

# The Alliance

## Self-Help and Mutual Support Workshop

Presented by the Mental Patients Liberation Alliance

Each time a [person] stands up for an ideal,
or acts to improve the lot of others,
[s]he sends forth a tiny ripple of hope;
and crossing each other
from a million different centers of energy and daring,
those ripples build a current
that can sweep down
the mightiest walls of oppression and resistance."

- Robert F. Kennedy -

This is an interactive workshop to explore, examine, and clarify perceptions of self-help and mutual support. Participants will help identify natural skills and expertise that can be offered to people experiencing emotional difficulties by people who have had similar experiences. The workshop is designed to address the interests of the participants and may include improvisation, roll playing, and discussion on mutual support plans, phone lines, crisis interventions, advocacy, support groups, and more.

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## **Table of Contents**

| Workshop Outline  | 2     |
|---|-------|
| Some Accomplishments                                    | 3-4   |
| Definitions   | 5-6   |
| Support Plan  | 7-8   |
| Support Conversation, Support Line Statement of Purpose | 9     |
| Sample Flyer Support Phone Line                         | 10    |
| To Whom It May Concern                                  | 11    |
| Sample Flyer Gatherings                                 | 12    |
| How to Start a Self-Help Group                          | 13-16 |
| Advocacy  | 17    |
| Resources / Contact Information                         | 18    |

## Workshop Outline

- I. Self-Introductions
- II. Backgrounds of Presenters
- III. Brief History of The Alliance
- IV. Introduction of The Alliance Peer Advocacy Training Manual
- V. Definitions
- VI. Topics: Self-Help, Mutual Support, Advocacy
- VII. Methods: Improvisation, Roll-Play, Interactive Discussion
- VIII. Application
- IX. Wrap Up



## MENTAL PATIENTS LIBERATION ALLIANCE

## Some of our accomplishments:

The Alliance began in Syracuse in 1972 and quickly gained nationwide recognition as one of the first human rights organizations of people who had been labeled "mentally ill".

The organization incorporated in 1982. Alliance members have since assisted over a dozen other peer organizations with their incorporation process.

The Alliance hosted the 11<sup>th</sup> International Conference on Human Rights and Psychiatry in 1983, which brought 150 people to Syracuse, New York.

The 1984 Organization Award for Mental Health Advocacy was awarded to the Mental Patients Liberation Alliance.

In 1985, the State Office of Mental Health met to discuss implementation of federal law 99 - 660 (include stakeholders involvement in state planning processes). The first person with a psychiatric label to sit on the Mental Health Planning Advisory Council was an Alliance member

Prior to public funding in 1986, The Alliance established drop-in centers in three cities in Central New York (Oswego, Ithaca, Syracuse) through membership donations and with volunteer staff.

In 1986, The Alliance opened our Advocacy, Education, and Social Center in Syracuse through a member item grant from the New York State Senate. That Center served our community until 2002.

The Alliance negotiated with Hutchings Psychiatric Center through 1987, and then in 1988 signed an access agreement to provide people receiving treatment at that facility with trained and supervised advocates.

The precedent setting access agreement prompted the New York State Office of Mental Health to establish a workgroup of Alliance representatives, other advocates, and state officials to develop the official state Policy known as PC 1500. The policy still encourages development of relationships between state-operated facilities and independent peer advocacy organizations.

The Alliance developed the first Peer Advocacy Training in New York State. The training continues to receive national attention and attendance. The Alliance has helped train over 900 people at these institutes. Many of the people now work in peer support and advocacy and help train others in this field.

The Alliance developed a 200-page manual to accompany its advocacy training.

The Alliance published eight issues of the newsletter "the fine line" with over 16,000 copies distributed throughout the State and The United States.

The Alliance received *The Community Service* Award March 19, 1990 in recognition of "Outstanding Service and Commitment" from The Association of Community Living Agencies in Mental Health (ACLAIMH).

On May 30, 1991, The Alliance was presented the Rehabilitation Support Services, Inc. (RSS) Certificate of Recognition "in recognition of dedication and commitment to the advancement of consumer operated initiatives".

In 1993, The Alliance negotiated an agreement to provide advocacy service to people at Mohawk Valley Psychiatric Center. Significant to that agreement is the location of the Alliance Peer Advocacy Office on the grounds of the facility.

In 1996, The Alliance opened the Alliance Peer Support Center in Utica with reinvestment funding through Oneida County.

In 1997, The Alliance purchased a building in the City of Utica to house our peer programs in that community. The down payment was made possible by donations from our membership and supporters.

The "voice" journalism award - The Best Op/Ed Award was presented to "Forced Psychiatric Treatment" by George Ebert, Mental Patients Liberation Alliance in 1999 by NEW YORK CITY VOICES, a consumer-run project of Park Slope Center for Mental Health.

The Janice E. Brown Memorial Award "For Lifetime Dedication to Human Rights in Mental Health" was given to George Ebert by V.O.I.C.E., Inc. on October 9, 2002.

In 2004, The Alliance took title to and began renovating an apartment house in Utica that serves as a retreat for our members.

The Alliance established a toll-free Peer Support Line in 1989. In 1998, funding made it possible to provide uninterrupted, around-the-clock service. The line receives up to 900 calls each month.

The Alliance has helped to co-sponsor and coordinate the Annual "Our Time Has Come" conference. Over 1200 people have attended this conference.

The Alliance was invited to provide a support group on the psychiatric unit at St. Joseph s Hospital.

The Alliance presents at numerous conferences and was part of Syracuse University's School of Social Work curriculum, presenting each semester.

The first Lifetime Achievement Award "For Outstanding Advocacy" was presented to George and Mary Ann Ebert on May 20, 2004 by The Empowerment Center.



## MENTAL PATIENTS LIBERATION ALLIANCE The Alliance

## **DEFINITIONS**

- advocate/advocacy Advocacy is to speak or write in support of something. An advocate is a person who pleads another's cause, such as a lawyer.
- alternative An alternative is something different from, and able to serve as a substitute for, something else. The mental health system, for example, is an alternative to natural supports.
- empowerment Empowerment means to give authority to someone or to inspire confidence and/or self-esteem. For many people who have experienced emotional disturbances and/or have undergone treatment for those disturbances, empowerment is often used to describe the regaining of self-confidence.
- facilitate Facilitate means to make something easy or easier to do. Used in the context of groups (to facilitate the group), the term is often mis-used as a synonym for govern or control.
- group A group generally means a number of people (perhaps two) who share something in common, such as, an interest or experience. The importance of this definition is its simplicity and broadness. Group is NOT a psychiatric term.
- key stakeholder Stakeholder is somebody who holds a direct interest. In regard to the mental health system, everyone is a stakeholder people who have or may access services, people who provide services, community members, etc. Key stakeholder, however, refers only to people who have a psychiatric label.
- mutual support Support is generally defined as encouragement, assistance, comfort, corroboration, or reinforcement. Mutual support is much more unique; it embraces two essential elements 1) the commonality of the experiences of the people involved; and 2) the understanding that the people involved are each (all) giving AND receiving within the act of mutual support.
- peer Peer refers to a person of equal standing with another or others. It can refer to a companion or friend. Each of us is a peer in many contexts. At times, for example, when we are together with another or others who have had a psychiatric experience or emotional difficulty, we generally refer to ourselves as peers.

- peer advocacy Peer advocacy refers to the process or act of a person of equal standing pleading the cause of a person who shares that equal standing. For example, a lawyer who provides a legal defense for another lawyer. Another example is a person who has an experience of emotional difficulties or challenges providing advocacy for another person with similar experiences.
- recovery There is no single definition of the term *recovery* or how each of us applies the word in our lives. This is not because of any vagueness or ambiguity; it is simply because we are each fundamentally unique, and our lives' journeys are self-defined and self-determined. In fact, people have different understandings of what they are recovering *from*. While one individual may be recovering from an emotional crisis or particular period of his/her life, another may be recovering from the aftereffects of that crisis.

It is only possible for people to choose their own meaning of recovery as it pertains to him/her. For some, the process of doing this offers personal clarity. Some people change their perception of recovery and acknowledge recovery to be a dynamic process of growth and healing. At a time, for example, a person may feel that recovery is "getting back on my feet". At a later time, that same person may choose recovery to mean "regaining my dreams".

While acknowledging the personal journey that is recovery, a general definition applied for the recovery within the mental health system might be: **meaningful social roles for every person**.

- **self-determination** A Thesaurus offers several nouns for *self-determination* that readily offer definition such as, freedom, independence, autonomy, self-rule, and freewill.
- self-help The adverb *help* means to assist. It also can mean to make things better. Self-help means to assist one's self and/or to make things better for one's self. A broader definition includes gaining help of one's choice or by one's own design.



## MENTAL PATIENTS LIBERATION ALLIANCE The Alliance

13 Hopper Street, Utica, New York 13501 Phone (315) 732-5377 FAX (315) 732-5625

## 24-Hour Toll-Free, Peer Support Line 1-800-654-7227

Please Note: It is recommended that each individual complete an Advance Directive for his/her own protection. A Support Plan does **not** take the place of an Advance Directive. If you would like more information, please ask a staff member or volunteer to assist you.

#### SUPPORT PLAN

Complete the following answers to create your personal Support Plan. If you need assistance or would like to discuss any items, please ask a staff member or volunteer. The Alliance will be happy to keep your Support Plan on file. All information will be kept confidential.

| Name  | Phone                |
|---|----------------------|
| Address   |                      |
| If I am having difficulty, I prefer these things that have he | lped me in the past: |
|   |                      |
|   |                      |
| Please Contact  | Phone                |
| Address   |                      |
| This is how you can tell if I need help                       |                      |
|   |                      |
|   |                      |
| How can The Alliance be helpful to you in difficult times?    |                      |
|   |                      |

| lay we help you to make an alternative plan to hospitalization?   |
|---|
| someone suggests that you go to the hospital, would that be acceptable to you?  |
| yes, under what circumstances?  |
|   |
|   |
| s there a hospital that you prefer?   |
| ist any medications that you find to be NOT helpful, damaging, or under no ircumstances want:   |
| low do you feel about electroconvulsive practice?   |
|   |
| low do you feel about seclusion?  |
|   |
| low do you feel about constraints?  |
| re there any medical conditions for which you would like us to be aware?  |
|   |
| lease add any additional comments or elaborate on anything you would like us to now. For example, do you have any children or pets that will need assistance if you re having difficulty? |
| ·   |
|   |
| ıgn: Date:  |
| o you currently have a completed Advance Directive on file?YESNO ocation:   |
| ign: Date: NO NO  |

Support Conversation: Any conversation between two or more people in which support is gained and given by the participants. Support can be encouragement, information, assistance, or companionship. Is it as simple as that? Yes. Most people gain and give support from and to others throughout their daily lives in almost imperceptible means and moments... a friend speaking to a friend, coworkers discussing the minutiae of day-to-day life, or a quick conversation with a friendly sales clerk. A smile might be the easiest expression of support; a returned smile demonstrates mutual support.

It certainly can seem more complicated when we are faced with new, painful, sudden, perplexing, or seemingly extraordinary circumstances. An emotional disturbance can embrace all of that; it can pull us into a hurricane of confusion and fear - perhaps particularly the first time we experience one. For many, the experience finds us without preparation - resources to gain support, understanding, information, safety and comfort. Such experiences may range from "challenging" to "horrific".

Most believe that support from a person or people who have experienced similar circumstances and feelings is vital to their recovery. Many people who have had those experiences feel it is equally vital to their recovery to offer support to others.

## **SUPPORT PHONE LINE - STATEMENT OF PURPOSE**

The purpose of The Alliance Mutual Support Line is to provide the opportunity to offer mutual support to people calling the line with active listening and participation.

Support Line volunteers are self-defined as people with personal experience of the mental health system and experience with emotional difficulties/challenges. We do not claim any expertise other than our knowledge of the success of self-help and mutual support. With acceptance and empathy, we offer our own understanding and experiences to help others move toward wholeness and recovery. Our responses are person-centered. We impose nothing. We share our perspectives and experiences, if it is appropriate to the caller's expressed desire or need. We have no hidden agendas.

Thinking Outside the Box: Some of the people who phone The Alliance Mutual Support Line have stated that they "have no one else to call" and that is fully understood. The Alliance Mutual Support Line began among a small number of people who knew that they needed and wanted "someone to call" for support as part of their personal support system. In other words, they agreed that they would benefit from always having a number available to call, 24-hours a day, as part of their recovery journey or just in case.

The Support Line began with a handful of people who took turns "operating the line" on a scheduled basis that provided them defined boundaries and provided callers a comfortable sense of "not intruding" on the person answering the phone. A couple of rules were agreed to and applied - respect and privacy was strictly maintained, for example. Today, although the Support Line has grown to be statewide and receives from 700-900 calls each month, it remains the same and is still fully operated by volunteers.



# The Aliance

When you need someone to listen

## **AVAILABLE AROUND THE CLOCK 24/7**

732-5377 or toll free @ 1-800-654-7227

## The Alliance Peer Support Line

## When to call the Support Line:

- When you want to talk to someone confidentially
- When you need support from a "peer" who has "been there"
- When you are feeling sad or upset
- When a friend or family member doesn't understand, but a peer might
- When you have an advocacy issue
- When you don't know where else to turn

## What the Support Line is about:

- Opportunity for confidential discussions about the kind of support that would be helpful to you now
- Non-judgmental listening
- Open sharing of thoughts and feelings
- An alternative approach to growth and healing
- Referrals to peer-run self-help groups
- A way to help ourselves and each other

## To Whom It May Concern:

On occasion, I have called the mutual support line. At times, I have been very up front with my need for support. At other times, I was not - benefiting from a short chat with the person who answered - without his/her awareness of my particular need. I have used the line in a time of personal crisis, as well as a time when I simply needed to "check in".

When I needed the line the most - in a crisis - I don't recall having said thank you to the person who helped me. I may have been too preoccupied with myself or my stress. It doesn't seem likely that I said thank you when I called for a brief chat, either; though perhaps I did. For me, the gratitude isn't realized at the time. It comes afterward or beforehand, when I consider that you are all there for me whenever I need you. It's true that I am not always grateful and take it all for granted. But when I stop and remember that the line (PEOPLE who understand) are <u>always</u> available to me... I DO feel great gratitude.

I guess that is how it works for lots of folks. "Thank you's" may or may not be stated. It's good to know that it doesn't matter much. You'll answer the phone when anyone calls, regardless of the reason, regardless of the outcome.

It's also good to know that none of you are better than me, or even think you are. You aren't working on the line because you are without troubles, challenges, and concerns. You still work hard on feeling happy and getting through the day. Just like me.

It is very important to me that the support is mutual. I need to know that I have some value to you. If it was all one-sided, I wouldn't call. Oh, sometimes it is one-sided, I know! Sometimes I am so caught up in myself and my life that I am not thinking about you and yours. But still, even then, there is balance to our relationship, and that is important. You know that I DO have something to offer, and that matters.

Just this once while everything is pretty okay in my life and I can think of you, let me say thank you. Thanks for having been there for me; thanks for sticking around for the future. You've helped me to stay free. You've helped me get through a day, or a tough morning, or even a desperate moment when your voice was the only one that could help. And there you were!

Sometimes I'd like to think that you get paid generously for what you do. Sometimes I need to know that you do it for free. Either way, I like knowing that you are compensated... in the only ways that truly matter. You are part of my life at times, and I am part of yours.

Thank you for sharing with me the best of who you are.

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## **HOW TO BEGIN A SUPPORT GROUP**

#### Introduction

Say hello. The beginning of a support group starts with one person greeting another. It can be as simple as that. When two people have made an initial contact, inviting additional people you know or meet to get together at a scheduled time, will help the support group to grow. Posting information about the group in places where people who might be interested in joining will see it, may cause the group to expand further.

The term "support group" can be misleading. The words are appropriate, but the fact that there is a term to label the essence of two or more people offering encouragement, testimony and/or the comfort of simply being together, often misleads some people into thinking there **must** be "more to it". There needn't be.

In times past, people who lived in cities may have had the opportunity to spend time talking over the backyard fence, perhaps while hanging laundry on the line to dry; perhaps while doing yard work. People who lived in rural areas often created the opportunities to meet with others through social events, such as dances, town gatherings, and/or weekly worship. Imagine women gathered in the kitchen together, men smoking cigars in the den, and two or more people huddled on the back steps. In other words, any gathering of two or more people with shared experience or interests is considered a *support group*.

Self-help groups form from the initiative of people interested in pursuing a particular topic or from their desire to gain/give support from/to others. <u>Essential to genuine self-help groups is the self-determination of its members and the group's independence</u>.

#### Build from what you know

If you would like to begin a support group, it may be desirable to select a topic or theme for the group. This is a starting point of common interest or experience. Groups seldom focus continually on any one topic. A mutual experience, interest, or theme, however, creates the frame of who will join the group and provides the best opportunity for the group to be a valuable support to its members. The consensus of participants in attendance leads each gathering.

Selecting the theme for a group might be accomplished through self-inventories or personal assessments. Such materials are available through a number of sources, but a simple questionnaire can be created for this purpose. The desire to begin a group is a perfect theme to actually begin the group around!

## A support group is forming!

People who are interested in participating in a support group are gathering together to explore a theme and create this opportunity with others. Join us!

TUESDAY, March xx, 2006 - 6:00 PM to 7:00 PM
The public library (Mc Donald's, local church, coffee shop, park)
XXX Street, XX, New York 10001
Contact person/people: XXX XXXXXXX (315) 555-555
No registration required. Walk-ins welcome. Hope you can come!

It is not required or even important to use the term *support group* to identify this initiative, goal, or process. Holding a *meeting* or *series of meetings* could have the goal of discovering the interest and needs of participants or potential participants. Members of the meeting may define objectives of the group. Perhaps a workgroup could develop to seek resources for future meetings - workshops, trainings, seminars, or the creation of additional groups. Resources may include community organization leaders, peer-run organization leaders/members, educators, trainers, etc. **Participants may simply desire to share** their personal knowledge of a topic(s) with each other. Following is a sampling of topic ideas and is not intended to be inclusive or restrictive:

Personal Inventory / Assessment Process

**Developing Leadership Skills** 

Networking / Resourcing

Problem Solving Skills / Techniques Community Activities / Organizations

Empowerment / Self-Reliance

**Advance Directive** 

Assertiveness and Communication

Socializing/Social Activities

Goal Setting - Developing a Vision

**Crisis Management** 

**Child-rearing Techniques** 

Finding a Job

Self-Esteem

**Relaxation Techniques** 

Education

Self-Determination

**Peer Advocacy** 

Support Plan

Self-Help Skills

**Making Friends** 

Money Management

Housing

Relationship Enhancement

A support group could easily be formed around the entire list above. Attendees would meet for the *purpose of exploring the above topics together*. Participants could take turns facilitating the group, supplying materials, or arranging for a presenter. Topics could be added to the list in response to the interest expressed by members of the group.

## **Group Development (growth)**

People interested in beginning a group may desire to gain membership from their community. Here are some useful suggestions:

- 1. Decide on a convenient date, time, and place for yourself (/selves, if you have another/others interested in doing this with you)
- If you plan to meet in a church basement or at the local library, for example, you may need to make arrangements with the management of those places
- 3. Invite everyone you know (or meet). Get the word out! Stress that there is no obligation to future meetings or gatherings. Elicit help from friends and family. Word-of-mouth publicity can be very effective.
- 4. Flyers are important tools to generating interest and providing information.
  - Make flyers visually attractive, uncluttered, easy-to-read, and answer who, what, when, where (sometimes why and how)
  - Colored paper helps to highlight the flyer and catch the eye of people browsing bulletin boards
  - smaller flyers are less likely to be removed or posted over GENERAL FORMAT

Heading: (Optional) Members may decide to choose a name for

the group or an initial name at the outset that could be

changed at some point by consensus;

i.e. THE EXPLORERS CLUB

Title: Subject or name of activity or event,

i.e. OPEN MEETING

When: Day, date (including year), and time

Where: Name of location and address

(with telephone number and contact person)

Why: What the event or activity hopes to accomplish

#### **RESOURCES**

Besides yourself, you will need paper and a pen/pencil. (Original flyers from The Alliance from the '70s were hand-written in pen or pencil on half sheets of paper. They were beautifully done AND effective!)

You might wish to gain assistance from a local store or other community resource, such as the library, for supplies

#### **POSTING**

It is beneficial to post flyers at least two weeks before the scheduled event. If possible, it is also beneficial to return about one week before the event to ensure that the flyer is still posted.

The more flyers that are posted, the more opportunity for people to see them. Choose community boards (often in stores, churches, and community centers - public places that generate "traffic"). Ask people to help, even if they hold no interest in the group.

Most local and/or community newspapers offer a listing of public events free of charge.

Think of groups, meetings, or gatherings that will be getting together before yours. You might want to distribute or post your flyer at that opportunity.

5. Be prepared for "no shows". Sometimes people agree to attend events and then do not show up. Twenty people may attend the first gathering, or only one or two. It is very possible that no one will come.

Plan the next meeting! Oftentimes, people look to see if a particular flyer is posted repeatedly. This would mean, to them, that the group is continuing to meet, continuing to be established, and was not a one-time effort.

Every group MUST fully incorporate the concepts of self-help - people helping themselves. Many people have been dis-empowered (lost confidence) by their life experiences or the aftermath of those experiences. By far, what most people need to accomplish their goals is support. Self-help support must be offered and given in an atmosphere of reciprocity or mutual support - people helping each other.

#### ADVOCACY

The Alliance developed the first Peer Advocacy Training in New York State. The training continues to receive national attention and attendance. The Alliance has helped train over 900 people at these institutes. Many of the people now work in peer support and advocacy and help train others in this field. The Alliance developed a 200-page manual to accompany its advocacy training that is still used throughout New York State and nationally. From The Alliance Peer Advocacy Training Manual:

I sit on a man's back choking him and making him carry me, and yet assure myself and others that I am sorry for him and wish to lighten his load by all possible means — except by getting off his back.

- Leo Tolstoy

#### WHAT IS AN ADVOCATE?

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As an advocate, you are representing someone else's interests. The client is the person who should define his/her interests — within the bounds of the law and mutual propriety — not the advocate. Your job is to get for your client as much as you can of what your client wants and is legally entitled to. While in an advocate role you appear to be in charge, but this should never result in you setting the goals for the client.

## TWELVE PRINCIPLES OF ADVOCACY [Syracuse University Center on Human Policy]

- 1. Know your case well and document your facts.
- 2. Know the opposing case and the possible arguments and strategies. (Roll play this.)
- 3. Operate from a sound base of support.
- 4. Know your resources and your allies.
- 5. Intervene at a high enough level to get the job done.
- 6. Take a positive approach; reinforce. Assume the agency really wants to help the people involved in its services.
- 7. Demonstrate to the system how it is interfering with its own goals.
- 8. If there has to be an overt battle, only do so after completion of steps 1 to 7.
- 9. If you have to battle, don't pussyfoot. Know how far you have to go and take it to the limit.
- 10. Strengthen the recipient group. Self-advocacy is the most powerful form of advocacy.
- 11. Be aware of the vulnerability of the people involved in services. Let them know the risks involved. Beware of exploitation.
- 12. Before you begin, know the risks and weigh them against possible gains.

#### **COMMUNITY ORGANIZATION**

[taken in part from Au Contraire, 1983 - Advocacy Today: Changing Strategies]

It is through the fostering of coalitions of all kinds of advocates that further change and improvement in the mental health system can be achieved and progress sustained.

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# The Mental Patients Liberation Alliance The Alliance

#### Who We Are

The Mental Patients Liberation Alliance (The Alliance) is a self-help, mutual support, and advocacy human rights organization of, by, and for people who have received psychiatric treatment. Our intention is to have a powerful impact at the state level. For almost four decades, we have influenced mental health decision makers, governmental officials, the media, the public, and each other.

**Career Opportunities** 

The Alliance offers opportunity to help broaden candidates' experience of people who have been labeled with psychiatric disability, alternatives, and interaction with the mental health system at all levels.

**Volunteer Opportunities** 

Volunteer opportunities range in all aspects of our organizational makeup from board membership to housekeeping tasks and include: human rights activism, advocacy, peer support phone line, marketing and promotion, grant writing, community outreach projects, and the inventory and preservation of historical materials.

Internships

Internships are open to the individualized focus of candidate interest and availability. Participants assist in formulating an internship program suited to their personal pursuits and educational goals.

**Trainings** 

The Alliance offers a myriad of trainings and will design a training to meet your needs or that of your group or organization. We can be contacted to arrange a presentation of <u>Infusing Recovery-Based Principles Into Mental Health Services</u>. A White Paper by People who are New York State Consumers, Survivors, Patients and Ex-Patients (September 2004), which is presented collaboratively with people from two or more organizations.

#### Contact Us

George Ebert, Coordinator (315) 947-5888 - Email georgeebert@yahoo.com Anne Dox, Coordinator (315) 732-5377 - Email aotau@yahoo.com

> Support, advocacy, and information (315) 732-5377 Or toll-free at 1-800-654-7227 24 hrs/day Mutual Peer Support Phone Line

Our corporate offices, The Alliance Center, and The Mad Market Thrift Shop are located at:

Mental Patients Liberation Alliance
13 Hopper Street
Utica, New York 13501

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