinstatement of benefits if vou lose a job. This means if you have a job and your benefits are cut off, then you lose that job, you can ask for the benefits to be reinstated without filing a new application. Once you make the request

you will receive payments while SSA considers your request.

Another important change is that Medicare eligibility was extended for up to 93 months (approximately 7.5 years) for people who were eligible as of October 1, 2000. This means you remain eligible (without having to reapply or ask for a review) for the entire period.

For information about the amount of money you can earn and still receive benefits, including the amount students (under the age of 22) can earn contact the Social Security Administration, your local Vocational Rehabilitation office, or the Vermont Center for Independent Living. Contact information for these services are found at the end of this chapter.

Keeping the System on Your Side

As a job seeker and potential employee you need to make sure your separate support teams are talking to each other. Without keeping these various teams in touch

with one another your wishes and needs may go unheeded and unmet.

Each program that you apply to for services has its own way of dealing with problems when they arise. If you have the time, ask an agency's counselor to provide you with adequate information regarding your rights to appeal any decision, and to be informed of how to file a complaint if you feel that your request is not being handled properly.

If you feel that a particular agency is not helping you to the best of its ability or you have questions about where to seek out services, the Client Assistance Program (CAP) is an independent advocacy program designed to help. CAP can help if you are applying or receiving services from the following agencies: Division of Vocational Rehabilitation, Vermont Center for Independent Living, Division for the Blind and Visually Impaired, Vermont Association of Business, Industry and Rehabilitation, Vermont Association for the Blind and Visually Impaired, as well as Supported Employment and Transition Programs. (1-800-747-5022 for the Burlington office and 1-800-769-7459 for the Rutland office.)

CAP can tell you about the services available through each agency, as well as about each agency's internal appeals process, or how to file effective consumer complaints. CAP is part of the Disability Law Project of Vermont Legal Aid, and its services are free and confidential.

Making sure programs and services do what they are designed to do — which is support your needs in the workplace and in your everyday life — is a primary objective. When these services all work in your favor, the results can be rewarding.

As one worker recalls when all the pieces fall into place for him: "There is hope. It's nice to have supports to help you like a therapist and a case manager and a job coach. It's also helpful to be on the right medication and get well enough to actually go back to work and feel good about it."



employment resources

CLIENT ASSISTANT PROGRAM – BURLINGTON

(Vermont Legal Aid) 264 North Winooski Avenue Burlington, VT 05401 (802) 863-2881 (800) 747-5022

CLIENT ASSISTANT PROGRAM – RUTLAND

(Vermont Legal Aid) 57 North Main Street Rutland, VT 05701 (802) 775-0021 (800) 769-7459

VERMONT DEPT. OF LABOR- BARRE

(802) 476-2600 5 Perry Street, Suite 200 Barre, VT 05641 Employment services.

VERMONT DEPT. OF LABOR – BENNINGTON

(802) 442-6376150 Veterans Memorial Dr, Suite 2,Bennington, VT 05201-1998Employment services.

VERMONT DEPT. OF LABOR - BRATTLEBORO

(802) 254-4555

232 Main Street, P0 Box 920, Brattleboro, VT 05302-0920 Employment services.

VERMONT DEPT. OF LABOR - BURLINGTON

(802) 863-762663 Pearl Street,Burlington, VT 05402Employment services.

VERMONT DEPT. OF LABOR - MIDDLEBURY

(802) 388-4921700 Exchange Street,Middlebury, VT 05753-1157Employment services.

VERMONT DEPT. OF LABOR - MORRISVILLE

(802) 888-454563 Professional Dr.Morrisville, VT 05661Employment services.

VERMONT DEPT. OF LABOR - NEWPORT

(802) 334-6545 Hebard State Office Bldg., 100 Main St., Suite 120, Newport, VT 05855 Employment services.

VERMONT DEPT. OF LABOR - RUTLAND

(802) 786-5837

200 Asa Bloomer Building, 2nd floor, Rutland, VT 05701-9413 Employment services.

VERMONT DEPT. OF LABOR - SPRINGFIELD

(802) 885-216756 Main StreetSpringfield, VT 05156-2900Employment services.

VERMONT DEPT. OF LABOR - ST ALBANS

(802) 524-658520 Houghton Street, Room 101,St Albans, VT 05478-2246Employment services.

VERMONT DEPT. OF LABOR - ST JOHNSBURY

(802) 748-3177 1147 Main Street, P0 Box 129, St Johnsbury, VT 058 19-0129 Employment services.

VERMONT DEPT. OF LABOR - WHITE RIVER JUNCTION

(802) 295-8805220 Holiday Dr.White River Jct., VT 05001-0797Employment services.

VABIR (Vermont Association of Business, Industry and Rehabilitation) – Main Office

1-800-639-2909 75 Talcott Road, #30 Williston, VT 05495 Website: www.vabir.com

VOCATIONAL REHABILITATION - BARRE / MONTPELIER

(802) 479-4210
McFarland State Office Building
5 Perry St., Suite 100
Barre, VT 05641
Employment services and support.

VOCATIONAL REHABILITATION - BENNINGTON

(802) 447-2780200 Veterans Memorial Dr, Bennington, VT 05201Employment services and support.

VOCATIONAL REHABILITATION - BRATTLEBORO

(802) 257-0579
Marlboro Technology Center
28 Vernon Road, Suite 400
Brattleboro, VT 05302
Employment services and support.

VOCATIONAL REHABILITATION - BURLINGTON

(802) 863-7500108 Cherry StreetBurlington, VT 05401Employment services and support.

VOCATIONAL REHABILITATION - MIDDLEBURY

(802) 388-4666
282 Boardman Street
The Community Service Building
Middlebury, VT 05753
Employment services and support.

VOCATIONAL REHABILITATION - MORRISVILLE

(802) 888-597663 Professional DriveMorrisville, VT 05661Employment services and support.

VOCATIONAL REHABILITATION - NEWPORT

(802) 334-6794100 Main St, Suite 210Newport, VT 05855Employment services and support.

VOCATIONAL REHABILITATION - RUTLAND

(802) 786-5866 190 Asa Bloomer Building Rutland, VT 05701-9408 Employment services and support.

VOCATIONAL REHABILITATION - SPRINGFIELD

(802) 885-2279 100 Mineral St., Suite 308 Springfield, VT 05156-2306 Employment services and support.

VOCATIONAL REHABILITATION - ST ALBANS

(802) 524-795020 Houghton St., Rm. 105St Albans, VT 05478Employment services and support.

VOCATIONAL REHABILITATION - ST JOHNSBURY

(802) 748-871667 Eastern Ave., Suite 3St Johnsbury, VT 05819Employment services and support.

VOCATIONAL REHABILITATION - WHITE RIVER JUNCTION

(802) 295-8850220 Holiday Drive, Suite AWhite River Jct., VT 05001Employment services and support.

VERMONT CENTER FOR INDEPENDENT LIVING

(800) 639-152211 East State Street, Montpelier, VT 05602Website: www.vcil.orgPeer advocacy counseling program.

VERMONT PROTECTION AND ADVOCACY

(800) 834-7890
141 Main Street, Suite 7, Montpelier, VT 05602
Website: www.vtpa.org
PABSS program - Protection & Advocacy for Beneficiaries of Social Security
52

Institutionalization & Alternatives

Aside from the social stigma associated with institutionalization, many expatients speak of a deeper fear when they speak of such facilities in Vermont. The threat of being institutionalized is seen as an oppressive weapon that has devastating effects on individuals.

Although society considers mental institutions as treatment facilities, ex-patients perceive them as places used to make individuals behave according to the "golden rule of the mental health system." The golden rule is that a person must admit he or she is mentally ill and accept treatment in order to be deemed well enough to be released.

"I've talked to many people at Vermont State Hospital. There's anger and hopelessness because people are overwhelmed, I think, by their treatment teams. They feel like they have no access to legal services or legal advice," says one advocate and ex-patient.

Many ex-patients dislike the restrictions placed on personal activities and use this as an example to show how facilities enforce the golden rule. Other coercive methods, as claimed by patients in a paper issued in January 2000 by then-Mental Health Commissioner Rod Copeland, include solitary confinement and forced medication.

Other examples of coercion reported to the Commissioner include: arresting and locking up children and adults; putting pressure on individuals so that they feel their ideas or ways of doing things are not respected; the use of seclusion and restraint; controlling a citizen's choice of agencies or service providers; withholding services if citizens do not agree to engage in certain actions, and not giving individuals the

"People are overwhelmed, I think, by their treatment teams. They feel like they have no access to legal services or legal advice." opportunity to communicate.

Whether a facility chooses to honor a person's crisis or recovery plan varies widely. One of the best ways to secure control of a treatment method, even if it means no treatment or a refusal of forced treatment, is through an Advance Directive (or AD). An AD can also

Patient Rights

Patients have all the rights of any other citizen, but in many cases an institution may restrict these rights to protect the health and safety of the patient or others.

As detailed in a paper by Rod Copeland, former Commissioner of Mental Health, coercion remains a problem in Vermont's mental health system, which makes it all the more imperative to know the rights that cannot be taken away, and which rights can be restricted.

When you arrive at a hospital, treatment center or other inpatient facility ask what rights you can expect to enjoy and which can be altered or restricted by doctors or staff.

And, make sure your rights are explained to you in a language you understand. be used to transfer decision-making to a relative, loved one or guardian. You can also make clear where you wish to be transferred during a crisis, and where you don't (This procedure is discussed at length in the "Advocating for Yourself" chapter).

Treatment services, and treatment in general, is an area full of emotion, beliefs and scientific arguments. Whether an individual decides to pursue treatment during a difficult period in his or her life is less important than making sure people are in control of their treatment method.

Voluntarily committing yourself to an institution often gives you more leverage when seeking certain privileges such as unlimited coffee breaks. Each institution has different rules regarding privileges, and depends on whether a person has requested services on their own, or has been committed by an outside agency or individual.

As a patient, regardless of what facility you enter, you have some basic rights but you must understand that most of your rights can be restricted and those

restrictions vary from hospital to hospital, treatment center to treatment center. A more detailed list is included in this chapter but the basic ones are:

- the right to converse with others privately;
- the right to communicate by sealed mail;
- the right to receive visitors and make telephone calls;
- the right to vote;
- the right to humane care and treatment;
- the right to ongoing participation in the planning of your mental health services; and
- the right to be informed of your rights in a language you understand.

The right to make telephone calls, receive visitors and participate in the planning of your mental health services can be reduced if the staff believes it would improve your chances of recovery. Make sure you receive a paper copy of these rights when you are admitted. However, there are a few rights that no person or program can deny. The rights are:

- the right to counsel;
- the right to humane care and treatment;
- the right to communicate by sealed mail;
- the right to apply for a writ of habeas corpus;
- the right to periodic court review if you are an involuntary patient;
- the right to grieve any aspect of your care and treatment services, including the use of involuntary treatment procedures;
- the right to have a lawyer in any proceedings in court; and
- the right to have periodic administrative review of your situation.

Examples of Coercion

In the position paper released in early 2000, Vermonters mentioned following as examples of coercive methods:

- Locking up children and adults.
- Putting pressure on individuals so that they feel their ideas or ways of doing things are not respected.
- The use of seclusion and restraint.
- Controlling a citizen's choice of agencies or service providers.
- Withholding services if citizens do not agree to engage in certain actions.
- Not giving individuals the opportunity to communicate.
- Involuntarily hospitalizing and medicating citizens.
- Not having access to information.
- Speaking on behalf of people with psychiatric disabilities in paternalistic, controlling ways.

There are a number of skilled legal advisors who can help you during times of involuntary commitment including Vermont Legal Aid's Mental Health Law Project and Vermont Protection & Advocacy. There are also a number of peer advocates who can ensure your rights are being protected as provided by law.

Six hospitals and centers in Vermont serve as locations for emergency examinations, informally referred to as the 72 hour hold and long-term treatment centers, whether voluntary or involuntary. Those are: The Vermont State Hospital in Waterbury, Rutland Regional Medical Center, the Windham Center in Bellows Falls, Retreat Healthcare in Brattleboro, Fletcher Allen Health Care in Burlington and Central Vermont Medical Center in Berlin.

Why Coercion Occurs

The 2000 paper concluded that coercion is found throughout the state's mental health system, and is caused by a variety of factors. It is important to be able to recognize these patterns and anticipate warning signs. These factors include:

- Coercion can occur particularly when the decisions on where a person is going to live, and with whom, are controlled by others.
- Pessimistic views about recovery and self-determination lead to overcontrol, coercion and neglect.
- The conflict between healing and public safety can lead to coercion.
- Fears in the provider community of being sued for failing to keep citizens healthy and safe can lead to over-control.
- Power, in any relationship, can lead to coercion. Professionals often have power over the lives of others, and may see people in a narrow light through the service system.

Whether a long-term or short-term stay, the rights mentioned above cannot be restricted. However, whether the stay is voluntary or involuntary can often determine how your remaining "rights" will be granted. Some programs offer smoke breaks more frequently than others do, and those breaks are often reduced for people who have been committed involuntarily. However, many facilities no longer offer smoking on the grounds.

However, if you are committed involuntarily a strict legal process must be followed. When you commit yourself voluntarily, there is no legal process and unless you know your full rights as a patient, legal advocates say there can be abuses. Just because you are admitted voluntarily does not mean you can leave when you want, either. A doctor can turn around and think it medically inappropriate for you to leave, perhaps even dangerous, and require a 72-hour hold. At that point, you can seek legal advice but are likely to be stuck at the facility for another three days.

Orders of Non-Hospitalization

Increasingly, people who have been committed by the state to the Vermont State Hospital, or into the care of the Mental Health Commissioner in some capacity, are released with a set of conditions they must follow after a brief stay rather than being hospitalized for a long-term stay.

These conditions are spelled out in what are called orders of non-hospitalization (ONH). These orders, which are court-mandated and enforced, include four or five provisions, which usually include taking your medication as prescribed and keeping

Rights that Cannot Be Taken Away

When we talk about coercion, one example is the restriction of rights in the mental health system. However, there are several important rights that cannot be taken from you.

These are the rights that cannot be restricted:

- Your right to counsel.
- Your right to humane care and treatment.
- Your right to communicate by sealed mail with the Chief Executive Officer, the Commissioner of Mental Health, your attorney, your clergy and the judge who ordered your hospitalization.
- Your right to apply for a writ of habeas corpus.
- The right to periodic judicial review if you are an involuntary patient.
- The right to have periodic administrative review of your situation.
- Your right to grieve any aspect of the care and treatment, including the use of involuntary treatment.
- You have the right to request, and fill out, Advance Directives. If you ask, the hospital must provide you with information about these directives. How closely those institutions adhere to those wishes, however, is not governed by law or guaranteed.

appointments with a psychiatrist, case manager or therapist. ONHs often forbid the use of drugs or alcohol, too. Violating these conditions can put a person back in a hospital or bring him or her back to court where the conditions can be made more restrictive. Many conditions are vague in nature, such as "following a treatment plan," and offer no specifics on that plan making it difficult to request personalized treatment options since courses of action are predetermined by mental health officials.

"It's another form of control that people are seeing, are facing," says one legal advocate, regarding ONHs. "In some cases, asking for a change in your treatment plan - while on an ONH can trigger re-hospitalization. This leaves people feeling powerless to change a regimen that is not improving their situation."

There are two types of ONHs. The first is the 90-day ONH and the second is a one-year ONH. Usually, the state moves directly from a 90-day ONH (during which time a person's case is "evaluated") to a one-year request. An ONH can be revoked and a person re-hospitalized if there have been violations of the order, regardless of whether or not he or she is considered a danger to herself/himself or others.

Because ONHs are used more widely today and often requested by local mental health agencies, advocates strongly urge people to write up an Advance Directive for Health Care. This process is discussed in the chapter, "Advocating for Yourself." Simply complying with an ONH may restrict your rights and ability to seek

You Have the Right To (Sort of)

Along with a list of rights that cannot be taken from you is a longer list of so-called "paper rights" that are most often offered, but which can be, and often are, restricted by hospital staff or doctors if they determine your health and safety or that of others, is in jeopardy.

Be direct and ask under what conditions these rights can be restricted. Institutions and hospital-based programs often have a list of patient responsibilities that go with this list of rights.

- The right to see your mental health records, unless the doctor has made a written determination that access to specific material would be detrimental to your health.
- The right to appropriate treatment under conditions that are the most supportive of your personal liberty
- The right to ongoing participation in the planning of mental health services provided to you.
- You have the right to be free from seclusion or restraint, other than by written physician's order for safety reasons in an emergency.
- The right to communicate by sealed mail.
- The right to converse with others privately.
- The right to receive visitors and make telephone calls.

out alternative approaches to wellbeing in the future even if you are being ordered to seek services from a local mental health agency rather than VSH. Though some of these local services often provide peer-run support groups, all are patterned after the long-established medical model.

Community Services

Institutionalization is not the only avenue for people who have been labeled mentally ill. The slow dismantling of the Vermont State Hospital increased the availability of services for people with psychiatric disabilities at the community level. Community care settings are available throughout the state and there are consumer-run models that have also proven beneficial to many individuals.

These alternatives often approach a person's crisis or emergency in very different ways than an institution. Most realize there are unique paths to recovery and that each person has his or her own path to follow. This could mean catching up on sleep for a few days, or performing a particular activity that helps re-focus on life and surroundings.

"Many people come into a crisis

(Continued)

- The right to carry out business dealings.
- Be outdoors at regular and frequent intervals, medical conditions permitting.
- To a professional staff/client relationship without fear of exploitation financially, socially, physically or emotionally.
- To be free from unnecessary or excessive medication.
- The right to keep personal possessions and wear your own clothing, unless your safety will be put at risk.
- The right to information and education on issues such as the treatment that is being offered, treatment alternatives, expected benefits, side effects and risk associated with the medications and procedures used during treatment.

place, whether it's a psych ward or a place like Home Intervention, to escape from life. They need to rest. After two or three days of catching up on their sleep and getting good food, people feel better. After having neighbors in their building making a racket or being fearful that their boyfriend will beat them up or whatever it is, to know that they're in a safe place and that they will be taken care of is a relief. They aren't pushed through a hurried schedule like they are at the places where they are run all day long, but instead are able to relax and get themselves together," says one peer support advocate.

One organization that offers a number of peer- and consumer-run support groups is Vermont Psychiatric Survivors (VPS), based in Rutland.

VPS began as a sponsor of peerrun support groups that could be either support, educational, or social. There are usually between 7 and 12 peer support groups operating in Vermont that receive money to run various activities. VPS also has six paid staff, two outreach workers, and one director, who visit groups and attend meetings. They have more going

on now, too, with peer support joining the recovery education project, Counterpoint newspaper, and the Safe Haven shelter for homeless/survivors that is operated in Randolph.

Safe Haven, licensed as a therapeutic community residence, is an innovative shelter in Randolph serving homeless, people labeled mentally ill in Washington, Orange, and upper Windsor counties. The shelter is greatly needed because people need housing without too many conditions attached at the outset. VPS's goal is to engage guests in services without dictating that any are necessary to stay at Safe Haven (1-802-728-5233).

Aside from Save Haven, there are a number of shelters and drop-in centers throughout Vermont. These locations do not offer the same kind of support services

Looking to Peers for Help

Peer and consumer-run organizations and support groups are more available today than at any other time in the history of the psychiatric survivor movement.

There are currently 7 peer support groups operating in Vermont that receive money to run various activities.

One organization that offers a number of peer-run and consumer-run support groups and drop-in centers is Vermont Psychiatric Survivors (VPS), based in Rutland.

These groups serve as an emotional safety net for those times when we need it most, and turning to friends and family isn't what we need.

For a list of these groups, turn to the resource listings at the end of this chapter. (List of operating peerrun groups are also published in Counterpoint.) as Safe Haven and, in many cases are simply a safe place to sleep and catch up on some needed rest.

Along with changes to the day-today operation of Vermont's institutions, the psychiatric survivors' movement has spurred the creation of nearly a dozen peerrun support groups. These groups offer a safe, peer-directed setting designed to ensure that individuals, and not a system, are what count. VPS maintains an up-todate list of these groups. Counterpoint, the newspaper for people with psychiatric disabilities, prints a complete list of support groups, shelters, drop-in centers and other resources on the back page of each issue.

Community mental health agencies offer a mix of consumer and peer-run support groups along with their standard professional-led groups. These groups provide people a choice of how they want to proceed with recovery.

Community-based agencies are today most people's first avenue of choice as they do the work once done centrally

by the state in Waterbury. There are numerous agencies located statewide, and they include: The Clara Martin Center (Orange County), Howard Center for Human Services (Chittenden County), Counseling Services of Addison County, Lamoille County Mental Health Services, Health Care and Rehabilitation (Brattleboro, White River Junction, Springfield), Washington County Mental Health (Montpelier, Barre), Northeast Kingdom Mental Health Services (Newport and St. Johnsbury), United Counseling Services (Bennington-Manchester), Northwest Counseling and Support Services (Franklin/Grand Isle counties), and Rutland Mental Health Services.

Alternative Paths

The best resources for being sane and healthy are already inside us," says one psychiatric survivor. "Finding them again is the challenge."

Support groups are comprised of many people who have tried, and continue to try, methods that help to bring out the healthy person inside. It may be journaling, combined with exercise and a good diet of fresh vegetables, or stopping smoking or drinking. It might be painting or some other form of artistic expression coupled with a faithful devotion. It might be singing in a choir or with a group of friends and working with a massage therapist or acupuncturist. Once you seek methods outside the clinical-medical model, a door opens to another world of possibilities.

Alternatives

Outside of the clinical treatment model, there are plenty of "alternative" or "holistic" approaches to well-being that do not involve medication.

In some cases, they involve herbal remedies, a better diet, and exercise. Meditation, yoga and other mental and physical relaxation techniques have often been known to help reduce the stress of everyday life.

Support groups are often a wealth of information for people seeking alternate forms of treatment. People in support groups have often tried other methods, and can give you feedback on a path you are considering.

A list of alternative resources can be found at the end of this chapter.

It should be noted, however, that art is not treatment — it's creative and intuitive in ways that go beyond "treatment." By labeling art treatment, we diminish the wonderful work created by artists who have a psychiatric disability. Think of it, if Vincent Van Gogh were painting in Vermont today, he'd probably be on an order of non-hospitalization. Art is expression and sometimes being able to express oneself without the restraint created by other activities helps to free emotions and thoughts that otherwise are lost to us. G.R.A.C.E. in the Northeast Kingdom is one organization that provides artistic support to people with psychiatric disabilities.

Many people who seek to improve their health outside the clinical system often look toward yoga, deep breathing techniques and visualization for solace. Nutrition is also important; numerous experts point to poor diet or malnutrition as leading causes of depression.

The first step is to talk with people who have tried these approaches and determine what will work best to complement your needs and current regimen. There are a number of resources in Vermont that can provide more information on holistic and alternative healing practitioners and where they are located throughout the state. Bookstores and libraries offer sections exclusively devoted to the healing arts and alternative "medicine." Community bulletin boards are also a good place to find flyers

announcing yoga and other meditative classes.

In all of this, no matter what path you seek for treatment, that path needs to be one thing: your own. Taking responsibility for treatment, and establishing what you will and won't agree to, is one of the single most important steps to make.

Once you choose a path, follow it and make sure you keep yourself open to alternate approaches if the choices you've made are not working out. With each change in your approach, talk to friends, peers and family about these options and then seek out resources that will enable you to make an informed choice.

Knowledge is power and the more you know about a particular treatment method or alternative approach the more at ease you will be with your decision. And being at ease will make your mind and body more receptive to healing.

> Support groups are comprised of many people who have tried, and continue to try, methods that help to bring out the healthy person inside, Once you seek methods outside the clinical-medical model, a door opens to another world of possibilities

alternative resources

Peer Support and Drop In Centers

VERMONT CENTER FOR INDEPENDENT LIVING

(800) 639-152211 East State Street, Montpelier, VT 05602Website: www.vcil.orgPeer advocacy counseling program.

VERMONT PSYCHIATRIC SURVIVORS, INC.

(800) 564-2106
1 Scale Avenue, Suite 52, Rutland, VT 05701
Website: www.sover.net/~vpsinc/
Mental health advocacy and support.

ANOTHER WAY DROP IN CENTER

125 Barre Street, Montpelier, VT 05602(802) 229-0920Website: http://gmsg-anotherway.blogspot.com/

BRATTELBORO AREA DROP-IN CENTER

60 South Main Street, Brattleboro, VT 05302-0175 (802) 257-5415, (802) 257-2005, (800) 852-4286 Website: www.brattleborodropin.org

OUR PLACE DROP-IN CENTER

6 Island Street, Bellows Falls, VT 05101 (802) 463-0786

Website: www.ourplacevt.org

COTS DAYSTATION

179 Winooski Ave., Burlington, VT 05401 (802) 864-7402 Website: www.cotsonline.org

BLACK RIVER PEER RECOVERY CENTER

197 Union Street, Springfield, VT 05156(802) 885-4588Website: www.vermontrecovery.com

SUNRISE PEER RECOVERY CENTER

157 Barre Street, Montpelier, VT 05602 (802) 233-7544

SAFE HAVEN

4 Highland Ave., Randolph, VT 05060 (802) 728- 5233 Shelter for people with mental illness.

legal resources

SOUTH ROYALTON LEGAL CLINIC

(802) 831-1500 159 Chelsea St., So Royalton, VT 05068 Legal services

VERMONT LEGAL AID, INC

(800) 265-0660 **64** Mental Health Law Project, 121 South Main Street, P0 Box 540, Waterbury, VT 05676 Website: www.vtlegalaid.org Legal services for the mentally ill.

VERMONT PROTECTION AND ADVOCACY

(800) 834-7890 141 Main Street, Suite 7, Montpelier, VT 05602 Website: www.vtpa.org Mental health advocacy.

WOODBURY DISPUTE RESOLUTION CENTER

(800) 820-044261 Elm Street, Montpelier, VT 05602Website: www.woodbury-college.eduMediation and conflict resolution.

Therapeutic

SPRING LAKE RANCH, INC.

(802) 492-3322 Spring Lake Road, P0 Box 310, Cuttingsville, VT 05738 Website: www.springlakeranch.org Therapeutic community.

Support Groups

For a full listing of support groups operating in your area contact Vermont Psychiatric Survivors at (800) 564-2106 or visit their website at www.sover.net/

~vpsinc/. A current listing is also available in Counterpoint.

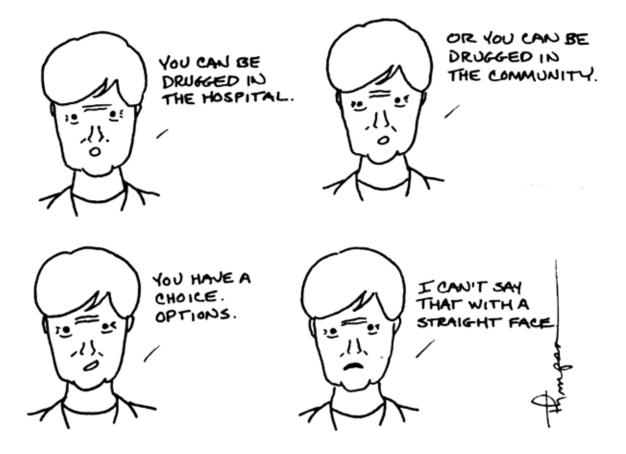
Holistic

There are a number of alternative health practitioners throughout Vermont. There are number of ways to find them, using the phone book or often through flyers distributed at area health food stores, or local book stores. Most book stores have sections devoted to alternative healing/medicine.

In your local phone book, look for providers under the headings "Acupuncturists," "Acupuncture Physicians," Naturopathic Physicians," "Massage-Therapeutic," and "Nutritionists."

You can also look for services in the phone book under the headings "Herbs" and "Health & Diet Food Products - Retail."

These listings will provide the location of health food and herbal stores in your region that are likely to have a bulletin board for local alternative practitioners to post services. Each will have books on the use of herbs and various natural approaches to well-being.



The Path to Recovery

Recovery is a term that, on the surface, may not seem controversial, but remains one of the more hotly debated topics among people with psychiatric disabilities. Defining recovery remains intimately personal, and is almost never the same from person to person. This holds true not only for people labeled mentally ill, but also for recovering alcoholics, workaholics, shopaholics, and the like. Each of us copes with difficulties in our lives differently. Some methods work better than others do, but as individuals we are allowed to seek out what works best for ourselves.

People who have been interviewed for this book have repeated, again and again, that each person's path to recovery needs to be honored for what it is. No one can be forced down a path to recovery and no one else can define that path for you. Recovery is an active process of self-healing, not something imposed by a system or specialist. As one advocate puts it bluntly: "Force and treatment can't go together: the punishing cop can't also be the trusted helper."

As with self-advocacy, what remains important in people's journeys to recovery is that they maintain a grip on their plans rather than ceding those rights to a third party. There will be times during a journey to recovery that might require brief hospitalization, but your long-term goals need to remain in focus.

"Force and treatment can't go together: the punishing cop can't also be the trusted helper." Find sources of strength to build on. Comforts along the way are necessary to maintain, whether they are pets, friends, a day at the library, a walk in the woods or a night out at the movies. What kept one survivor going in the face of negative societal

messages and oppressive mental health assistance was "a sort of divine assistance... in the ultimate justice that I was a human being [and] deserved to be treated as a human being. I knew in a way that there would be justice; when I most needed some roots, intervention took the form of my cats..."

Recovery: What it Means to Different People

For most people recovery is more than just being medicated, given a place to

It's a WRAP

According to Mary Ellen Copeland, a licensed therapist in Brattleboro, the following supplies are needed to develop a Wellness Recovery Action Plan (WRAP). It's important to note that a WRAP, unlike an Advance Directive, is not a legally-binding document.

To make a WRAP, you need:

- 1. A one-inch thick three-ring binder.
- 2. A set of five dividers, or tabs.
- 3. A package of three-ring filler paper.
- 4. A writing instrument of some kind.
- 5. A friend, or other supporter, to give you assistance and feedback.

Section One: Daily Maintenance List

Onthefirsttab, write: "Daily Maintenance List." Insert it in the binder followed by several sheets of filler paper.

On the first page describe, in list form, yourself when you are feeling all right.

On the next page make a list of things you need to do for yourself every day to keep yourself feeling all right.

On the next page, make a reminder list for things you might need to do. Reading through this list daily helps keep you on track.

Section Two: Triggers

These are 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 stay for a couple of days and sent back into the community with a pat on the head. It is about becoming self-aware and understanding one's role in one's immediate network of friends, family members and possibly co-workers. This network has been aptly described by some as one's "social economy." This social economy has a wealth of resources, both physical and emotional, to help us in good times and bad.

As a nation we are very wealthy when it comes to money and resources. However, in our relationships we may feel powerless or impoverished. That is where organizational memberships, friendships and networking with others through support groups can help build up our social and spiritual economy from which to draw strength.

Rebuilding those connections to draw strength may take some time. That is because one trait many ex-patients have to purge as they move toward recovery, an ex-patient says, is "learned helplessness." Facing years of being brushed off by service providers and ignored by society takes its toll on the human spirit. Moving toward recovery takes some inner fortitude that must overcome this sense of helplessness. "Compared to other systems, you may have to do extra advocacy and face more brush-offs," the ex-patient adds.

That is one lesson of the recovery movement. That persistence and selfawareness can pay off dividends in the long run toward a richer and more rewarding life outside of the mental health system. in your life, but if you don't respond to them and deal with them in some way, they may actually cause a worsening in your symptoms.

On the next tab write, "Triggers" and put in several sheets of binder paper. On the first page, write down those things that, if they happen, 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 designed to offer ways to diffuse these triggers when they occur.

Section Three: Early Warning Signs

Early warning signs are internal and may be unrelated to reactions to stressful situations. In spite of your best effort to reduce symptoms, you may begin to experience early warning signs, subtle signs of change that indicate you may need to take some further action.

On the next page, write an action plan to use if early warning signs come up.

Section Four: Things are Breaking Down or Getting Worse

In spite of your best efforts, your symptoms may progress to the point at which they are very uncomfortable, serious and even dangerous, but you remain able to take some action on our own behalf.

On the next tab, write: "When Things are Breaking Down." Then make a list of the symptoms which, for you, mean that things have worsened and are close to the crisis stage. Treatment options can vary: medicated, non-medicated, herbal, therapy, hospitalbased, community-based, or homebased. There's a treatment model out there for everyone, and everyone is different. Too often, however, square pegs are forced into round holes. This is where consumer education can help empower any decision you make. Be aware of any potential treatment you may be given, and understand its possible side effects, both short- and long-term. If you can't find out on your own, ask your provider to give you the information in a clear and readable format. Just because a doctor says something is so, doesn't make it such. Get a second opinion, or a third, until you feel comfortable with the results. Remember, you are the consumer.

Another important tool to be used during recovery is an action plan. This is not a legally-binding document, but it helps many people focus on what it is that makes their journey to recovery a bit smoother. Mary Ellen Copeland developed one such plan, and it is called a Wellness Recovery Action Plan (WRAP). (A book detailing its use is published by Peach Press in Brattleboro, VT, and costs \$10. You can purchase the book online at www.mentalhealthrecovery.com). Many people use a WRAP in conjunction with an Advance Directive to reinforce the wishes they set out in a legal document. However, a WRAP can be used on a daily basis and is designed to keep you attuned to what pleases and distresses you on a regular basis. It offers ways to evaluate and plan your own path to recovery.

(Continued)

Section Five: Crisis Planning

In spite of your best planning and assertive action, you may find yourself in a crisis situation where others will need to take over responsibility for your care.

Develop this plan slowly when you are feeling well. The crisis planning form includes space to write:

- Those symptoms that would indicate to others they need to take action on your behalf, and whom 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.
- Acceptable and unacceptable treatment facilities.
- Actions that others can take that would be helpful.
- Actions that should be avoided.
- Instructions on when the plan no longer needs to be used. ..are very uncomfortable, serious and even dangerous, but you remain able to take some action on our own behalf.

A WRAP, or similar recovery plan, helps to externalize your symptoms and experiences, allowing for some detached judgments about your condition. It also helps to remind you of external needs that make you well, external needs that don't require medication, or forms of "treatment."

Focusing on recovery in this manner makes time for other things in life. And making time for other things in life is what recovery, in part, is about.

As one psychiatric survivor aptly puts it, "Recovery has been having something left over to share with someone else. Before, I never had time for anything or anybody except my own pursuits, my own thoughts, what I wanted to do, my own symptoms, my own illness, my own treatment. There was really nothing left for anyone else. I think that's been the biggest change in my life — time left for somebody else. I think that's a sure sign that people are recovering."

Support Groups

Despite our best efforts, there are times when we need peers to boost our confidence, help us sort through difficult times or simply talk and offer intelligent, friendly distraction from our own daily tasks.

Vermont's psychiatric survivors' movement has spurred the creation of nearly a dozen peer-run support groups throughout the state. The success of these support groups, however, is not merely determined by their longevity. In many cases, these support groups have flourished because they recognize the core need for people to have a circle of people to turn to in times of need and in times of joy. The give and take of such a network of friends and people of common interest helps to strengthen ties to the community-at-large.

Vermont Psychiatric Survivors, based in Rutland, keeps an up-to-date list of these peer support groups. Each issue of Counterpoint, the newspaper for people with psychiatric disabilities, prints a complete list of support groups and other resources on its back page.

Peer-run recovery groups once resided outside the system, designed for people who were tired of every symptom having a label, and every symptom having a medicated solution. These support groups act as a gateway to other resources, such as holistic and all-natural approaches to recovery — putting you into contact with people who do not all tread the same treatment and recovery path.

Today, peer-run recovery groups are part of a mental health agency's routine offering for anyone who utilizes services. In fact, many of the peers who lead these groups got their start with a peer- run group offered by VPS or were trained by a VPS educator. They remain committed to keeping you as the person determining your path to recovery.

In short, mental health professionals are beginning to understand that having peers to talk with, learn from, or teach is a valuable, if not an essential, step toward recovery.

recovery resources

Drop-In Centers

ANOTHER WAY DROP IN CENTER

125 Barre Street, Montpelier, VT 05602(802) 229-0920Website: http://gmsg-anotherway.blogspot.com/

BRATTELBORO AREA DROP-IN CENTER

60 South Main Street, Brattleboro, VT 05302-0175 (802) 257-5415, (802) 257-2005, (800) 852-4286 Website: www.brattleborodropin.org

OUR PLACE DROP-IN CENTER

6 Island Street, Bellows Falls, VT 05101 (802) 463-0786 Website: www.ourplacevt.org

COTS DAYSTATION

179 Winooski Ave., Burlington, VT 05401(802) 864-7402Website: www.cotsonline.org

BLACK RIVER PEER RECOVERY CENTER

197 Union Street, Springfield, VT 05156 (802) 885-4588 Website: www.vermontrecovery.com

SUNRISE PEER RECOVERY CENTER

157 Barre Street, Montpelier, VT 05602 (802) 233-7544

Peer Support

VERMONT CENTER FOR INDEPENDENT LIVING

(800) 639-152211 East State Street, Montpelier, VT 05602Website: www.vcil.orgPeer advocacy counseling program.

VERMONT PSYCHIATRIC SURVIVORS, INC.

(800) 564-21061 Scale Avenue, Suite 52, Rutland, VT 05701Website: www.sover.net/~vpsinc/Mental health advocacy and support.

Therapeutic

SAFE HAVEN 4 Highland Ave., Randolph, VT 05060 (802) 728- 5233 Shelter for people with mental illness.

SPRING LAKE RANCH, INC.

(802) 492-3322 Spring Lake Road, P0 Box 310, Cuttingsville, VT 05738 Website: www.springlakeranch.org Therapeutic community.

Community

CLARA MARTIN CENTER - BRADFORD

(802) 222-4477 Route 5, P0 Box 278, Bradford, VT 05033-0278 Adult outpatient and community support programs.

CLARA MARTIN CENTER - RANDOLPH

(802) 728-4466P0 Box G, Randolph, VT 05060-0167Adult outpatient and community support programs.

COUNSELING SERVICES OF ADDISON COUNTY

(802) 388-6751

89 Main Street, Middlebury, VT 05753

Adult outpatient and community support programs, including deaf and hard of hearing services.

HEALTH CARE & REHABILITATION -BELLOWS FALLS

(802) 463-3947 One Hospital Court, Bellows Falls, VT 051011991 Adult outpatient and community support programs.

HEALTH CARE & REHABILITATION - BRATTLEBORO

(800) 622-423551 Fairview Street, Brattleboro, VT 05301Adult outpatient and community support programs.

HEALTH CARE & REHABILITATION - WHITE RIVER JUNCTION

(802) 295-303149 School Street, Hartford., VT 05047Adult outpatient and community support programs.

HOWARD CENTER FOR HUMAN SERVICES

(802) 658-0400

300 Flynn Avenue, Burlington, VT 05401

Website: www.howardcenter.org

Provides adult outpatient, community support, cooperative apartment, community rehabilitation and treatment, social and vocational rehabilitation services.

LAMOILLE COUNTY MENTAL HEALTH SERVICES

(802) 888-4914
(800) 585-0021
520 Washington Highway, Morrisville, VT 05661
Adult outpatient, community rehabilitation and treatment programs.

NE KINGDOM HUMAN SERVICES, INC.

(802) 334-6744
(800) 696-4979
154 Duchess Street, P0 Box 724, Newport, VT 05855
Website: www.nkhs.net/ment_health
Provides adult outpatient, community rehabilitation and treatment programs.

NE KINGDOM MENTAL HEALTH SERVICES, INC

(802) 748-3181(866) 639-65472225 Portland Street, St Johnsbury, VT 05812Website: www.nkhs.net/ment_health

Community rehabilitation and treatment program.

NORTHWEST COUNSELING & SUPPORT SERVICES

(800) 834-7793107 Fisher Pond Road, St Albans, VT 05478Website: www.ncssinc.orgAdult outpatient and community rehabilitation and treatment programs.

RUTLAND MENTAL HEALTH SERVICES

(802) 775-2381
(800) 253-0191
78 South Main Street, P0 Box 222,
Rutland, VT 05702-0222
Website: www.rmhsccn.org
Adult outpatient and community rehabilitation and treat ment programs.

UNITED COUNSELING SERVICE - BENNINGTON

(802) 442-5491100 Ledge Hill Drive, P0 Box 588, Bennington, VT 05201Website: www.ucsvt.orgAdult outpatient, community rehabilitation and treatment programs.

UNITED COUNSELING SERVICE - MANCHESTER

(802) 362-3950 Route 7A, P0 Box 815, Manchester Center, VT 05255 Adult outpatient program.

WASHINGTON COUNTY MENTAL HEALTH

(802) 229-0591 PO Box 647, Montpelier, VT 05602 Website: www.wcmhs.org Outpatient, community rehabilitation and treatment programs.

Hospital-Based

BRATTLEBORO RETREAT

(800) 345-5550
(802) 257-7785
Anna Marsh Lane, P0 Box 803, Brattleboro, VT 05302
Website: www.retreathealthcare.org
General outpatient, adult psychiatric inpatient, cognitive rehabilitation and women's specialized inpatient services.

CENTRAL VERMONT MEDICAL CENTER

(802) 371-4316130 Fisher Road, P0 Box 547, Bane, VT 05641Website: www.cvmc.hitchcock.orgInpatient psychiatric service.

CHESHIRE MEDICAL CENTER

(603) 354-6577590 Court St., Keene, NH 03443-0095Website: www.cheshire-med.comInpatient mental health services.

COPLEY HOSPITAL

(802) 888-8888528 Washington Highway, Morrisville, VT 05661Website: www.copleyvt.orgPsychotherapy services

DARTMOUTH MEDICAL SCHOOL

(603) 650-5000 One Medical Center Drive, Lebanon, NH 03756 Website: http://dms.dartmouth.edu/patient/ Behavioral medicine.

FAMILIES IN RECOVERY

(800) 258-2804 139 Main Street, Suite 501, Brattleboro, VT 05301 Women's addiction program.

VERMONT STATE HOSPITAL

(802) 241-1000103 South Main Street, Waterbury, VT 05671Inpatient psychiatric service.

WINDHAM CENTER

(802) 463-1286 18 Old Terrace, Bellows Falls, VT 05101 Inpatient psychiatric service.

FLETCHER ALLEN HEALTH CARE - FAHC

(800) 847-0000111 Colchester Avenue, Burlington, VT 05401Website: www.fahc.orgInpatient psychiatric service.

FRANKLIN MEDICAL CENTER

(413) 772-0211

164 High Street, Greenfield, MA 01301 Behavioral health services.

RUTLAND REGIONAL MEDICAL CENTER

(800) 649-2187160 Allen Street, Rutland, VT 05701Website: www.rrmc.orgBehavioral health services.

SPRINGFIELD HOSPITAL

(802) 885-215125 Ridgewood Road, P0 Box 2003, Springfield, VT 05156Website: www.springfieldhospital.orgInpatient psychiatric service.



"I can help with the learned helplessness but it will take a long time."

Final Thoughts: Moving Forward

self-help: the act or an instance of providing for or helping oneself without dependence on others.

advocate: one who pleads the cause of another; one who defends or maintains a cause.

These definitions are found in any standard collegiate edition of a Merriam-Webster dictionary but they hold much more meaning than what is printed on paper.

As has been explained throughout this book self-advocacy is challenging, but the rewards are great. Think of it this way: you are the one person who knows what works best for you emotionally, physically and medically. You are the one person who knows what does not work for you. You are the best spokesperson to explain your needs and defend your rights, which is perhaps the greatest single cause each of us experiences on a daily basis. When you can find the support necessary to make it possible to speak out, your voice joins a chorus of others who did the same thing yesterday, and others who will do the same tomorrow.

This does not mean that there will not be times when you need someone to help you during a difficult time. Careful planning can ensure that if you ever become incapacitated your wishes will be followed. The chapter "Advocating for Yourself" focuses on a couple of techniques to set up a plan that takes effect during an emergency or crisis, but maintains the integrity of your wishes by entrusting decisions to be made on your behalf by a loved one, a skilled advocate or legal adviser.

Throughout the book self-help and advocacy tips are offered, whether it's seeking support services that allow you to get back into the work force, find alternate forms of healing, or be a better parent.

The fact remains that coercion exists in Vermont's mental health system — top to bottom. The position paper by former Mental Health Commissioner Rod Copeland listed a number of coercive methods consumers identified as having been used against them. These methods included involuntary hospitalization and medication, withholding services if a person does not agree to take medication or engage in group therapy, shutting off people from loved ones and friends as a form of punishment, and controlling a person's choice of agencies or service providers.

Copeland's report raised more questions than it answered. It offered some possible solutions, but nothing concrete other than the formation of action plans. In the face of this type of extensive coercion, more than action plans need to be implemented. It will take a major change in how service providers and professionals take into account the rights of consumers to play an active role in their treatment.

Enter self-advocacy and the psychiatric survivor's movement. During the past three decades, psychiatric survivors and consumer advocates have succeeded in educating mental health service providers about the right to self-determination and that not everyone's path to recovery is the same.

What has evolved is a civil rights struggle that crosses all boundaries of race, gender, sexual orientation and class. This struggle is a minority group's effort to be recognized as citizens and valued as individuals, with identities that include, but are not defined by, their experiences with psychiatric disabilities.

Ample evidence exists that despite the tireless work of outspoken consumers and advocates, more work needs to be done in order bring about full recognition of these civil rights. More and more people with psychiatric disabilities, in Vermont and around the U.S., are being shuffled into the care of the corrections system and receiving limited, if any, treatment. Furthermore, when treatment is provided it is often inadequate or coercive. Despite the hard work of consumers and peer advocates in Vermont, Act 114, an involuntary medication law, places the balance of power into the hands of mental health service providers and public safety officials rather than in the hands of individuals.

Never give up hope. Believe in yourself and others. Together a system can be changed for the better. These beliefs will keep this movement from becoming another chapter in a history book. Recognizing the hundreds of brave people who already blazed the trail gives us comfort as we continue with each new challenge, each new opportunity. We are no different from them; we are individuals seeking the same dignity, respect and valued recognition as any other person in society.

When that day of recognition arrives books like this will be no longer needed — relics of a failed system and a testament to the struggle that set millions free.

Name:
Phone Number:
Support they provide:
Additional Comments:

Name:____

Phone Number:_____

Support they provide:_____

Additional Comments:

Name:
Phone Number:
Support they provide:
Additional Comments:

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Name:
Phone Number:
Support they provide:
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