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#### ABSTRACT

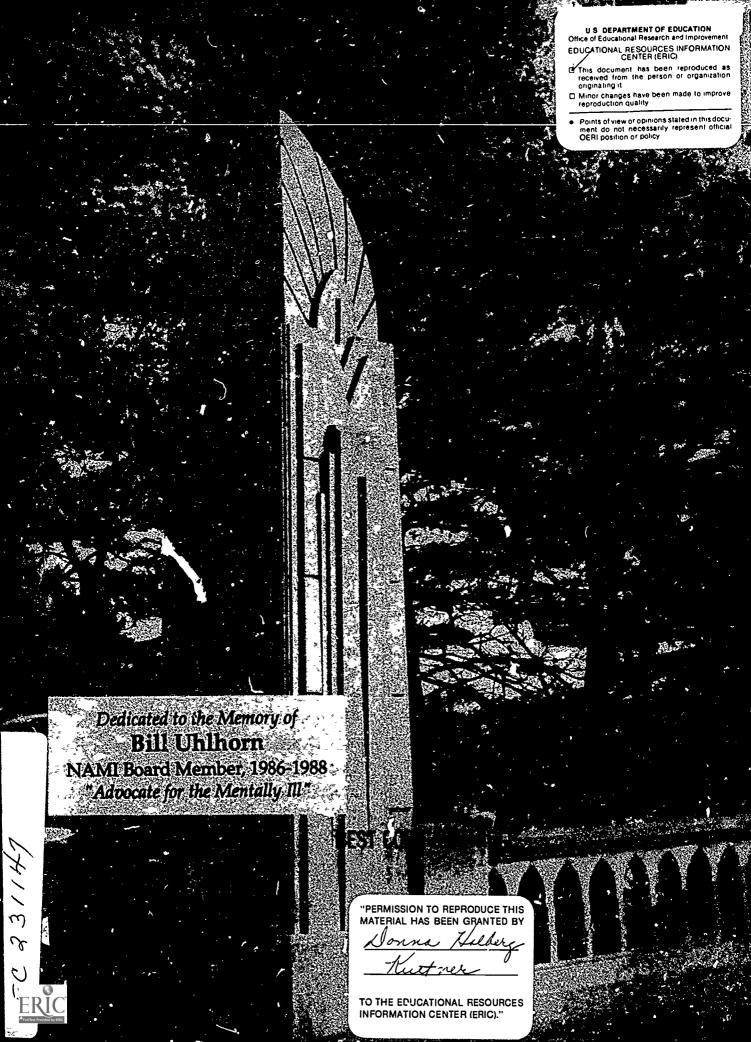
This publication presents papers and reprints of articles aimed at family members of persons with mental illnesses. After an introductory chapter, the second chapter reviews definitions of mental illness, and discusses what is known about medicating such conditions as well as the relationship of substance abuse to mental illness. The next chapter covers mental illness in a family context, including grieving, sibling reactions, communication skills, and crisis management. A chapter on advocacy groups is more specifically focused on resources available in Oregon. Chapter 5 covers the mental health service system, including a history of public mental health treatment in Oregon and descriptions of residential programs and community programs. Chapter 6 discusses the rights of families and clients, confidentiality, and estate planning. The last chapter covers voluntary and involuntary hospitalization. Appendices include a list of 35 recommended readings and a glossary of terms and acronyms. (PB)

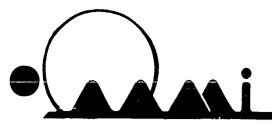
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TO: All recipients of the "Bridges" manual

The resource material in this manual was gathered from many sources across the country. Professional and family members reviewed together volumes of written words and chose what to them was most appropriate to help understand and cope with Mental Illness. Those of us who worked on the project want you to know that this manual is the best effort of professional and family members at the time of publication. As new treatment procedures and medication changes occur, it is our desire to send out updates to be added to the manual.

This manual also further enhances our efforts to work together as family members and professionals resulting in a better life for those who suffer from mental illness.

I want to thank everyone who worked on the publication of this manual, and a very special thank you to Syd Hatch and Jim Carlson of the Oregon Mental Health Division. They guided us through this entire process. Without their patience and arbitration skills this manual could never have been finished.

I speak for all participants who worked on this project when I say, "We hope the effort that was spent will have great payoff for family members, professionals and most importantly our friends who suffer from mental illness."

Don Norfolk & President, OAAMI





# Department of Human Resources

# MENTAL HEALTH DIVISION

2575 BITTERN STREET N.E., SALEM, OREGON 97310-0520

January 30, 1989

It is exciting to be writing an introduction to the Oregon Family Education Manual. It is exciting because of the collaborative nature of the process, because of the depth of the writing, the information exchanged, and the opportunity to reinforce our understanding that family education is a crucial factor in the outcome of treatment for people with mental illness. The notion is a simple one, the more families know about mental illness, the better they will meet the various needs that they, and their family members have. Families recognize it is difficult to "hang in there" with their relatives who have mental illness. There is stress, uncertainty, stigma and denial. Resources are inadequate, support is difficult to come by, and access to services is likened to the "eye of the needle". In this environment, knowledge is power!

The educational activities and information in this text are a sincere attempt to empower and strengthen families to promote even greater independence and more positive outcomes for their family members with mental illness.

The outcomes studies of family education programs undertaken by Anderson and Hogarty at Pittsburgh School of Medicine leave no doubt. Family education, when combined with appropriate medication and stress management training, was the key element of successful outcomes. In Oregon, our goal is to extend these services to include housing and rehabilitation leading to meaningful work.

It is my hope, and expectation, that this training enterprise will be one of many initiatives in the direction of an effective mental health services system. Reading this book joins us in partnership.

Richard C. Lip incott, M.D.

Assistant Director, Human Resources Administrator for Mental Health



## TABLE OF CONTENTS

#### I. Introduction

Letters of Introduction Table of Contents List of Contributors

#### II. Mental Illness

What is Mental Illness Medication and Mental Illness Substance Abuse and Mental Illness

## III. Mental Illness and the Family

The Meaning of Mental Illness to the Family Grieving and Stages of Loss Siblings and Mental Illness Communication Skills Crisis Management

## IV. Advocacy Groups

The National Alliance for the Mentally III
A Brief History of the Oregon Alliance of Advocates for the Mentally III
OAAMI Affiliates
Advocacy

## V. The Mental Health Service System

A Brief History of the Public Mental Health Treatment System in Oregon Adult Mental Health in Oregon—A League of Women Voters Pamphlet State and County Funded Mental Health Services Contacting a Community Mental Health Program Critical Mass and Priority 1,2,3 Residential Programs Entitlements

## VI. Families and the Service System

The Clients' Bill of Rights
Rights of Families
Confidentiality
Effective Professional Collaboration With Family Support Groups - a reprint
from the Psychosocial Rehabilitation Journal
Estate Planning

# VII. Voluntary and Involuntary Hospitalization

Psychiatric Hospitalization
State Hospitalization
A Family Member's Guide to Civil Commitment
The Psychiatric Security Review Board

## VIII. Appendix

NAMI Suggested Reading List
Alphabet Soup—A Glossary of Acronyms and Abbreviations



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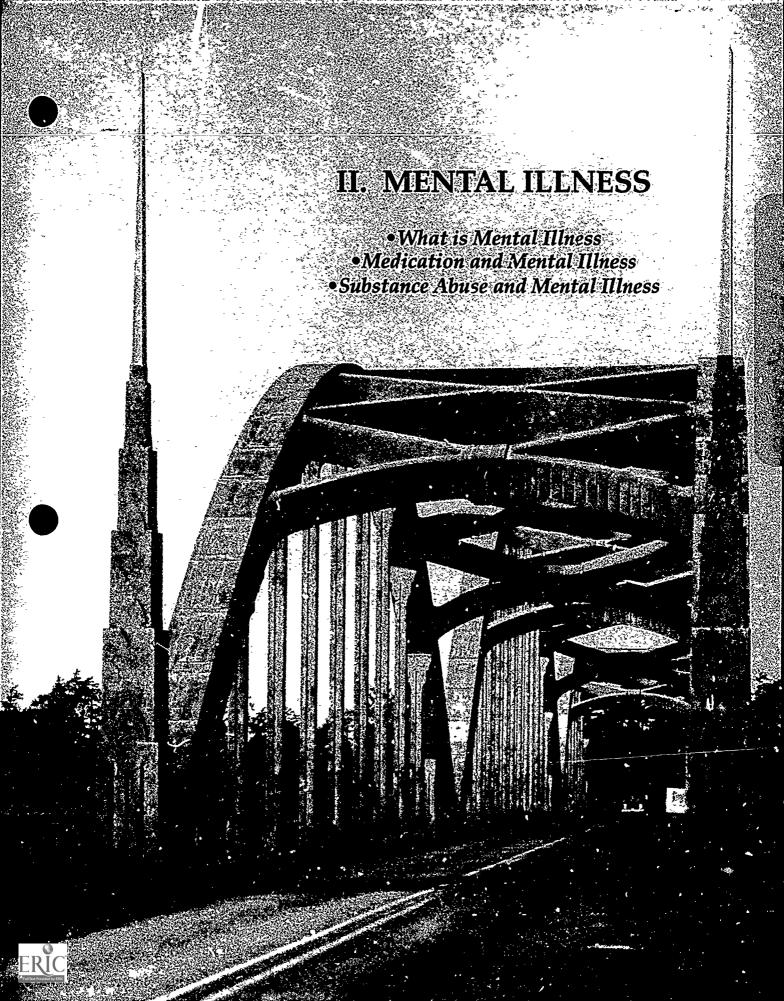
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Mental illness is a term used for a group of disorders causing severe disturbances in thinking, feeling and relating. They result in substantially diminished capacity for coping with the ordinary demands of life. Mental illness can affect persons of any age - children, adolescents, adults, and the elderly - and they can occur in any family. Several million people in this country suffer from a serious, long-term mental illness. The cost to society is high due to lost productivity and treatment expense.

Mental illness is not the same as mental retardation. The mentally retarded have a diminished intellectual capacity usually present since birth. Those with mental illnesses are usually of normal intelligence although they may have difficulty performing at a normal level due to their illness.

Mentally ill people occupy more hospital beds than persons suffering from cancer, lung and heart diseases combined. Many others struggle with their illness in non-hospital settings - alone, in group homes, in their parents house, or on the streets. But those persons afflicted with mental illness are not the only ones to suffer. Their families often face tremendous challenges - economic, emotional, and sometimes even social.

Schizophrenia is a brain disease, now definitely known to be such. It is a real scientific and biological entity as clearly as diabetes, multiple sclerosis, and cancer are scientific and biological entities. It exhibits symptoms of brain disease, symptoms which include impairment in thinking; delusions, hallucinations, changes in emo-

tions and changes in behavior. And, like cancer, it probably has more than one cause. Thus, though we speak of schizophrenia and cancer in the singular, we really understand them as being in the plural; there are probably several kinds of schizophrenia of the brain just as there are several kinds of cancer of the brain (Surviving Schizophrenia, 1983, E. Fuller Torrey, M.D.). Schizophrenia affects 1 percent of the population.

Affective Disorders are terms used to describe the most common group of serious mental illness. They are generally less persistently disabling than schizophrenia, but often go untreated. The most common types are Major Depression and Bipolar Disorder (Manic Depression). The term affective disorder refers to changes in mood that occur during an episode of illness marked by extreme sadness or excitement, or both. These diseases affect about 6 percent of the population.

NAMI members are persuaded by current research that serious mental illnesses are biologically caused brain diseases, without cure or prevention at this time. We do not believe that the cause lies in the family interaction. Our experience is that medication and rehabilitation can be very helpful.

Formed in 1979 by 80 local self-help groups of families, the number of local and state groups has risen to over 900, covering all 50 states, Canada, Guam, and Puerto Rico. Thereare over 37,000 member families. NAMI has expanded at the rate of one new affiliate group every 36 hours. These groups help in many ways.



- •Support: At the local level including sharing sorrows, joys methods of coping, and information about providers who are helpful. At the state and national levels, support means networking: helping families find a local group, or, where none exists, helping to form one.
- Education: Books, papers, films, educational programs, and AMI newsletters serve as tools for educating families, patients, and the public. State and national conventions present the latest in medical research, rehabilitation, housing, and other facets of community support systems. Many members take an active role in combating the stigma surrounding mental illness.
- •Advocacy: AMI groups use their consumer voice alone or in coalitions to make state and local governments more effective in serving mentally ill people. NAMI advocates for a better quality of life for mentally ill people and for more and better research into the causes and cures of mental illness.
- •Research: Believing that the hope for a better future lies in research, NAMI has helped establish the National Alliance for Research on Schizophrenia and Depression (NARSAD), a voluntary non-profit research alliance.

In addition, NAMI has standing committees for special interest groups such as siblings, mentally ill people who are in jail or prison, recovering patients, and ethnic minorities.

To find out more about serious mental illness and the family movement, contact your local Alliance for the Mentally Ill affiliate, or contact the national office:

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(This article is reprinted from materials prepared by the National Alliance for the Mentally Ill)



#### I. THE ROLE OF MEDICATIONS

Schizophrenia and depression are thought, by medical experts and researchers, to be caused by a disturbance of brain chemicals. This imbalance is aggravated by stress. Although medicines cannot cure schizophrenia or depression, they can reduce (or in some cases) even remove the symptoms. These medications can help to prevent relapses. The actions of the medicines are to partially correct the imbalance of chemicals that pass messages through the brain. In so doing, the mood and thought processes are altered toward more normalized function for the mentally ill person.

#### ADVANTAGES OF MEDICATIONS

Advantages of these medicines are as follows:

- Reduction, and in some cases, elimination of thought disorder (psychosis) and restoration of mood.
- Promotion of greater return of function due to decreased psychosis and/ or depression and/or anxiety.
- 3. Increased ability to profit from rehabilitation, socialization and/or preventive programs.
- 4. Increased possibility for the chronically mentally ill person(s) to function sufficiently to reside in the community.
- 5. Reduced need for hospitalization and/or physical restraints.

#### **DISADVANTAGES OF MEDICATIONS**

Not all individuals experience similar symptoms with the same intensity. Higher doses may produce more side ef-

fects in almost all individuals. These side effects are not permanent and most can be decreased and/or eliminated with specific medication and with careful supervision and medication adjustment.

- 1. Unpleasant side effects include dry mouth, constipation, some vision blurring, decreased sex drive/function, menstrual disturbances, muscle tremors, decreased feelings of creativity and spontaneity.
- 2. Uncomfortable side effects include feelings of inner restlessness, pacing. muscle rigidity. Less frequent symptoms include muscle spasms, urinary retention, rapid heart beat, dizziness due to low blood pressure, sunlight sensitivity leading to severe sunburn and/or rash.
- 3. Dangerous side effects are toxicity and convulsions. These are much less frequently found and are preventable.
- 4. Tardive Dyskinesia is the term given to involuntary, non-purposeful movements which may be permanent and which may diminish social acceptability and the ability to function in daily life. Not all mentally ill persons who take anti-psychotic medicines develop these movements. There is an abnormal involuntary movement scale (AIMS) for early detection of the presence of involuntary movements. There is the risk of this condition for all persons who take anti-psychotic medicines.



### II. CATEGORIES OF DRUGS

#### A. ANTI-PSYCHOTIC MEDICINES

These are chemical compounds which have been developed specifically for treatment of the symptoms of psychosis which include unusual or bizarre behavior, auditory, olfactory, tactile, and/or visual hallucinations, disorganized/disordered thinking, and delusions and suspiciousness which interfere with the individual's ability to function in the community. These medicines can prevent relapse and/or hospitalization.

Examples of anti-psychotic medicines are as follows: Thorazine, Trilafon, Stelazine, Prolixin, Haldol, Mellaril, Navane, Loxitane, Moban. Each drug also has a generic or chemical name. See chart for additional information.

Desired Actions include normalization of thought processes and behavior with increased ability to function in daily life activities.

Uncomfortable and undesirable side effects include the following: tremor; slower, shuffling gait; less facial expression; less vocal expression; muscle stiffness; pacing; inner restlessness; muscle spasms. (These are not permanent and can be decreased and/or eliminated by anti-cholinergic medicine.)

When combined with alcohol the effects of alcohol are increased.

**NOTES:** 



Note regarding all medication charts: For accurate dosages & current information, consult the *Physicians' Desk Reference*.

## **ANTI-PSYCHOTIC MEDICINES**

	1,,67	
Brand Name	Generic Name	Typical Dose Range * (Milligrams)
Prolixin Permitil	Fluphenazine	1 - 40 Oral 25 - 50 weekly or bi-monthly injections
Haldol	Haloperidol	1 - 40
Navane	Thiothixene	5 - 60
Stelazine	Trifluoperazine	5 - 50
Trilafon	Perphenazine	8 - 80
Loxitane	Loxapine	15 - 100
Moban Lidone	Molindone	50 - 225
Mellaril	Thioridazine	75 - 800
Thorazine	Chlorpromazine	100 - 1200
Clozaril**	Clozapine	not yet available

<sup>\*</sup>Acute symptoms may require much higher doses.

NOTE: These medicines carry a risk of development of Tardive Dyskinesia.



<sup>\*\*</sup>Clozaril, (generic Clozapine) is due to be released sometime in 1989. At this time there is no information regarding dosage. The FDA report on this medication is not available at the time of this publishing. This medication has been shown to be useful for many severe psychiatric conditions which have not been responsive to current medications. Its uses will require regular blood tests as one possible side effect is destruction of a type of white blood cell (neutrophils).

#### **B. ANTI-CHOLINERGIC MEDICINE:**

These medicines have been found to be extremely useful in diminishing and/or eliminating the uncomfortable/undesirable side effects of anti-psychotic drugs. These medications are not designed to treat the symptoms of psychosis.

Examples are as follows: Benadryl, Cogentin, Artane, Kemadrin, Akineton. These medicines also have generic names and have varying dosages

Desired actions are to relieve and/or eliminate unpleasant/ uncomfortable side effects of anti-psychotic drugs.

Uncomfortable side effects include the following: blurred vision, constipation, dryness of mucus membranes, increased thirst (not permanent and are eliminated when medication is stopped).

When combined with alcohol there is an increased sleepiness (primarily with Benadryl).

Symmetrel which is not an anti-cholinergic medicine has also been found useful for relief of anti-psychotic medication side effects.

#### C. ANTI-DEPRESSANT DRUGS

Anti-depressant drugs are chemical compounds which have been developed to relieve and/or eliminate the thinking disorder and restore the mood in those individuals who demonstrate depression with symptoms of appetite and weight loss/gain, mood(s) of sadness/hopelessness, slower/agitated thinking, excessive feelings of guilt and/or misinterpretation of reality.

Some of the anti-depressant medicines are calming, reduce anxiety, and are more sedating. Others produce increased energy. The type used is dependent upon the symptoms.

Examples of anti-depressant medications include Tofranil, Pertofrane, Norpramin, Elavil, Endep, Pamelor, Aventyl, Vivactil, Sinequan, Surmontil, Asendin, Ludiomil, Desyrel. Nardil, Parnate, Marplan. (See chart for generic names and dosage.)

Desired action of the medicines is to eliminate the thinking disorder and the extreme feelings of depression with a return of function to the level prior to the onset of depression.

Unpleasant side effects include mouth dryness, increased thirst, some blurring of vision, sweating, urinary retention, heart-rate changes, and weight gair. A craving for sweets has been identified by some. (These side effects frequently decrease spontaneously within a month and will disappear when the medicines are reduced/adjusted or are discontinued.) There are diet restrictions for some drugs.

Dangerous side effects include blood pressure changes—particularly for those medicines requiring diet restrictions. Extreme dizziness from low blood pressure can result in falls. Extreme high blood pressure can result in strokes. These are preventable by maintaining diet and treatment compliance.

Effect When Combined With Alcohol Alcohol ingestion along with use of anti-depressant medicines can be FATAL.



## **ANTI-DEPRESSANTS**

Brand Name	Generic Name	Typical Dose Range * (Milligrams)	Least Secation
Vivactil	Protriptyline	15 - 40	
Asendin	Amoxapine	100 - 300	
Norpramin Pertofrane	Desipramine	100 - 300	
Prozac	Fluoxetine	20 - 80	
Tofranil	Imipramine	100 - 300	
Aventyl Pamelor	Nortriptyline	50 - 150	   
Ludiomil	Maprotiline	75 - 150	
Desyrel	Trazodone	150 - 400	
Sinequan Adapin	Doxepin	156 - 300	
Elavil Endep	Amitriptyline	150 - 300	Most Sedation

The usual time for relief of symptoms of classic depression is two to three weeks. Improved sleep and reduced anxiety may be apparent earlier than three weeks.



<sup>\*</sup>Precautions may be necessary—may be lethal in suicide attempt.



Monoamine Oxidase Inhibitor (MAOI) medicines, which are anti-depressants, require a restricted diet. See chart for details.

#### **MONOAMINE OXIDASE (MAO) INHIBITORS \***

Brand Name	Generic Name	Typical Dose Range (Milligrams)	
Nardil	Phenelzine	45 - 90	
Parnate	Tranylcypromine sulfate	20 - 60	
Marplan	Isocarboxazid	30 - 80	
*All are non-sedating			

#### DIET RELATED SIDE EFFECTS

The combination of MAO inhibitors (Nardil, Parnate & Marplan) and certain foods can produce severe side effects which include the following: very high blood pressure, rapid pulse, headaches, visual problems, and sometimes paralyzing or fatal strokes. These are preventable.

#### FOODS TO AVOID

Avoid foods which are high in tyramine or histamine: including beer, red wine, aged cheddar cheese, chocolate, yogurt, pickled fish, meat tenderizers, fava beans, sour cream, soy sauce, and raisins. AVOID stimulants, caffeine and allergy pills.

#### D. ANTI-ANXIETY MEDICINES

Anti-anxiety medicines are chemical compounds which have been developed for reduction of severe anxiety. Usually these medicines are not used in the treatment of disorganized/ disordered thinking. All of these compounds have some sedative properties which may assist sleep. Many of the medicines have muscle relaxing properties.

Examples include Centrax, Klonopin, Ativan, Valium, Librium, Tranxene, Xanax. Each drug has a generic name. Dosages vary according to the need.

The desired action of these medications is to reduce anxiety and tension in those individuals who are in contact with reality. These medications assist sleep.

Undesirable Side Effects—These drugs may be habit forming for some individuals. There is a risk of substance abuse when taken over a prolonged period of time. In addition to dependency development, these medicines may impair driving ability and/or ability to operate equipment. In some individuals these medicines diminish inhibition. Some people lose the ability to control rage. Mental confusion is another side effect which may develop.

Effect When Combined With Alcohol - Combining these drugs with alcohol may be FATAL. These drugs increase the effects of alcohol.



#### **ANTI-ANXIETY MEDICINES \***

Brand Name	Generic Name	Typical Dose Kange (Milligrams)
Xanax	Alprazolam	0.5-4.0
Ativan	Lorazepam	2-6
Centrax	Prazepam	20-60
Klonopin	Clonazepam	0.5-10
Serax	Oxazepam	15-120
Tranxene	Clorazepate	7.5-60
Librium	Chlordiazepate dipotassium	10-100
Valium	Diazepam	2-40
BuSpar**	Buspirone HC1	15-30
<b>r</b>	Daophone 1101	10 00

<sup>\*</sup>Reminder: All of these medicines may be habit forming.

Effect When Combined With Alcohol—All may be FATAL when combined with alcohol.

#### E. LITHIUM CARBONATE

Lithium carbonate is a unique medicine. Unlike most other compounds used in the treatment of mental illness, it is neither a stimulant nor a sedative. For most people it has relatively few side effects, although it can be extremely dangerous and life-threatening if toxicity occurs. This substance, which is a mineral salt, is used almost exclusively in treatment of mood or affective disorders. Recently, there has been success reported with the use of Lithium for treatment of mental illnesses which have both the characteristics of schizophrenia and a disturbance of mood.

Examples of lithium medicines are Eskalith, Eskalith CR, Lithonate, Lithobid.

Desired actions include the following: to prevent mania and/or depression. to normalize mood and behavior; to diminish extreme highs and lows which interfere with an individual's ability to function. These highs and lows impair judgment, affect concentration, and disorganize thinking. There is no tardive dyskinesia risk with this medicine.



<sup>\*\*</sup>BuSpar is reported to be less likely to develop drug dependency.

Disadvantages of Lithium Medication—Successful lithium therapy is dependent on daily compliance of medicine. Lithium leaves the body rapidly. Attention to nutrition and fluid intake is important. There must be a willingness to undergo blood tests and other laboratory tests which are necessary to determine thyroid, and kidney function, and serum lithium level (upon which dose is determined). This medicine is not safe for those individuals who fast, use alcohol excessively, or are at risk for inadequate nutrition and dehydration.

Unpleasant Side effects—Particularly during the initial adjustment, which may be several weeks, some of the following side effects may appear: increased thirst, increased urination, mild nausea, mild stomach cramps, mild daytime sleepiness, slight muscular weakness, decreased sexual ability, fine tremor (shakiness of the hands), slight dizziness, occasional loose stools, weight gain, metallic taste in mouth, worsening of acne or psoriasis. Most of the symptoms will go away or lessen in the first few weeks. The symptoms most likely to persist are increased thirst, weight gain, and fine tremor of the hands.

Dangerous Side Effect—Toxic levels can lead to convulsive episodes, permanent brain damage, and death.

Effect When Combined With Alcohol—Ingestion of alcohol may cause the serum lithium level to be altered either lower or higher depending upon the individual's response to alcohol.

#### F. ANTABUSE

Antabuse (generic: disulfiram) is a chemical compound developed specifically for use in the management of alcoholism. Antabuse produces a sensitivity to alcohol which results in a highly unpleasant physical reaction when an individual taking Antabuse ingests even a small amount of alcohol. Alcohol in liniments, skin preparations (such as shaving lotions and cologne), mouth wash, and breath preparations, as well as cough syrups and other over-the-counter products which contain alcohol, may produce a reaction.

#### **Desired Effects**

The desired action is to assist the alcoholic individuals in their efforts to remain alcohol free until permanent self-control is developed.

#### Undesirable Side-effects

Initially the person who is starting Antabuse therapy may be aware of increased drowsiness, some increased feeling of fatigue and may experience a metallic or garlic-like taste in the mouth.

#### Effects When Combined with Alcohol

The "Antabuse Reaction" results when Antabuse is ingested with alcohol. It includes flushing, throbbing in head and neck, respiratory difficulty, nausea, vomiting, sweating, thirst, chest pain, racing heart beat, weakness, dizziness, rapid-shallow breathing, low blood pressure, blurred vision, and mental confusion.



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#### Severe Reactions

Severe reactions can include respiratory failure, collapse of the cardio-vascular system, irregular heart beat, heart attack, convulsion, and death.

This medication must be used only under close medical supervision and for those individuals who are motivated to remain free from alcohol. This medicine cannot be combined with certain other medicines and cannot be used if the individual is also being treated for specific cardiac and/or circulatory conditions.

It is imperative the person taking Antabuse be aware of the above side-effects and the "Antabuse Reaction." All individuals who are taking Antabuse should carry an Antabuse identification card or wear an identifying bracelet.

# FREQUENTLY ASKED QUESTIONS

## 1. How important is compliance with medicine?

Medicine has been the major reason people with mental disorders have been able to live in the community.

Experience and research have demonstrated fewer relapses occur with those individuals who take their medicine on a regular basis.

Many times the person who is consistent in taking medicine is able to be maintained on lower amounts of medication. Lower amounts frequently produce fewer and/or less severe side effects.

## 2. Are there alternatives to medicines?

Mega-vitamin therapy and renal dialysis have become publicized as alternatives. To date there is no long-term success in maintaining remission of symptoms and/or preventing relapses with these methods of treatment.

3. How can a person ask someone he/she loves to take medicines which may cause permanent involuntary body movements?

This is one of the most difficult of all questions, for family members, and professionals in both the medical and counseling fields. Sometimes it is helpful to recall the behavior during acute illness. Could the person live in the community without medicines? What is the quality of life with medicine and without medicine? What are the risks involved to the person with the mental disorder and to others who are also involved with him/her?

Ultimately each of us must decide whether or not we can support medication therapy.



## 4. Is medicine the only needed treatment for mental illness?

Medicine is designed to assist in clearing the disorganization and unusual thinking associated with mental disorders.

The ill person continues to require safe housing, good autrition, attention to other possible physical illness, social/recreational activity, and meaningful structured activity, as well as an ongoing financial base.

A treatment team using a multi-faceted approach is best for optimal return of function.

## 5. What should the person who is taking the medicine be told?

It is important for the person to know what the medicine is designed to do, what side effects might develop, and what can be done to reduce them. An explanation of the tardive cyskinesia risk with anti-psychotic medicine is vital.

In addition, the mentally ill person needs education and counseling in understanding the nature of his/her illness, the importance and purpose of the medication, and self-monitoring for signs of decompensation.

## 6. Who is responsible for the person taking the medicines?

The person who ingests or takes the medicine(s) is ultimately the person who makes the choice and is responsible. Accurate information as to the advantages and disadvantages is frequently the most effective method of obtaining consistent voluntary participation in medication treatment.

# 7. Can a person be given medicine against his/her will in outpatient treatment?

Medication therapy is voluntary in almost all cases—the exception being an individual on probation by the Psychiatric Security Review Board who may have participation and compliance in medication treatment as a condition of community placement.

The person involved does have the choice of cooperating by taking medicine or returning to the institution.

# 8. Are there any medicines that even a single dose can't be forgotten?

Everyone will occasionally miss a dose of medicine. Usually there is no problem, provided the missing of medicine is not too frequent such as daily, several times a week, etc.

Lithium Carbonate is the one medicine which is most strongly affected by missed doses. The serum blood level is affected by even one missed dose.



## 9. What can be done to prevent "missed" doses?

Use of a daily or weekly pill container has proven helpful for some.

A medicine schedule that is as simple as possible—once or twice daily only—is very helpful in compliance.

Linking pill-taking with a regular habit such as brushing teeth, breakfast, supper, at bed time, etc. is another way to insure daily compliance with medication.

#### References and Suggested Readings

Other information on medications can be found in the following publications. These and other publications are available from your local OAAMI affiliate.

Greist, J., and Jefferson, J. (1984). Depression and Its Treatment: Help for the Nation's No. 1 Mental Problem. Washington, DC: American Psychiatric Press.

Papolos, D. and Papolos, J. (1987). Overcoming Depression. New York: Harper and Row.

Kalvelage, J, et al. . Questions and Answers About Tardive Dyskinesia. Arlington, VA: NAMI.

Torrey, E. (1988). Surviving Schizophrenia: A Family Manual. New York: Harper and Row.

Walsh, M. (1986). Straight Talk for Families and Friends. New York: Warner Books.

Medical Economics Company. Inc. (1988). Physicians' Desk Reference.



# SUBSTANCE ABUSE AND MENTAL ILLNESS

There is now emerging a new generation of mentally ill people who also abuse alcohol and drugs. Some of these people do not accept treatment and view mental health workers as intrusive. This group is often referred to in literature as the young adult chronic. The diagnoses of mental illness and substance abuse identifies the young adult chronic as one of the "dually diagnosed" populations.

John Talbott writes: "There is evidence that substance abuse can both precipitate the onset of psychiatric conditions and relapse as well as interfere with treatment of underlying mental illness." Even those who use alcohol and street drugs occasionally can be adversely affected. Any use of alcohol or other substances can produce psychiatric symptoms.

There is little research on the effects of alcohol and drugs on medications the mentally ill take. However, it is known that small amounts of alcohol may impact Lithium levels. (See "Medication and Mental Illness.") Mixing alcohol with anti-depressants and/or anti-psychotic medications aggravates symptoms of depression and can be lethal.

Frequently used substances include alcohol, marijuana, cocaine, "crack", amphetamines, and hallucinogens. Alcohol and barbituates are depressants. They cause a generalized depression of the central nervous system. Amphetamines such as "speed" or "crank," and cocaine stimulate the cardiovascular and central nervous system. Hallucinogens such as LSD and PCP induce altered perceptions, thoughts, and feelings. Marijuana and hashish have the properties of both sedatives and psychedelics.

In a study to determine reasons why the young, mentally ill use drugs, twothirds of 34 respondents reported that they smoked marijuana to be accepted by their peer group. Forty percent used alcohol and marijuana to self-medicate. Self medication can be an effort to ease the pain of the mental illness. Young adults who have a mental illness are extremely vulnerable to stress. Their reactions to personal rejection and the pressures they feel to conform to social expectations raise their anxiety and increase their feelings of despair. An individual with a major mental illness who has difficulties coping with an independent life and who also uses alcohol and/or drugs as a response to stress, delays or destroys the possibility of growth.

Psychiatric treatment becomes very complex when working with a client who may have a mental illness and is also using alcohol and/or drugs. The professional must determine the answers to a number of questions.

- Is the client suffering from two independent illnesses, one being psychiatric and the other related to alcohol and/or drug abuse?
- Is the client using alcohol and drugs to "selfmedicate" an underlying psychiatric disorder?
- Is the client suffering from a FIRST psychotic episode brought on by a drug experience?
- Are the psychiatric symptoms caused by chemical abuse?
- Another issue the therapist must address is the frequent response: "What's in it for me? Why should I stop smoking dope or drinking? I have nothing to do anyway."



The challenge for both families and clinicians is how to engage the person in his/her own treatment. Some may be mandated by the courts to seek treatment for substance abuse. Most other clients need help to find an external, tangible reason to quit. The internal reasons like controlling psychiatric illness, learning new ways of coping, and improving their quality of life are not immediate enough. For instance, they want to work and want to get into a Vocational Program. To do this they must be off alcohol or drugs for six months. Some programs require antabuse as a prerequisite for admission. This is called "leverage" and is an effective method for motivating the mentally ill person to seek treatment for his/her substance use. Through "leverage," offering something that is wanted or needed, the first step of seeking treatment can begin. Once in treatment the long-term goal of internalizing the reasons for staying away from substances can be addressed.

Because of the nature of the current service delivery system in Oregon, dually diagnosed clients often are inappropriately and/or under-served in programs. The mentally ill individual who uses drugs or alcohol will frequently encounter barriers to needed services. The Dual Diagnosis Task Force sponsored by the Office of Alcohol and Drug Abuse Programs in cooperation with the Mental Health Division found that many Community Mental Health Programs assess clients' chemical problems and send them to the Alcohol and Drug (A & D) system. If A & D does the initial intake and assesses their psychiatric problems, clients are usually referred to the Community Mental Health Program. In either case, only one of the client's problems may be treated—mental illness or substance abuse.

Many of these people turn up repeatedly in emergency rooms or crisis centers. When these individuals have been referred to vocational/socialization programs, their needs have not been met.

Joth the Mental Health and the A & D systems feel the impact of these treatment failures, and they are taking a closer look at the problem. What is now happening in several counties in the state is an attempt to combine the techniques of A & D and MED (Mentally and Emotionally Disturbed) in order to coordinate aspects of both treatment approaches. Alcoholics Anonymous (AA) and Narcotics Anonymous (NA) groups are beginning to understand the importance of psychiatric medications. This is a major step for organizations which strongly recommend that members should not take any drugs even if prescribed.

In summary, the dilemmas facing the treatment are:

- 1. The individual's denial of a problem and resultant unwillingness to seek treatment.
- 2. Lack of age-appropriate and client effective treatment programs for the dually diagnosed.
- 3. Lack of clinical cooperation and treatment planning between alcohol treatment and mental health treatment agencies.



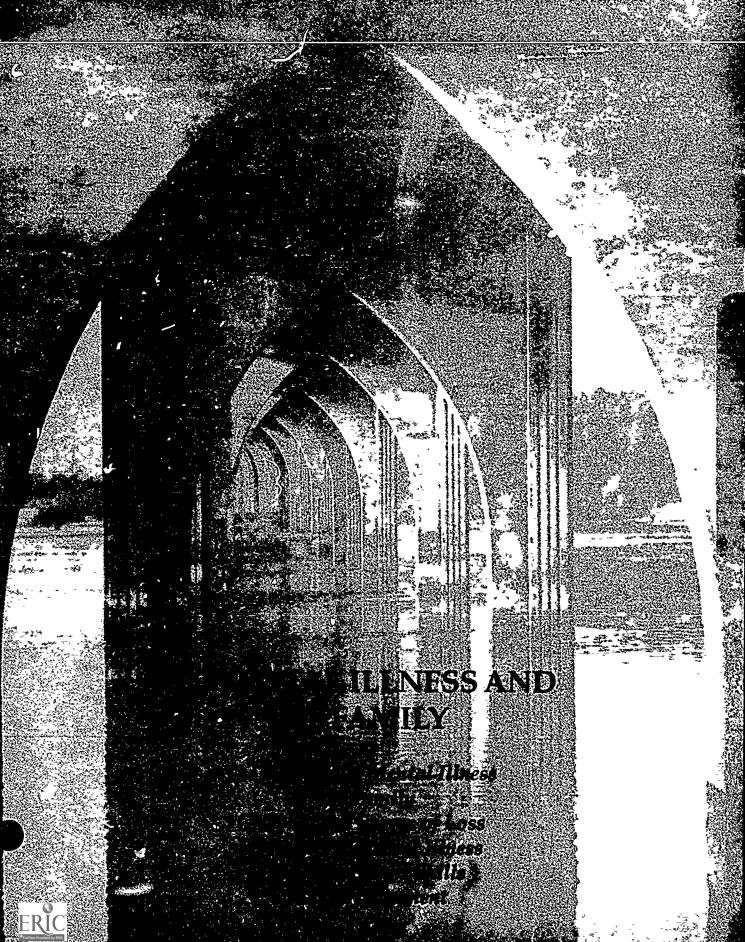
## WHAT FAMILIES CAN DO.

- •1. Call the therapist's attention to the drug or alcohol use. If the therapist seems to be unaware or unresponsive, keep bringing up the substance use and the effects of it that you see.
- •2. Share your concern and observations with your drug-using family member. Try to be realistic and matter-of-fact about the issue. For you, as for the clinician, preaching is not helpful, nor is an overly emotional attitude. But don't ignore or tolerate the substance use, and do set appropriate, realistic limits—e.g., someone who is intoxicated or who repeatedly comes home intoxicated should not be given use of a car.
- •3. Involve yourself in self-help groups for family members—e.g., family support groups such as AMI and Al-Anon. These may give a fresh perspective and support in setting limits.
- •4. Press for appropriate awareness, approaches and services in the treatment system to deal with substance use problems. Pressure the county and state to allocate funds to implement these services.
- •5. Encourage participation in alternative activities to substitute for drug use (i.e. psychosocial rehabilitation, socialization programs).

#### REFERENCES & SUGGESTED READINGS

- Bergman, H. & Harris, M. (1985). Substance Abuse Among Adult Chronic Patients. Psychosocial Rehabilitation Journal, 9(2), 49-54.
- Johnson, Bassin, & Shaw, Inc. (1987). Relationship of Chemical Abuse and Dependency to Psychiatric Disorders and Problems, Dual Diagnosis Training, Assessing and Treating the Client with Both Alcohol and Drug and a Mental Health Diagnosis, Participants Manual, (Vols 1 & 2).
- Office of Alcohol and Drug Abuse Programs, (March, 1988). *Dual Diagnosis Task Force Report*. This is available from the Office of Alcohol and Drug Abuse Programs, 1178 Chemeketa St. NE, #102, Salem, OR 97310, 378-2163.
- Pepper, B. & Ryglewicz, H. (1985). Guidelines for Treating the Young Adult Chronic Patient. Tie Lines, 2(4), 1-6.
- Pepper, B. & Ryglewicz, H. (July, 1984). The Yeung Adult Chronic Patient and Substance Abuse. Tie Lines, 1(7).
- Talbott, J. (July 1, 1986). Chronic Mentally Ill Young Adults (18-40) with Substance Abuse Problems: A Review of Relevant Literature and Creation of a Research Agenda. Submitted to Alcohol, Drug Abuse, and Mental Health Administration, U.S. Dept of Health and Human Services and Department of Health and Mental Hygiene, State of Maryland, p2.
- Bouricius, J. (1987). Dealing with Drugs: Psychoactive Medications and Street Drugs: Their Good and Bad Effects on the Mentaliy Ill. Amherst, MA: Jean Bouricius.
- Caragonne, P., & Emery, B. (1987). *Mental Illness and Substance Abuse: The Dually Diagnosed Client*. Published by the National Council of Mental Health Centers, 6101 Montrose Road, Suite 360, Rockville, MD 20852, 301-984-6200.
- Thorp, A. & Nikkel, V. (1983). Alcohol's Effect on Psychiatric Problems. Marion County: Marion County Mental Health.





# THE MEANING OF MENTAL ILLNESS TO THE FAMILY

When a loved one is stricken with mental illness, every member of the family feels pain. Whether the patient is your mother, father, son, daughter, sister, brother, grandchild, or grandparent, you share in his suffering. But you have other feelings that confuse and frighten you.

Before the doctors gave you a diagnosis, you probably went through a long period of uncertainty—trying to make sense of what was happening. You were stunned and bewildered. You hoped that the odd behavior and scary talk would stop, that soon things would be back to normal. Maybe a crisis occurred.

In one way or another, your family member was brought to treatment. Once the diagnosis was made, you began asking questions: "Will my loved one get better and lead a normal life again?" "What have I done wrong?" "Why did this happen to me, to us?"

Your questions and your feelings are quite natural. Your grief, shame, and anger, your sense of helplessness, your hours of anxiety—all are shared by others going through similar experiences. But depending on your relationship to the mentally ill family member, you also have feelings that are not shared by others.

Perhaps it is your child who has fallen ill. Suddenly a promising young person, on the threshold of becoming an adult, takes a sharp turn. Now, there is a stranger in your midst. Your once happy

and content son or daughter becomes withdrawn, unkempt, and unable to function. He argues, destroys possessions, says and does things that make no sense You, like other parents, want to protect and nurture your child. When your desire is thwarted, you feel that you have failed. Perhaps you blame him. Such feelings are not unique to parents of mentally ill persons. Parents of children with severe physical illnesses such as cancer or heart disease also tend to blame themselves, to harbor feelings of resentment toward the victim. Because mental illness affects such intensely personal aspects of our being, it is not surprising that parents of niental patients do likewise. Professionals-often unwittingly-may augment your guilt by blaming you for the tragedy.

When it is your spouse who becomes mentally ill you have special problems. This is, after all, the person you chose to marry—your mate, companion, and lover. Not only do once-shared responsibilities fall solely on you, but you must try to find help for your spouse. Perhaps help is not welcomed. Without diminishing your partner's status, you must juggle the roles of mother, father, homemaker, and breadwinner all at once.

Other family members may escape the responsibilities that fall to a parent or spouse of the mentally ill person, but they share equally painful feelings. Brothers and sisters are bewildered, hurt, and sometimes ashamed and angry. Grandparents are perplexed and saddened. Adult children

This article is reprinted from Agnes Hatfield's Coping with Mental Illness in the Family - A Family Guide. It is published by the National Alliance for the Mentally Ill.

Throughout this article, he, his, and him are used as the pronoun when both males and females are meant to be included.



find it difficult to assume the role of caretaker when a parent becomes incompetent.

One out of four families has a close relative who is mentally ill. They, like you, typically go through a period of intense searching. Patients, family members, and doctors alike tend to place blame—to identify an event or a person responsible for the breakdown. "Why me?" is an understandable cry.

In time, most families come to accept the illness. Somehow, they find resources to sustain themselves over the rocky period. Many become stronger in the process. When they look back over years of living with chronic mental illness, they almost invariably remember the earliest period as the hardest. They may have been surprised by the amount of energy, resourcefulness, and courage they were able to muster. They come to feel pride in their capacity to face tragedy and conquer defeat.

While no cure is now known for the more severe, chronic mental illness, almost everyone can be helped to live worthwhile and meaningful lives. Caring relatives must continue to hope for improvement, set reasonable expectations and maintain faith in the patient's recuperative and restorative powers. Realities change. What may have been impossible at one time may become quite possible. There will be regressions, plateaus when all anyone can expect to do is "hang on," and forward movement.

A short time ago families who had known mental illness for a long time were asked how it affected them. As might be expected, many reported the negative consequences. But many also saw positive changes in their lives. One mother said she no longer takes life for granted. learned to appreciate the little things in life," she said. "I make it a point to find something to enjoy each day." Other family members reported that they were more compassionate, less judgmental, more understanding of others. Most had made what they considered a more mature reevaluation of their lives, thereby achieving a truer vision of what really counts. They believed that their lives had become more significant, more basic, more meaningful.

Most families, in short, found they had wellsprings of strength they never knew they had until they met the great challenge of mental illness.

### **Summary**

Mental illness has a profound effect on the patient and his family. Invariably, families go through a period of shock and disbelief at first. Only slowly do they adjust adequately to the demands that severe mental illness makes on them. They need to know as much as possible about the illness and to learn how best to support the patient.

#### REFERENCES AND SUGGESTED READINGS

Bernheim, K., Lewine, R., & Beale, C. (1982). The Caring Family. New York: Norton.

Hatfield, A. (1978). Psychological Costs of Schizophrenia to the Family. Social Work, 23:355-359.

Vine, P. (1982). Families in Pain: Children, Siblings, Spouses, and Parents of the Mentally Ill Speak Out.

New York: Pantheon Books.

Wasow, M. (1982). Coping with Schizophrenia, A Survival Manual for Parents, Relatives, and Friends. Palo Alto, California: Science and Behavior Books.



Families facing chronic mental illness experience a major change in their lives since the illness is frequently life long. Relationships are altered for all family members. The whole family is affected and compensates for the loss.

Elizabeth Kubler-Ross has written about the stages of emotional and attitudinal adjustment to illness and death in *On Death and Dying*. Dr. Kubler-Ross classified these stages as denial or shock, anger, bargaining, depression, and acceptance. These stages of response to death and dying are also recognizable in all human response to serious loss or life changes. For families of the mentally ill, the loss is devastating because it is lingering and without the finality of biological death. Many family members experience the stages listed below.

## Stage 1—Denial

The mind's first defense against a drastic change or loss is to interpret it as only a temporary aberration of normal life—denial. There may be a growing sense of uneasiness.

Is it sickness or just laziness.? There is no mental illness, only fatigue or a temporary moral lapse. This sort of thing happens. It is normal. Hospitalization is only a temporary 'nervous breakdown" due to stress.

Auditory and visual hallucinations may be seen as authentic religious experiences. Families may seek different opinions going from doctor to doctor believing that when they find the "right" doctor or the "right" diet everything will be alright. Ken Turkelson, a psychiatrist from New York City, calls this stage "Normalization." During this stage the attempt is to make this event fall within the normal range of expe-

rience, and in coping, the individual expects a speedy restoration to the previous "normal" level of functioning.

Another tactic of denial is keeping outsiders from seeing the dysfunctional and disturbing behavior. Families may become increasingly isolated. The usual visits from friends are discouraged. Family members may make excuses as to why they are no longer involved in their usual social and recreational activities. They may begin to blame one another for the increasing disturbances that occur. A growing sense of panic may develop out of fear that someone will be hurt.

HELPFUL STRATEGIES: Seek and receive maximum information on mental illness and the family experience. Ask questions from treatment professionals. Discuss as a family the consequences of the impairment and decide future plans for getting the maximum assistance for the patient and family.

# Stage 2—Guilt or Shame

In this phase, family members move from denial of the existence of the mental illness toward acceptance of the illness and its consequences. Families may seek to determine what they have done to cause the illness. Attitudes that child rearing practices cause mental illness still prevail. Families may have been treated as intruders or patients by mental health professionals. At this stage it is easy for families to "buy into" this guilt. Or family members seek some individual internal fault which brought on this punishment. (See Kushner's When Bad Things Happen to Good People.) A cloud of shame and embarrass-



ment may hang heavily on the family. They may withdraw from friends, their neighbors, their church, in order to avoid explanations.

In an attempt to cope during this phase, families may become involved in frantic efforts to find a cure or solution. The increasing likelihood of a long term degenerative, or at best a long term up and down prognosis, becomes increasingly clear. Families ride an emotional roller coaster of hope and fear.

HELPFUL STRATEGIES: Use professionals, family, and community support people (i.e. clergy, A.M.I.) as a sounding board for guilt and frustration issues. Initiate discussions with family and involved professionals.

## Stage 3—Anger/Fear

As the situation looks more and more grim for a "return to normal," increasing physical, supervisory, and emotional burdens of care are placed on the immediate caregiver. Frequently this is the mother or wife in the household. She becomes stressed. She must increase the time spent caring for the ill family member. This may cause her to deprive either her family or herself in order to compensate for the energy spent. She may feel neglected; she may feel abandoned by her family to carry the burden alone. The family may resent the ill member for depriving them of the mother's/wife's time. This growing anger may be turned outward towards hospitals, doctors, the mental health system, or inward onto the patient/family member. Anger toward the mentally ill person may be followed by more feelings of guilt.

There are many unanswered questions. Why can't he behave? When will the next blow-up happen? Will he hurt someone or hurt himself? What will happen when I die? Why won't mental health take care of him?

A generalized feeling of helpless rage toward life, toward God, toward family members, toward the person who has the mental illness can be present. Then there are the returning bouts of guilt for thinking such thoughts.

HELPFUL STRATEGIES: Recognize that anger is a normal human response. Ventilate feelings through a support group or with a person who will not try to "fix" feelings, but allow expression of them in a neutral setting. Venting anger through intense physical activity is helpful as well.

## Stage 4—Depression

At this stage in the grieving process the family begins to recognize the mentally ill member may not return to normal. That person may be limited educationally, vocationally, and emotionally. He/she faces life-long treatment with limited results and symptom control. The family may anticipate a series of intermittent crises requiring hospitalization interspersed with plateaus of stability. They begin to accept the reality that the future once planned and anticipated, will never become a reality. They become sad as they resign themselves to the enormity of the loss. In some ways, their worst fears may have been realized. They become more isolated as their lives revolve around the sick person. Family and marital relations may take a downward spiral as the illness takes control. The family experiences the ongoing death of the loved one without the finality of biological death.

HELPFUL STRATEGIES: Recognize that although one may have little control over the mental illness, one does have control over many aspects of one's life. Family members can begin to focus on themselves. This may be a time of recollection, insight, and self protection. If depression remains, one may wish to seek assistance from a family doctor or mental health professional.



# Stage 5—Acceptance/Adjustment

Acceptance marks the final stage of a kind of permanent mourning which is experienced by the close relations of a mentally ill family member. The acceptance of the full implications of the disease helps the family to seek an equilibrium between the needs of the mentally ill person and the needs of the individuals in the family. An understanding of the limitations of family assistance helps them restore this balance. This stage is also marked by an acceptance of the limitations of professionals. There may be a greater willingness to cooperate with the range of services which are available.

This stage in the grieving process may be marked by a need for family members to share their experience with others in similar situations. They may become involved in community education or in advocacy efforts for the mentally ill.

## **Looking Beyond**

"Most families, in short, found they had wellsprings of strength they never knew they had until they met the great challenge of mental illness."

~Agnes Hatfield

One must never lose hope. Research continues to uncover information about major mental illness and its treatment. What seemed hopeless yesterday may be possible tomorrow. While setting reasonable expectations, families can maintain faith in their loved one's recuperative powers. No family need face the battle alone. Others have faced the burden and survived. They are there to help you do it too.

#### REFERENCES AND SUGGESTED READINGS:

Kubler-Ross, E. (1969). On Death and Dying. New York: Macmillan.

Kushner, H. (1981). When Bad Things Happen To Good People. New York: Schocken Books.

Hatfield, A. Coping With Mental Illness in the Family: A Family Guide. Arlington, VA, NAMI. [This book is available from NAMI.]

Hatfield, A. & Lefley, H., (Eds.) (1987). Families of the Mentally Ill: Coping and Adaptation. New York: Guilford. [This book is available from NAMI.]



More and more, families and professionals accept that the lives of all family members are affected when one family member is afflicted with mental illness. Siblings may have a unique perspective on the situation. It is important that their feelings and viewpoints be heard (Bank and Kahn.)

Because each family is unique, it is difficult to describe a typical sibling reaction. Parental attitudes and expectations about their children, and the ways parents cope with stress are both factors which influence sibling reactions. The role of the sibling in the family, the economic status of the family, and the age, sex, and birth order of the children are all important factors affecting a sibling's perspective. However, three variables seem particularly relevant to ways in which siblings are affected when a major mental illness strikes their family. These variables are as follows: the preexisting relationship between siblings prior to the onset of the mental illness, the respective ages of the siblings at the onset of the illness, and whether the well sibling was living at home when the illness occurred.

## Grieving and Loss

Siblings react to the loss of a loved one in ways similar to their parents. (See "Grieving and Stages of Loss"). Many younger siblings note that they moved from the role of a care receiver to one of care giver. For many, there is no longer the satisfying peer relationship; only a fragment remains. Siblings experience this loss. Parents sometimes overlook their childrens' expressions of loss, pain, and even guilt, for being healthy, or for having negative feelings. Their children experience a different kind of loss, but a loss which must be acknowledged.

#### **Genetic Concerns**

The genetic implications of the mental illness may also influence sibling response. First, siblings may fear that they too will become mentally ill. This fear is particularly common when the sibling is younger than the mentally ill brother or sister.

The prevalence of schizophrenia in the general population is 1%. Among siblings of individuals with schizophrenia, the prevalence is 10%. Clearly, a sibling faces a greater risk of developing schizophrenia than if a brother or sister did not have the disease. However, statistically, this percentage is only slightly greater.\* Research indicates that mood disorders have a higher heredity factor than schizophrenia. The occurrence of mood disorders among siblings is 30%.\*\*

Siblings may not be as concerned about having the disease as passing it on to their offspring. This is definitely a concern. But when one compares the genetic risks of mental illness to those of cystic fibrosis or Huntington's Chorea, and realizes that most of the couples with this genetic concern do have normal children, one sees the risk of mental illness in a different perspective.

It is helpful for siblings to learn as much as they can about the genetic risks to themselves and their potential offspring. Genetic counseling is one source of reliable information. Though psychiatric genetic counseling is not widely available, it is perhaps the best source to seek this service.



<sup>\*</sup> Andreasen, N. (1984). The Broken Brain: The Biological Revolution in Psychiatry. New York; Harper & Row, pg. 228 \*\* ibid. pg. 251

Genetic counselors examine the family history to determine what risks exist. The counselor may outline preventive measures that may be taken.

Another helpful strategy for any persons at risk for schizophrenia is to avoid even small amounts of LSD, cocaine, marijuana, phencycliding (PCP), and other street drugs.\* (Gottesman.)

## Stigma

Siblings may experience confusion and embarrassment about handling friends who visit or who may see them out with their mentally ill brother or sister. These feelings are also typical of siblings of persons with other disabilities. There are successful groups and workshops which can help children and adolescents deal with their feelings. There is a need for more activity in this area.

Although the reactions of siblings of those with many handicapping conditions may be similar, one must acknowledge that the public at large is less informed and more fearful about mental illness. Consequently, it may be more difficult for siblings to reveal to others that they are related to someone with a mental disease. Support groups, where others openly share their feelings about their own situations, are therapeutic.

Sometimes siblings with children are particularly unsure or fearful about having the mentally ill brother or sister around their children. Knowledge about mental illness, planning non-stressful family situations, and prior preparation of children and self, can facilitate a positive relationship between aunt/uncle and niece/nephew.

<sup>\*</sup>Gottesman, I. (1985) Schizophrenia and Genetic Risks. St. Louis: Washington University School of Medicine. (Available through NAMI).



## Long Term Responsibility

Perhaps the most weighty issue siblings face is the concern that they may have the life-long responsibility for the care and welfare of the mentally ill brother or sister. In most instances, the sibling, being a peer, will out-live the parents.

The concerned sibling must ask families to share these concerns. It is important to determine whether the family expects him/her to eventually shoulder the responsibility for the mentally ill family member. Another issue to consider is that of the expectations of other siblings in the family. Do other members of the family just assume that it is the female siblings responsibility? Is there an assumption that they will share this burden? Will they share in the physical care, the financial care, or both? It is important to discuss these concerns before the death of the parents. It may be advisable to consult an attorney to make future arrangements. (See "Estate Planning.")

This does not mean that every conversation should revolve around the mentally illperson. The family has relationships with one another that need to be nurtured. This nurturing can be accomplished by the family sharing in all aspects of life. Nonetheless, the issue of future responsibility should not be neglected until the time comes when some immediate decision must be made. Several alternatives should be ready to implement before such a crisis develops.

## What A Sibling Can Do

- 1. A sibling can write down his/her feelings and make sure that the family is made aware of them. A sibling may be unable to change how parents or other siblings feel. He/she may not be able to influence the level of responsibility siblings are willing to assume. However, it is important that feelings are vented and expectations made clear.
- 2. The sibling can locate a sibling support group. The National Sibling Network's mission is to "recognize and build on the special needs, interests, and contributions of siblings of the mentally ill in achieving the goals of the National Alliance of the Mentally Ill." A focus is to provide siblings with education and resources which will enhance their lives. This network publishes a quarterly newsletter, "The Sibling Bond." If one is unable to locate a sibling group, one should contact an AMI affiliate. There may be other siblings in the chapter who wish to start such a group. Educational materials, including those which address siblings' concerns, are available through these groups.
- Another support group, The Sibling Information Network, is composed of siblings whose family members have many kinds of handicapping conditions. This group has bibliographies of journal articles on siblings, a listing of organized sibling groups, and publishes a quarterly newsletter.
- 3. Siblings can educate themselves, examine feelings and beliefs, and become informed about major mental illness, its treatment, and resources available in the community.

SUPPORT GROUPS
National Sibling Network
PO Box 30040
Minneapolis, MN 55403

The Sibling Information Network
Box U-64
School of Education,
University of Connecticut
Storrs, CT 06268

#### References and Suggested Readings

Andreasen, N. (1984). The Broken Brain: The Biological Revolution in Psychiatry. New York: Harper & Row.

Bank, S., & Kahn, M. (1982). The Sibling Bond. New York: Basic Books. [Chapter 9, "The Embroiled Family: 'Well' and 'Disturbed' Siblings" is most valuable.]

Dearth, N., Labenski, B. Mott, M., & Pellegrini, L. (1986). Families Helping Families: Living with Schizophrenia. New York: W.W. Norton. [Chapter 3, "How Brothers and Sisters See It," pp. 32-55.]

Gottesman, I. (1985). Schizophrenia and Genetic Risks. St. Louis: Washington University School of Medicine. [Available through NAMI] Vine, P. (1982). Families in Pain: Children, Siblings, Spouses, and Parents of the Mentally Ill. New York: Pantheon Books. [In one of the case studies the sister takes the responsibility for her mentally ill brother. In the chapter entitled "Families Adjust," there is a section on brothers and sisters, pp. 204-209.]

Wasow, M. (1982). Coping with Schizophrenia: A Survival Manual for Parents, Relatives, and Friends. Palo Alto, CA: Science and Behavioral Books, Inc. [See chapter 7, "How to Tell Your Family, Friends, and Neighbors."]



The disabling effects of mental illness on human relationships often mean that families become more and more interested in enhancing their ability to communicate and to respond appropriately to the special needs of their mentally ill relative. This section deals with communication skills and issues. It is divided into two parts. Part A reviews some communication techniques that are appropriate when dealing with any interpersonal relationship. These techniques can be utilized to enhance any interaction. With most conversations with friends or associates, people learn to use many of these techniques through life experience and trial and error. When one or both conversationalists use these skills, the conversation generally flows smoothly.

With a mentally ill person, often the conversation does not flow smoothly. Due to their internal conflicts, disorganization of speech and thought, the conversation may be difficult to follow. Careful listening and clear communications are essential to have a smooth conversation or, at times, any conversation at all.

Part B deals with the communication skills more specific to use with persons who have a mental illness.

# PART A—General Communication Strategies

## I. ATTENDING BEHAVIORS

Attending behaviors are verbal and nonverbal ways to let other people know that you are interested in what they have to say. These behaviors put other people at ease and create an atmosphere of comfort.

A. One's body communicates along with one's words. Try to be physically relaxed and, if seated, have a natural posture.

- B. Leaning forward toward the other person conveys interest; sitting back or slouched conveys disinterest or lack of concern.
- C. Personal space is the distance between people when they communicate and is generally determined by the level of intimacy in the relationship. Sitting too close can make people uncomfortable, sitting too far can denote lack of interest and interfere with communication. With a mentally ill person, physical proximity can be a very sensitive issue. Presence of anxiety may signal the need to allow more space. Allow the mentally ill person to set the distance.
- D. Voice volume needs modulation. An overly loud voice pushes people away. Speaking too softly frustrates others.
- E. Pauses (latencies)—taking too long to answer—stops communications. Speaking too much may have the result that the other person does not feel free to talk. Due to the effects of mental illness, many mentally ill individuals have long latencies in which they say nothing for extended periods of time. Often they will speak quieter or slower as a result of the tone and speed of the person with whom they are speaking.
- F. It is best for one to initiate and maintain eye contact with the mentally ill person. However, eye contact, can be overdone. A varied use of eye contact is most effective, as staring fixedly and intensely makes some people feel uncomfortable.
- G. One should make comments which follow directly from what the other person is saying, taking cues from the mentally ill person. It is a good idea to avoid jumping from subject to subject.



#### II. OPEN INVITATION TO TALK

There are questions which cannot be answered by yes or no. Consequently, they avoid an abrupt end to the conversation. Also they keep one from unnecessarily structuring or influencing the other person's response. Generally, these questions begin with "how," "why," "what," "where." One should avoid questions beginning with "is," "do," "can," etc. as conversation openers.

## Examples:

- A) Closed: "Should we go swimming?"

  Open: "What should we plan for today?"
- B) Closed: "John isn't playing cards, is he upset?"

Open: "Why isn't John playing cards today?"

# III. MINIMAL ENCOURAGEMENT TO TALK

When conversing with a person with a mental illness, it is important to be particularly mindful of that person's responses. His/her difficulty concentrating, the likelihood of being easily overwhelmed by stimuli, his/her mental confusion can interfere with the ability to carry on a normal conversation. One, two, or several word comments can keep the flow going and also can help let the mentally ill person know you are interested. Avoid comments which take the focus away from the other person and focus on yourself. That is, reflect back on that person's experience; do not go on too long about your own experiences.

# **Examples:**

- A) "Um-hum"
- B) "And then..." "So..."
- C) "Tell me more."
- D) "How did you feel about that?"
- E) "What, for example?"
- F) The repetition of one or two key words.

## IV. FREE INFORMATION

"Free information" means sharing unsolicited material about yourself or listening for and responding to free information from others. This method can help the conversation get started and keep it moving. Of course, a balance of free information is necessary. Conversations are difficult to get off the ground without it. However, giving out too much free information can 1) scare the other person, 2) take the focus off the other person and onto yourself exclusively.

Examples of good free information sharing:

- A) "I'm exhausted from our trip! How is everybody else doing?"
- B) "I overheard you say you got an exciting letter today. I'd like to hear more about it."

### V. REFLECTION OF FEELINGS

A person tells the mentally ill person the unstated feeling one thinks he/she is expressing. This technique helps people get in touch with themselves. One must not interpret or analyze but merely feed back to the mentally ill person the feelings one senses he/she is expressing as a form of supportive contact. People with mental illness may be threatened by talking about feelings at certain times. One must use intuition about when to use and when not to use this technique. Generally though, most people feel a lot of support and caring when the conversationalist non-judgmentally reflects their feelings.

## **Examples:**

- A) Mentally ill person: "If another person comes up and asks me how I am, I'm gonna punch them in the nose."
- Response: "Boy, do you sound angry right now!"
- B) Mentally ill person: "I don't want to do anything today. Today's just not my day." (Person gets tearful.)

Response: "You look and sound pretty sad."



#### VI. BEHAVIOR DESCRIPTION

Describe non-verbal cues received from the mentally ill person. This technique helps the conversation move; it clarifies the meaning of the non-verbal messages; and it helps the mentally ill person get in touch with messages she/he is sending of which she/he may be unaware. Again, avoid any judgmental remarks, only describe what is observed. Examples of non-verbal behaviors are body posture, gestures, voice volume, facial expressions, delay of responses, grooming and attire. For people with a mental illness, this technique can be very helpful. It can help them understand themselves better in a very concrete fashion. Complicated discussions that might be confusing and hard for them to follow are condensed to a simple description of a concrete behavior.

#### **Examples:**

- A) "You are pacing a lot today. I doubt you've sat in one spot for more than five minutes."
- B) "I often see you in the kitchen. Sometimes you go into the other areas of the building but pretty shortly. you are back in the kitchen."
- C) "You were talking calmly and then all of a sudden your voice got excited and full of expression."

#### VII. PARAPHRASING

Repeat back in your own words what the mentally ill person said. This paraphrase contains no additions or deletions. This method will assure the mentally ill person that he/she is understood. This is accomplished without placing a judgment on what was heard. You are only trying to besure you understood correctly. Mentally ill individuals often are filled with their own distorted self-judgment; paraphrasing can help them to understand their own-thoughts more clearly.

#### VIII. PERCEPTION CHECK

Find out from the mentally ill person if the interpretation of what has been observed non-verbally and/or verbally is accurate. Mentally ill persons' words and behavior can be terribly confusing to others. They need to be encouraged to speak with clarity.

#### **Examples:**

- A) "You suddenly turned away from me. Did I say something that upset you?"
- B) "It sounds to me like you're willing to come with us as long as we let you know where we're going and when we'll be back. Is that right?"

#### IX. CLARIFYING

Attempt to clarify a conversation that has left room for misunderstanding.

#### **Examples:**

- A) "So you want to be left alone now and will come out of your room when you are less anxious?"
- B) "When exactly are we leaving?"

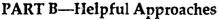
#### X. SUMMARIZING

Pull together in a brief statement the highlights of the conversation. Situations where this might be helpful are as follows:

- A) If the the mentally person was confusing or rambling and one wishes to bring about some order to the conversation.
- B) It is a good idea to summarize what has been said before proceeding.
- C) Summarizing helps to add impact to the conversation.

People with a mental illness often sound and feel scattered and disorganized. This approach can add a sense of control and clarity for both you and them.





Note: The use of the pronoun 'he' throughout this section is intended to refer to the application of both genders.

In communicating with a person who has a mental illness, the family may observe certain behaviors. Noted below are symptoms and observations of family members. Some people may find the approaches useful.

What the Client Experiences:

**Fearfulness** 

What the Family Observes:

Staying away from others; passivity; trembling; poor eye contact; refusal to

leave room or house; refusal to try anything new; agitation.

Helpful Approaches:

•Initiate conversation yourself-don't wait for them to do it.

•Introduce new people or situations one at a time.

• Praise all steps, even small ones.

Back off if agitation occurs.

• Talk about their fears with them if they are willing. Sometimes just talking can reduce their fears.

·Stay calm yourself.

• Allow them to escape or leave if need be.

What the Client Experiences:

Ambivalence (feeling two ways at the same time)

What the Family Observes:

Rapid mood changes; inability to make a decision, even a small one; pacing; agitation; beginning to engage in an activity, then stopping; changing plans; anger, outburst or withdrawal when pushed to make a choice.

Helpful Approaches:

•Give fewer choices, preferably only two.

Empathize: "Sometimes it's hard to make a choice."Make the decision yourself if the ill person is stuck.

Keep to one plan.

 Make the decision for the mentally ill person if he is suffering too much from indecision, but let him know that he can change the decision later. e.g., "Okay, we'll go to that movie. Once we get there we can always change our minds."

What the Client Experiences:

Difficulty Concentrating

What the Family Observes:

Loses track of what you or they are saying; is preoccupied; fails to understand what you are talking about; walks away in the middle of a conversation; has difficulty learning new tasks; has difficulty learning from one situatio. and applying it to another.

Helpful Approaches:

Speak slowly.

Speak concisely, one thought at a time using short sentences.Ask "Do you understand?" or "What do you think of that?"

• If he doesn't understand, start over and be clearer.

•Try to maintain eye contact.

•Remind him of past experiences. "Remember when you ended up in the hospital after you stopped taking your medications?"

•Be repetitious-you will need lots of patience.

•Give directions one at a time.

Encourage questions
 Tise a quiet place to talk.

• Reduce distractions (other people, TV, etc.).



What the Client Experiences: A Sense of Emptiness or Depression

What the Family Observes: Lacks motivation; sleeps alot; says very little; does very little; does n't look happy

\*Try to draw them out by initiating a conversation.

\*Talk about topics in which they are interested.

•Use physical touching (if tolerated) as a way to communicate.

•Encourage physical activity.

•Do something active together; keep it mild.

What the Client Experiences: Hallucinations (seeing things, hearing voices, smelling things, etc. that no one

else does)

What the Family Observes: Talks to himself; is not able to follow conversations; follows directions from

voices ("Hurt yourself", "hit 'so and so' ", etc.); laughs for no apparent reason.

\*Inquire about what they are responding to: "Why are you laughing? What are you saying? "When you talk to yourself, I feel left out."

• Encourage an increase in his activity level as diversion.

•Contact the physician or casemanager.

What the Client Experiences: Delusions (false beliefs, often with a paranoid flavor)

What the Family Observes: Suspiciousness; angry outbursts at others, with unfounded accusations often

addressed at the closest to him such as family members; expresses odd beliefs

("I am Jesus Christ"); exhibits poor judgement.

Helpful Approaches:

• Do not argue about the truth or falsity of his belief system.

•Steer conversation to something else.

•When accused, don't get defensive. Give a brief, heart-felt response, "I would

never try to hurt you. I love you too much."

• Explain matter-of-factly what you are doing and why. "I am closing the door because your voice is so loud, I wouldn't want to disturb the neighbors."

•Set limits in a non-emotional way, "I feel angry when you shout at me like that. I'd like it if you spoke quieter next time," or "I'd like you to go to your room

when you have those feelings rather than take it out on us."

Don't expect rational discussion.

•Be truthful.

•Be a good listener. Listen first, speak second.



What the Client Experiences:

Easily Overwhelmed (cannot filter out and prioritize stimuli he receives)

What the Family Observes:

Confusion; agitation; appears self-centered and not interested in others; concrete- takes what you say literally. "I'm so hungry I could die." "Oh Mom, you aren't going to die are you?"; loses his train of thought; thoughts don't make sense to you - jumps from one topic to another; stops talking in the middle of a

sentence.

Helpful Approaches:

Slow down your activity level.

• Present only one thought for discussion at a time.

• Reduce stimuli. Keep family gatherings small. Encourage the mentally ill person to take breaks when overstimulated.

• Recognize self-centeredness as a symptom of the illness and don't take it personally.

•Speak simply - don't be abstract.

•Remind the mentally ill person when he stops in mid-sentence.

Don't force conversation.

What the Client Experiences:

Lack of Self-Confidence

What the Family Observes:

Embarrassment; shyness; passivity; avoidance of others; refusal to try anything new; poor choice of friends, e.g., alcohol and drug abusers.

Helpful Approaches:

- Be positive. Give positive feedback. "You combed your hair. You look very nice."
- Encourage participation in programs with other mentally ill. Sometimes he may be less threatened by children or animals.

Be accepting.

• It's okay to set limits and give negative feedback. But don't be highly emotional or threatening, especially threatening with the withdrawal of love. State calmly the behavior you're unhappy about, giving an acceptable alternative and communicating a continued acceptance of the person.

NOTES:



#### The Crisis Situation

A crisis is a situation in which an individual's responses or behaviors are inadequate for the needs of a situation. Crises don't develop without warning. Families usually observe the escalations of symptoms which lead to the crisis. In a mental health crisis there is an implied deterioration of the ill person which may mean that he/she has less behavioral control and judgement. This deterioration may result in self-injury or injury to others nearby. Fear and apprehension are the predominant emotions. It is important for family members to be aware of what hazards might be presented if such a crisis arises. They should also be prepared to act to get help.

#### Causes

When individuals are under excess pressure or stress they tend to act differently. Sometimes they act irrationally, immaturely or impulsively and later regret their actions. With a mentally ill person, even small changes (such as the illness of a friend or a friend's going away on vacation) or stimulus (such as a change of job or finances) can add up to the excessive stress that can cause an increase in psychiatric symptoms and behavioral problems. A change of residence can be a major stressor. Discontinuance or irregular use of medications can trigger the crisis. Also, the use or abuse of alcohol or drugs can hasten a sudden onset of crisis symptoms. These substances may alter the delicate balance of medications and their effects on brain chemistry.

#### Warning Signs

The following are some indications that a mental health crisis is occurring or about to occur:

- Change in sleeping patterns (increase, decrease, or disruption)
- Changes in eating patterns (frequency, quantity, schedule)
- An unusually long or short attention span
- Increasing disorganization in thinking
- Decrease in personal care and hygiene
- Not taking medication
- Alcohol or drug use
- Ruminations about a previous crisis
- Changes in relationships
- Changes in appearance
- Increased withdrawal and physical isolation
- Increase in agitation and hostility
- Changes in mood or personality
- Hearing voices and/or seeing visions
- Drastic change in daily routine

#### Intervention

- Prevention is the best intervention for crisis situations. One can minimize the chance of a crisis by reducing the amount of stress and instability within the environment.
- When the family observes any of the warning signs (see above) they should contact the mentally ill person's psychiatrist or mental health professional. They can urge him/her to see the client assoon as possible for an evaluation and medication check.



- The family should have a crisis plan. The goal of the plan is to get professional help to the ill family member as quickly as possible. It is not the family's responsibility to solve the crisis or change the ill family member's behavior or symptoms. This plan should include
  - 1. Strategies for addressing aggressive and destructive behavior,
  - 2. Roles for each family member; how to effectively communicate with family members and the ill person during the crisis.
  - 3. How to make quick decisions and implement these to get help. Families must know the range of choices ahead of time so that during the crisis they can focus on which alternative to use. Each family member must know his/her role.
- Lines of communication between family members and the ill person must be kept open.
- Family members should remain accurate and straightforward as much as possible. The ill family member should be made aware of what the family is proposing in order to secure his/her voluntary cooperation with the plan.
- Emergency phone numbers should be posted in an open place and all family members should be made aware of its location and purpose.
- Family members should not hesitate to be firm and direct about setting limits with the ill person on what is acceptable behavior. Firm, concrete limits for one who feels out of control may be reassuring.
- Weapons, ammunition, medications, and other potentially dangerous items should be kept locked. The key should be kept away from the mentally ill person.

- Family members should educate themselves regarding psychotropic medications and their potential reactions and side effects.
- Strategies which have worked well in the past should be used in similar circumstances.

#### Professional and Legal Interventions

Since services from mental health and police agencies differ among communities, it is important to find out ahead of time what local services are available in a crisis.

- Community Mental Health Crisis Response — Every community mental health program has a crisis service available to all citizens regardless of previous history or involvement in services. These agencies provide levels of service from immediate telephone screening (minimum) to face-to-face evaluation which can lead to emergency treatment and medication. Crisis services can assist in arranging emergency voluntary hospitalization or referral for emergency involuntary commitment procedures. In some cases, respite care housing can be provided. If the ill person is already involved with case management services, the assigned casemanager and doctor should be contacted first for crisis consultation and intervention.
- Involuntary Commitment Procedures—
  A police officer in the line of duty is empowered to take the mentally ill person into custody and transport him/her involuntarily to a hospital. This can take place if the police officer believes the person to be imminently dangerous to him/herself or others, or is incapable of providing for needs necessary to health and safety. A community mental health professional may direct a police officer



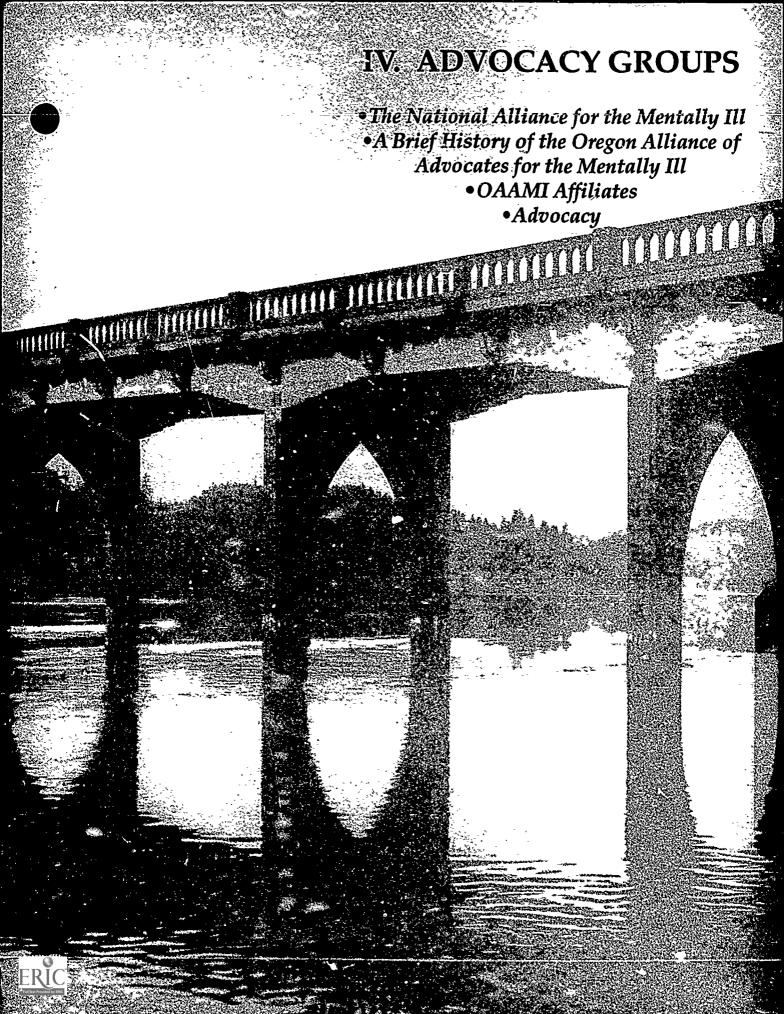
to place a person on an emergency hold for involuntary hospitalization under the same criteria. Also, a physician in consultation with another physician may implement such a hold upon examining the mentally ill person in a hospital setting. Family members may petition for an investigation by signing a two-party petition at the community mental health center. Expanded criteria extend greater assistance to families of persons who have had two state hospital commitments in the previous three years. These criteria allow for

commitment if the patient shows signs of serious deterioration and worsening of psychiatric symptoms. Evidence of self-danger or the inability to provide self-care are not required. This change allows for earlier intervention when mentally ill family members start to go into crisis. The new law also gives the choice of commitment to community treatment programs as an alternative to state hospitalization. See "A Family Member's Guide to Civil Commitment" in Chapter VII for more information about involuntary commitment laws.

For further reading see Agnes B. Hatfield's oping With Mental Illness In the Family: A Family Guide available from NAMI.

**NOTES:** 





## THE NATIONAL ALLIANCE FOR THE MENTALLY ILL

The National Alliance for the Mentally III was founded in 1979 when fewer than 300 family members of the mentally ill met in Madison, Wisconsin to share their pain and hopes. In less than nine years, NAMI has grown to include over 800 affiliated organizations and more than 60,000 members.

NAMI is a grassroots, family-based, self-help organization concerned with serious mental illness (schizophrenia and mood disorders). Membership includes parents, siblings, spouses, and friends of people with mental illness, professionals and service providers, and the mentally ill themselves. NAMI welcomes the participation of all citizens who share its goals.

NAMI is persuaded by current research that major mental illnesses are biochemical brain diseases which can affect anyone, and which are without known prevention or cure. At this time, science does not have a precise understanding of the origins and causes of these diseases, nor is there agreement on their taxonomy. Mental illness is not generally understood by the public, although these are not rare diseases, striking about 8% of all Americans, affecting as many as 1 in 4 families.

Schizophrenia, manic depression, and related disorders are severely disabling diseases and are a major public health problem. Families do not cause severe mental illness but they are greatly affected by its consequences. While families are often primary caregivers by default, they must be partners in treatment. Persons with serious mental illnesses are poorly served by a fragmented mental health system; Community services vary widely and are often inadequate.

The National Alliance for the Mentally III is a family based national organization whose purpose is to eradicate mental illness and improve the quality of life of those suffering from these diseases.



#### A BRIEF HISTORY OF THE OREGON ALLIANCE OF ADVOCATES FOR THE MENTALLY ILL

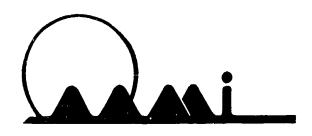
Prior to the organization of The Oregon Alliance of Advocates for the Mentally Ill (OAAMI), the Oregon Advocacy Project was funded by the Oregon Community Support Project (CSP), which was a federally funded project whose task was to improve mental health services to the chronically mentally ill in Oregon. Community Support Project funding for the Oregon Advocacy Project began in August, 1979 and ended January 31, 1982.

In order to determine how the Advocacy Project funds were to be spent, CSP staff met with three members each of the two existing support advocacy groups: Save-A-Mind (SAM) in Eugene, and T-Med in Portland. The representatives of these groups determined that the funds should be spent to hire a staff person to assist in starting new groups, recruiting more members for existing groups, and in developing public education materials.

In order to administer the Advocacy Project funds, the Community Support Project granted a subcontract of \$12,000 to the Mental Health Association of Oregon (MHAO). The contract specified that the Advocacy Project Coordinator would be supervised by the MHAO director, but that the project's priorities and direction would be set by an executive board composed of two voting representatives from each support-advocacy group and one voting and one non-voting representative of CSP.

This arrangement was in effect until April 1, 1981, when the Oregon Advocacy Project became an independent, unincorporated body. The CSP then contracted directly with the Oregon Advocacy Project. The Board remained intact except for the representative from the Mental Health Association of Oregon

Joan Kalvelage, the part-time staff person, was initially recruited through newspaper advertisements. She was hired by a committee representing SAM, T-MED, CSP, County Mental Health Di. ectors, and the Mental Health Association. During the second project year, another part-time staff person was hired, but she



subsequently resigned to take another job. The Oregon Advocacy Project then hired Ginny Krumdieck of SAM to assist in liaison with existing groups and the development of new groups.

In late 1981, representatives from all the Oregon advocacy support groups met at the home of Ginny and Oscar Krumdieck to decide whether the groups which had been set up through the Oregon Advocacy Grant (recently expired), wanted to form a statewide organization. As a result of that meeting, a bylaws committee was selected to write and present proposed bylaws at the first annual meeting which was held in January 1982. The bylaws were ratified and the first board of directors was elected and OAAMI was born. The local family groups rapidly joined the statewide organization.

In 1985 OAAMI received non-profit status from the federal government.

The advocacy movement began almost spontaneously in the late 70's throughout the United States. In Oregon, it grew from a small nucleus of about 100 members. There are now 24 groups representing over 2000 members including interested professionals and providers as well as the family group nucleus united with one common interest—advocacy for our mentally ill Oregonians.

For more information contact the local OAAMI affiliate.



**OAAMI** 

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AMI of Astoria PO Box 2745 Gearhart, OR 97102 738-3492

AMI of Baker County c/o David Gardner Rt. 1, Box 42 Baker, OR 97814 434-6483

AMI of Central Oregon PO Box 4216 Sun River, OR 97707 593-2214

AMI of Clackamas County PO Box 68627 Oak Grove, OR 97268 654-1042

AMI of Colombia Gorge 1600 E 11th The Dalles, OR 97058 296-1408

AMI of Coos County PO Box 3519 Coos Bay, OR 97420 888-3202

AMI of Coquille PO Box 21 Coquille, OR 97423 396-2287

AMI of Douglas Co. c/o Rosemary Spires 454 SE Eastwood Roseburg, OR 97470 673-7025 **AMI of Grants Pass** 300 Chinook Park Lane Grants Pass, OR 97527 476-7357

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AMI of Lincoln County PO Box 776 Newport, OR 97365 265-3125

AMI of Mid-Valley 2490 7th St. Lebanon, OR 97355 928-3704

AMI of Multnomah Co. 718 W. Burnside #310 Portland, OR 97209 228-5692

AMI of North Coast PO Box 104 Arch Cape, OR 97102 463-1554

AMI of Salem 1440 Beaumont Dr. NW Salem, OR 97304 588-7515 AMI of Umatilla County 2699 Westgate Pendleton, OR 97801 attn: Liz Pearson 276-0810

AMI of Yamhill County P.O. Box 96 Dundee, OR 97115 538-3420

AMI-SOS PO Box 821 Florence OR 97439 997-8673

Family of Friends Support Group PO Box 21 Coquile, OR 97423 396-2287

Peoples Store, Inc. PO Box 3519 Coos Bay, OR 97420 888-3282

**SOAMI**PO Box 924
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772-7063

The above OAAMI chapters are affiliated with The National Alliance for the Mentally III:

NAMI 2101 Wilson Blvd., Suite 302 Arlington, VA 22201 703-524-7600



Advocacy is striving for things in which you believe. Your efforts to make a difference—your advocacy—can take any number of forms. It may be that one form will be more comfortable and/or effective for you. You may be especially good at letter writing, while someone else may be particularly good at making public presentations. The more visible you are, the better, so don't rule anything out too soon.

Advocacy literally means to plead in favor of, defend, support. It can be internal (within a system and funded by it) or external. Traditionally, most advocates were attorneys; today, practically every social service professional considers him/ herself an advocate. Legal advocates, such as attorneys and specially trained paraprofessionals, focus upon protection of legal rights, restitution for damages, etc. Professional advocates, such as "case managers," social workers, etc., aim to match needy people with appropriate resources. Personal advocates intervene as personal assistants to provide specific support in securing financial aid, housing, etc. Selfhelp advocates have emerged with a primary thrust for "system change." Family advocates and patients' rights groups, while combining many of the other forms, have system change as their primary objective.

#### **HINTS FOR SELF-HELP ADVOCATES**

1. When dealing with a bureaucracy, get to know the people involved. Face-to-face meetings often work better than letters or phone calls. Do not be afraid to go to lunch with those you are trying to influence. A more informal relationship may help build understanding, trust, and assistance for your cause.

- 2. Some bureaucrats may actually assist your efforts. Others will try to ignore or resist them. The bureaucracy is not monolithic. If you can find someone to help from within the system, your efforts may be easier.
- 3. Keep the world accountable for its actions. Now that you have found your way onto boards and committees, into hearings and exclusive meetings, do not relax your vigil. Get people to make commitments to change and then hold them to those commitments. Be firm in your demands, deadlines, and follow-up.
- 4. Do not be co-opted. Administrators who are trying to appease you and keep you "off their backs" may try to keep you diverted by getting you on lots of committees. Changing the system means more than being on a committee. You should never forget that, and neither should the elected officials and public administrators with whom you will be working.
- 5. Become informed. Nothing changes without someone pushing somewhere. But you can't make changes without knowing your subject. Be that someone. Keep pushing. Powerlessness is largely self-imposed. You have the power to change the system, but it requires a conscious continuing effort on your part. You can build on your accomplishments, but you cannot afford to rest on them.



#### **AMI\* AS AGENTS OF CHANGE**

AMI groups now have the potential to bring about changes in services and public attitudes. Here is what must be done:

#### Services

- 1. Be involved with state hospitals. Regularly attend hospital family meetings.
- Regularly stay involved with and monitor community mental health programs.
   This can be accomplished by becoming a member of county mental health and state advisory boards.
- 3. Monitor the state hospitals and/or outpatient clinics according to quality of care for the seriously mentally ill, and publicly announce the findings.
- 4. Monitor and publicize the existence of large numbers of seriously mentally ill people not being cared for by the existing public or private treatment system.
- 5. Let JCAHO (Joint Comraission on Accreditation of Healthcare Organizations) know how the public and private psychiatric hospitals in your state are doing.
- 6. Become experts on the budget for the state department of mental health. Find out where the money is going, who is being served, and who is not being served.
- 7. Establish public awards at the local and state level for outstanding employees of the mental health system.
- 8. Change the services of the future by changing the attitudes of mental health professionals in training. AMI groups should be giving lectures at all training institutions for psychiatric nurses, social workers, psychiatrists, and psychologists.

#### **Fublic Attitude**

This can be changed. One need only look at what a group of mothers has done to change attitudes toward drunk driving (Mothers Against Drunk Driving). One must examine what the Association of Retarded Citizens has done to change attitudes toward the retarded. It takes working with the media utilizing public service spots, writing letters to editors, promoting anti-stigma campaigns, and persistent work by every AMI member.

#### How AMI Can Be Agents of Change

- 1. AMI chapters must work to increase membership base.
- 2. AMI members must promote solid state groups which hire paid staff.
- Local groups must be alive and imaginative.
- 4. The National AMI office must maintain a lean and professional staff.
- 5. Efforts should be made by AMI members and foundations to secure funding.
- 6. AMI members must participate on planning boards at all levels.
- AMI must foster coalitions with legislators, media, and religious groups.



<sup>\*</sup> Alliance for the Mentally Ill This material was freely adapted from a presentation given by E. Fuller Torrey at the NAMI Annual Conference in Boston on July 6, 1986.

#### LOBBYING FOR CHANGE<sup>†</sup>

A lobbyist addresses or solicits members of a legislative body with the intent to influence their votes. The goal of the lobbyist is to encourage the passage or opposition of a bill by use of personal influence. There are a number of steps in getting a bill introduced and passed in the state legislature. On the average there are about 3000 bills introduced during an Oregon session. Only about 800 are finally sent to the Governor for his signature.

The first step in the passage of a bill is getting it introduced and sponsored. An advocate may contact a Senator or Representative to introduce it. Other legislators may wish to co-sponsor it as well. Next the bill goes to Legislative Counsel where it is examined for conflict with existing law. Then it is assigned to a committee. This is the stage where the law makers are "educated" on the issues of the bill. Also at this stage, citizens have an opportunity to attend hearings on the bill. Citizens may wish to speak for or against the bill. Experts may be called in to testify on issues pertaining to it. The bill may be changed or rewritten during this phase. During this time concerned citizens may wish to contact the committee members to let them know how they feel about the legislation. Sometimes a committee chairperson will not move a bill out of committee unless he/she knows how many votes it will get. Therefore it is a good time to begin influencing legislators who are not on the committee examining the bill.

After the committee hearings, the bill is moved to the floor of the chamber for a vote. Unless the bill has been introduced into both houses at the same time, it will only be approved (or rejected) in either the House of Representatives or the Senate. If

the bill passes, the whole procedure is repeated in the other chamber. After it passes in the second chamber, it goes to the Governor for signing.

The passage of a bill is a fairly simple procedure to understand. In reality, the process is frought with complications. An advocate with an interest in a certain piece of legislation must work hard to locate sponsors for the bill. It may never go to committee if there is little interest in it. It may die in committee if there is not enough support to bring it to a vote. Bills which are not passed in one legislative session are not carried over into the following session. So if the session ends before the bill is passed and signed, the process must be initiated from the beginning at the next session. Other snags involve compromises which can substantially change the original intent of a bill. Or the bill may be attached to another piece of legislation as an amendment. It may fail passage due to the other bill to which it was attached.

It is a good idea for the advocate not to expect too much too quickly. The democratic process is not usually fast-moving. and each step is a major accomplishment. Our system is one of checks and balances, and even though we get frustrated, we can make a great difference for the people we all cherish so greatly.



<sup>&</sup>lt;sup>1</sup> This articfle was adapted from a speech delivered to the membership of the Lobby School by Nellie Fox Edwards, retired AFL-CIO lobbyist and president of the Portland Chapter of the Mental Health Association. Ms. Edwards has served as co-chairperson of OAAMI's Legislative Committee.





• Adult Mental Health in Oregon --A League of Women Voters Pamphlet

•State and County Funded Mental Health Services

• Contacting a Community Mental Health Program?

• Critical Mass and Priority 1, 2, 3

Residential Programs





## A BRIEF HISTORY OF THE PUBLIC MENTAL HEALTH TREATMENT SYSTEM IN OREGON

Oregon's public mental health system has seen establishment of the first state hospital in 1882, growth of the state hospitals to over 5000 patients by the late 1950's, and rapid decline to about 1000 patients by the late 1970's. For the last ten years, state hospital population has remained about 1000 patients with an upward trend beginning in recent years.

The rapid decline in state hospital population from the late 1950's to the late 1970's was called "deinstitutionalization." Deinstitutionalization was a nationwide movement based on the philosophy that patients were best treated in their local communities rather than being confined for long periods in state hospitals. This philosophy is shown in length-of-stay statistics for Oregon's state hospitals. In 1958, the peak year of state hospital population, only 15% of the patients had been in the hospital less man one year while 57% had been there five or more years. By 1977,75% of patients in state hospitals had been there less than one year and only 4% for five years or more.\*

Deinstitutionalization has been attacked as a promise that failed. Many of the homeless—estimates range from 25% to 50%—are said to be mentally ill though recent research suggests earlier estimates may have been exaggerated.\*\* The deinstitutionalized are now described as victims, lacking in community care and housing options, ignored by professionals more interested in treating the "worried well" than the "truly sick." Dr. E. Fuller Torrey says that "when the history of human services is written, the plight of discharged schizophrenics in the 1980's will surely be cited as a national disgrace."

Do these accusations apply to Oregon? Are Oregon's deinstitutionalized chronically mentally ill receiving the services that are essential to their well being? Are they being abused? Do they live in decent housing? Are their days filled with meaningful activity?

Part of the answer to these questions can be found in the history of the community mental health center movement. Nationally, and in Oregon, the first community mental health programs were child guidance clinics which began in the 1920s and 1930's. By 1952, there were 11 child guidance clinics in Oregon.

In 1959, Governor Mark Hatfield appointed a committee to design an improved mental health system for Oregon, and the 1961 legislature adopted the committee's recommendation to create the Oregon Mental Health Division (MHD). "The initial objective was to build a strong network of locally directed community mental health services...beginning with existing components: three psychiatric hospitals, two training centers for the mentally retarded, several child guidance clinics, and a single alcohol outpatient clinic."\*\*\*

Federal legislation in the 1960's provided funds for establishing comprehensive Community Mental Health Centers (CMHCs). Only a few federally funded CMHCs were established in Oregon—Eastern Oregon, Lane County, and in the 1970s, Clackamas County and Multnomah County. Instead, most Oregon CMHCs were developed using a 50:50 ratio mix of

<sup>\*\*</sup>Redburn, F., & Buss, T. (1986) Responding to America's Homeless, Public Policy Alternatives. New York: Praeger. (See Chapter 5.)
\*\*\*\*\*Adult Mental Health in Oregon." A report from the League of Women Voters, Salem, Oregon. (This report is included in this manual in its entirety.)



<sup>\*</sup>Program Analysis Section, State of Oregon Mental Health Division

state and county funds. By the early 1970's, there were 27 community mental health clinics and 17 contract programs providing mental health services to all 36 Oregon counties.

In 1973 the Oregon legislature passed the Community Mental Health Programs Act. This act redefined community mental clinics as community mental health programs (CMHPs) responsible for local planning and operation of programs, added mentally or emotionally disturbed, developmentally disabled, and alcohol and drug dependent persons to those persons required to be served by CMHPs, and redefined basic services required of CMHPs.\* In the mid 1970's, Oregon pioneered the performance contract approach in which the State Mental Health Division contracts with counties to provide specified levels and types of services in the CMHPs. Throughout these changes, admissions to CMI-IPs increased from about 6,000 in 1962-1963 to about 48,000 in 1975-76, a climb of 700 per cent.\*\*

Yet by the late 1970's, it became apparent nationally that CMHPs were failing to help the severely and chronically mentally ill. The National Institute of Mental Health (NIMH) began a Community Support Program, and the Carter Administration appointed a President's Commission on Mental Health. Both initiatives focused on the plight of the deinstitutionalized patient who was not being adequately served in the community.

Did the same abandonment of the deinstitutionalized occur in Oregon? Several aftercare studies completed during the late 1960's and early 1970's can help answer this question. A 1968 study showed an aftercare system, comprised of the private physician, the State Mental Hospital, public welfare, the public health nurse, and the clergy.\*\*\* A 1973 study of discharged schizophrenic patients showed about half living in private homes, often with their families, with the remainder in nursing homes, room and board, or homes for the aged. Problems were expressed with employment, meaningful relationships and activities, and transportation. Aftercare, when available, was limited to brief counseling and medication management.\*\*\*\* A study of patients placed from Eastern Oregon Psychiatric Center, Extended Treatment Unit, showed nearly all patients placed in community settings-group homes, nursing homes, adult foster care came to prefer the placement site even though many had initially been reluctant to leave the hospital.\*\*\*\*

Evidence of the inadequacy of this system is clear, as throughout this time, state hospital readmissions rose steadily and the "revolving door," a discharge/readmission cycle, became established. Who were these revolving door patients?" Data shows that they were not the elderly who in the 1950's occupied 33% of state hospital beds, 14% in 1978, 9% in 1988. Had discharged elderly patients been respon-

<sup>\*\*\*\*\*</sup>Carlson, J. (1974) Community Adjustment of Chronic Mentally III Patients in Northeast Oregon. Salem, Oregon: State of Oregon Mental Health Division.



<sup>\*(1973,</sup> October 1) A Turning Point for Mental Health Programs in Oregon. Salem, Oregon. State of Oregon.

<sup>\*\* (1976,</sup> June) State Plan for Services for Mentally or Emotionally Disturbed Persons. Salem, Oregon; State of Oregon Mental Health Division.

<sup>\*\*\*</sup>Berger, D. et al. (1968). A Study of Aftercare Services for Releases of Oregon Mental Hospitals. Salem, Oregon, State of Oregon Mental Health Division.

<sup>\*\*\*\*</sup>Adams, D. & Kenagy, C. (1973, April) A Report of Conversations with 13 People Who Have Been Patients at Dammasch State Hospital. Salem, Oregon: State of Oregon Mental Health Division.

sible for increased readmissions, their admission rate would have been expected to rise as deinstitutionalization proceeded. However, admission rates for the elderly actually fell. During the 1950's, the elderly had the highest admission rate of all age groups. By the late 1970's, admissions of the elderly had fallen nearly 50%, and young adults, primarily males, became the group with the highest state hospital admission rate.\*

It should be noted that some increase in readmissions is inevitable with deinstitutionalization. Persons discharged into the community should be expected to have occasional episodes when a brief hospitalization is necessary and desirable. However, the revolving-door syndrome, a continuing cycle of discharge, and inadequate community support leading to crisis and readmission, was far in excess for young adults of what might be considered a normal readmission rate for a discharged person who is adequately cared for in the community. To correct the revolving door cycle, several steps were taken with Oregon's community mental health system in the late 1970's. Oregon was an early participant in NIMH's Community Support Program. In 1970, the Legislature mandated the creation of a task force to study the needs of the chronically mentally ill, and the governor appointed a Task Force on Mental Health which published its report in 1981. This study resulted in the passage of the Local Mental Health Services Act, HB

2404, which still serves as the basis for Oregon's community mental health system. This bill established a clear priority system and mandated that community mental health services be focused on the most severely disabled clients. Community support programs were established statewide.

The result was a clear and impressive reduction in hospital readmissions by 35% between 1979 and 1985. This was the only significant reduction in state hospital admission rates in over 40 years.\* Further evidence for the success of community support in stabilizing the chronically mentally ill in the community comes from several other sources. Hammaker, in a 1983 study of 400 randomly selected community support clients, demonstrated reduction in hospital lengths-of-stay and reduced readmissions.\*\*

The value of community support services in helping achieve a reasonable quality of life for the discharged patient has also been repeatedly demonstrated. Several studies of severely mentally ill persons enrolled in community support services have shown their basic housing needs are met, appropriate medications are provided, active psychiatric symptoms are minimal, medical attention (with the exception of timely dental care) is available, and there are funds just adequate for basic needs. There is no evidence of abuse and most have at least some activity during the day.\*\*\*

Program Analysis Section, (1986, December) Report on Community Residential Programs for the Mentally III. Salem, Oregon: State of Oregon Mental Health Division.



<sup>\*</sup>Program Analysis Section, State of Oregon Mental Health Division

<sup>\*\*</sup>Hammaker, R. (1983, March). A Client Outcome Evaluation of the Statewide Implementation of Community Support Services. Salem, Oregon: State of Oregon Mental Health Division.

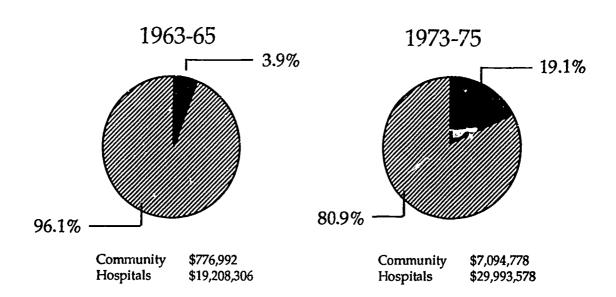
<sup>\*\*</sup>Hammaker, R. (1983, March) A Client Outcome Evaluation of the Statewide Evaluation of the Statewide Implementation of Community Support Services. Salem, Oregon: State of Oregon Mental Health Division.

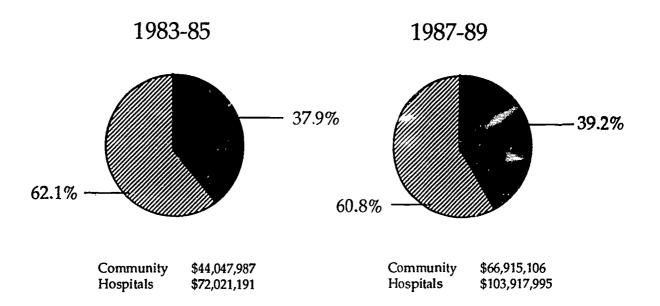
<sup>\*\*\*</sup>Young, D. (1981, May) Life in the Community for the Chronically Mentally III With and Without Case Management. Salem, Oregon: State of Oregon Mental Health Division.

Bigelow, D. et al. (1981, August) Implementation of a Case Management Program for the Chronically Mentally III. Salem, Oregon. State of Oregon Mental Health Division.

Barron, N. (1984, March 30) The Quality of Life of Community Support Clients. Salem, Oregon: State of Oregon Mental Health Division.

### **FUNDING FOR MED SERVICES**







Unemployment continues to be a problem, although it recently received legislative attention. The 1985 Legislature appropriated \$1,000,000 to the Vocational Rehabilitation Division to serve adults with severe psychiatric disabilities. The 1987 Legislature appropriated funds for a supported employment program for 100 persons with chronic mental illness.

Despite these improvements, much remains to be done. Funding for MED Services has increased steadily over time, yet, recent studies conducted by the MED Program Office have shown that 41% of the severely mentally ill and 49% of the chronically mentally ill are currently unserved. This tack of ability to care for all those who need services remains one of the biggest challenges to the mental health treatment system.

In sum, as deinstitutionalization has proceeded, the role of the state hospital changed from a center for long-term care, especially of the elderly, to a short-term facility for younger adults. Deinstitutionalization did not produce mass homelessness in Oregon. As has been demonstrated, much of Oregon's deinstitutionalization was of long-term elderly patients and this proceeded in a relatively successful manner. Moreover, homelessness has become a social concern almost ten years after any significant reduction in state hospital population. However, shortened lengths-of-stay in the state hospitals did affect a younger population who became the revolving door client. Focusing of mental health programs on this population has slowed the revolving door, but many who need community support still cannot get it. And some of the homeless are mentally ill and need an aggressive outreach program which annot be provided with current resources.

The challenge of the 1990s is to continue to adapt the system to meet the needs of the younger, non-institutionalized clientele that it now serves. The combination of mental illness and drug and alcohol abuse in this population must be addressed. There must also be refocused interest on children with integration of a service system that includes schools, private agencies, and multiple state agencies. The mental health needs of the elderly cannot be ignored after shifting the main sites of longterm care from state hospitals to nursing homes and other institutional settings. State hospitals must become active treatment facilities. Those currently unserved by CMHPs must somehow be served in a cost effective manner.

These challenges show there is much more work to be done. Yet is it fair to say that Oregon's treatment of the desinstitutionalized is a disgrace? A CMHP network has been developed by all counties. This has been focused by clear legislative direction on the most severely mentally ill. Repeated studies have shown that those persons who are served by this system have their basic needs met, not opulently, but adequately. Funding for this system has grown steadily. While there is a long way to go in providing mental health services to all who need them, Oregon can take reasonable pride in what it has accomplished so far and should look to the future with renewed dedication to what it has begun.





# ADULT MENTAL HEALTH IN OREGON



A Report from the League of Women Voters of Gregon

#### INTRODUCTION

Mental illness can strike anyone at any time. Between 30 million and 45 million Americans—nearly one in five—are suffering from some form of mental illness at any given time. Both men and women are afflicted, with men more likely to suffer from drug and alcohol abuse and personality disorders while women are at higher risk from depression and anxiety disorders, according to studies by the National Institute of Mental Health (NIMH) of the U.S. Alcohol, Drug and Mental Health Administration. The NIMH estimates that 15 percent of the population will suffer from at least one episode of major depression during their lifetime, and the annual direct cost of mental illness, excluding substance abuse disorders, is estimated at \$20.9 billion. When the indirect costs such as costs of social welfare programs and lost productivity are added, the total reaches \$67.4 billion per year.

In a recent study conducted by the Public Citizen Health Research Group, a spinoff Ralph Nader organization, Oregon was rated on the quality of inpatient and outpatient programs as being one of six states which is "moving ahead strongly." Yet only 58 percent of the state's chronically and severely mentally ill population received services in 1984-85, and families, professionals and citizens cite gaps in the mental health service delivery system. Questions are raised about the lack of treatment and facilities for the mentally ill who are homeless in Portland, Salem and Eugene. Caseworkers, families and judges are concerned about the "revolving door" to the state psychiatric hospitals for persons caught in the current commitment process. Funds for state and local mental health services are never sufficient to provide for all those who seek assistance, and even less adequate when those persons reeding treatment but who never get into the system are counted.

Oregon's state general fund budget for mental health in the 198° 7 biernium totals almost \$190 million. There are 29.433 adult Oregonians who can be classified as chronically and severely mentally ill out of the Oregon adult population of an estimated (July 1, 1984) 1,962,198, according to statistics from the Oregon Mental Health Division. While almost 60 percent of these persons are in the mental health service delivery system, additional data reveals that no more than 10 percent of those classified as moderately mentally ill and 1 percent of those classed as mildly mentally ill received any services in 1984-85

The state and local efforts in `regon reflect the impact of a trend that has been nationwide—the attempt to deal effectively and humanely with mentally ill and mentally retarded/developmentally disabled citizens, whether in hospitals or communities. Deinstitutionalization, which is a part of that overall concept, has created the need for services never before undertaken by communities, and local governments are called upon to develop complex systems of support for persons whose disabilities may require assistance in almost every aspect of their lives.

During the last 25 years, the state has moved from providing care for the mentally ill primarily in state institutions to developing community-based programs designed to deliver a range of services which state statutes spell out as necessary to meet the essential needs of mentally ill persons. Stimulated by the increasing public awareness of insufficient local services to assist individuals with mental disorders ranging from mild to chronic, the League of Women Voters of Oregon in 1985 initiated a study of the

adult mental health service system in Oregon. Its purpose is to review and evaluate the system, particularly addressing issues surrounding alternatives to hospitalization, civil commitment, state mental health legislation, funding sources, levels of service, and concepts of the mental health delivery system. This report is the result of the study research. The primary focus of the study is on the delivery of services to the mentally and emotionally disturbed, with brief references to substance abuse and developmental disabilities.

#### THE NATURE OF MENTAL ILLNESS

In 1977 the National Institute of Mental Health began the most comprehensive survey of mental health ever conducted. The initial phase of the study, which is designed to continue for several years, involved interviewing 10,000 percens, with the long-term plan calling for an additional 10,000 subjects and follow-up interviews for all study participants. The study results to date suggest that about 19 percent of adults living in the United States suffer from at least one mental disorder during a given six-month period. According to the study, about 8 percent of these suffer from anxiety disorders. Six to seven percent suffer from substance abuse or dependence, about four-fifths of which are linked to alcohol. Approximately 6 percent suffer from major depression or manic-depressive disorders. About 1 percent are afflicted with schizophrenia.

The American Psychiatric Association's Psychiatric Glossary defines "Mental illness" or "mental disorder" as "an illness with psychologic or behavioral manifestations and/or impairment in functioning due to a social, psychologic, genetic, physical/chemical or biologic disturbance. The disorder is not limited to relations between the person and society. The illness is characterized by symptoms and/or impairment in functioning "Inthe last several years, medical research has brought new insight into the bio-chemical base for some of the more severe mental illnesses, while pharmaceutical research has made possible the alleviation, to some extent, of the symptoms of these illnesses through the use of selected medications. As a result, many afflicted persons have been able to function more normally, although the degree of success varies greatly among individuals. The bio-chemical nature of the illnesses requires that, as with physical disorders such as diabetes, they be dealt with for a lifetime.

#### Categories of Disorders

Schizophrenia

Schizophichia is perhaps the most expensive and devastating of all the common mental illnesses. Its cost nationally has been estimated at between 10 and 20 billion dollars annually, including the costs of hospitalization, Social Security Insurance benefits for the disabled, welfare benefits, and lost wages. Demographically it is the most costly of any chronic disease, since the individual usually remains well throughout the years of rearing and education, then becomes ill and often dependent on society just at the point where he or she would enter the world of contributing wage earners. According to the President's Commission on Mental Health in 1978, there are as many schizophrenic persons in the



United States as there are people in Oregon, Mississippi and Kansas, or in Wyoming, Vermont, Delaware and Hawaii combined.

Schizophrenia is the diagnostic term used for a group of disorders involving disorders of thought primarily. It is believed that schizophrenia is not a single disease but rather a family of diseases which present similar patterns of symptoms. These symptoms can include paranoia, hearing voices, visual and tactile hallucinations, catatonia, and serious social impairment. If the condition is severe, distorted perception of the world can interfere with the person's ability to cope with even the most basic elements of daily functioning. Many schizophrenic disorders are chronic and progressive. Antipsychotic medications relieve the symptoms but do not cure the underlying cause of the illness. Because the nature of such illness is to affect the thought processes, the schizophrenic person often has poor insight into the condition and frequently refuses to seek treatment. At the present time it is estimated that about one-third of persons suffering from schizophrenia when treated can return to a normal life. One-third partially recover but find themselves returning periodically for further hospitalization. One-third snow no appreciable cliange even with medication.

#### Disorders of Mood

Mental illnesses involving major disorders of mood or emotion are often referred to as "unipolar" or "bipolar." Unipolar refers to a person's tendency to maintain or have recurrent episodes of one pronounced mood orientation—for example, periodic bouts of depression. Bipolar refers to a person's tendency to experience more than one mood extreme, sometimes experiencing a period of manic emotion and behavior, and at other times depression. Major Depression or Unipolar Disorder affects 18 million Americans. About 20 percent of our citizens will experience major depression at some point in their lifetimes. Of that number, some will commit suicide. Economic costs include loss of productivity, work-related losses, and treatment. The President's Commission on Mental Health (1978) placed the overall loss nationwide at 7.5 to 11 billion dollars. The symptoms experienced by those suffering from major depression include major mood disturbance (feeling depressed or blue), hypersommia, loss of energy, fatigue, feelings of worthlessness, inability to concentrate, thoughts of suicide, and physical pain with no apparent cause. Although to date there has been no revelation through research as to the precise cause of major depression, it can usually be treated successfully with antidepressants. By taking maintenance medication, even the psychotic episodes may be controlled. A recent and developing concern is for the relationship between depression and substance abuse. In an effort to block the psychic pain, some victims turn to drugs and alcohol for relief. The new awareness of the frequent overlap between mental illness and substance abuse is stimulating the development of new treatment approaches for "dual diagnosed" persons.

Manic-Depressive Illness or Bipolar Disorder refers to the illness of persons who usually have a series of episodes of either depression or mania. The attacks may occur only every few years, and between attacks the person may return to normality. The depressive phase resembles the above description of major depression. Sometimes the person may become nearly mute and able to handle only minimal physical activity. Hallucinations, when present, are in keeping with the depressed mood. During the manic episodes the person's mood is euphoric, high and expansive, but the person may become irritable at the slightest provocation. Though production and physical activity can be greatly accelerated, they are accompanied by talkativeness and short attention span. An inflated self-esteem may be reflected in grandiose delusions such as that of being the President or some other found in the person, or of being invincible. A person in a manic phase

may neglect food and/or sleep to the point of physical exhaustion. By taking maintenance medication, usually lithium. The episodes may be controlled and reduced in frequency. Many highly responsible and successful persons have been able to pursue careers between episodes of bipolar illness. Some persons with chronic mood disorders do not ever become totally symptom-free between episodes.

#### Other Mental Illnesses

There are other mental disorders such as phobias, multiple personalities, hypochondriasis, anxiety attacks, etc. which are highly troublesome to their victims and occur frequent!, enough among the general population to be matters of concern. However, they impact mental health systems to a lesser degree than do schizophrenia and the serious mood disorders.

#### Treatment From the Historical Perspective

Across time the mentally disturbed have been viewed with a mixture of fear and revulsion. Their fate was often one of rejection, neglect and ill treatment. Even the mental health reformers sometimes used methods of treatment which were harsh. During Europe's preoccupation with witchcraft from the fifteenth through the eighteenth centuries, the mentally ill often were accused of demonic possession and were burned at the stake. Frequently the church was supportive of these actions and used judy.nental standards in viewing the mentally ill. Some of this stigma prevails to this day.

One of the earliest facilities created for the mentally ill was the "madhouse", whose main purpose was to isolate rather than to help mentally ill persons. Until the 1840's there was little treatment for the mentally ill in the United States. One of the first persons to seek substantive help for such persons was Dorothea Dix. Her efforts led to the establishment of large, state-supported facilities, sometimes located far from the family and friends of the patient. Often these institutions become places of maltreatment and neglect despite the best efforts of reformers.

The modern mental health movement received impetus from a former mental patient, Clifford Whittingham Beers, who in 1908 published his account of what he had endured as a mental patient. His book, A Mind That Found Itself, proved to be so popular that it was printed in many languages. He later was instrumental in establishing the first National Committee for Mental Hygiene in 1909 Inspired by his work, others formed the National Association of Mental Health in 1950. After World War II came a flood of exposés dealing with the deplorable conditions found in mental hospitals Perhaps the best known of these was Mary Jane Ward's The Snake Pit, which rapidly became a bestseller.

In the early 1950s a new drug, chlorpromazine, was synthesized as an anesthetic in France Physician Henri Laborit noticed its unique ability to sedate patients without loss of consciousness and persuaded psychiatrist Jean P L. Delay and his colleagues to try the new drug on their schizophrenic patients, with remarkable results in moderating symptoms. This drug, better known by its brand name of Thorazine, heralded a new and hopeful period in the treatment of mental illness and spurred the development of other psycoactive medications for various mental illnesses. A new possibility was born. The mentally ill need not spend their lives in hospitals. With the support of alternative treatment strategies, most could return to their home communities.

#### The Oregon Perspective

The essence of the state of Oregon's philosphy in dealing with the mentally ill was put into law in 1979. "It is declared to be the policy and intent of the Legislative Assembly that the State of Oregon shall assist in improving the quality of life of chronically



mentally ill persons within this state by ensuring the availability of an appropriate range of residential opportunities and related support services."

The earliest outpatient mental health program in Oregon reflected the national concern that treatment be available to disturbed children. In 1931 the first mental health clinic for such children was established at the University of Oregon Medical School. In 1937 the Oregon Legislative Assembly extended this service to other parts of the state by passing the Child Guidance Extension act. This Act enabled mobile teams to travel throughout the state conducting regularly scheduled clinics. In 1946 the Portland Community Child Guidance Clinic was established. Between 1963 and 1972, eleven such clinics were put into operation throughout Oregon, through the efforts of the Mental Health Section of the Oregon State Board of Health These community clinics were funded by local and federal dollars.

Overail, Oregon's provision for its mentally ill citizens was not unlike that of most other states through the 1950s. Such persons were kept in state hospitals, the first of which in Oregon was opened in 1883 in Salem (Oregon State Hospital) with the admission of 370 patients transferred from a private hospital. Fairview Training Center in Salem opened in 1908 for the mentally retarded. Dammasch State Hospital was established in 1951 in Wilsonville, and Eastern Oregon Hospital in Pendleton began operation in 1913. In the early years, each hospital functioned as a nearly autonomous entity with major discretionary power in the hands of the superintendent.

Governor Mark Hatfield appointed a committee in 1959 to design an improved mental health system for Oregon, and the 1961 legislature adopted the committee's recommendation to establish the Oregon Mental Health Division (MHD). The initial objective of the system was to build a strong network of locally directed community mental health services which upgraded institutional care and treatment. It was believed that this two-pronged approach would serve more people more effectively by catching problems early, removing barriers to treatment, and shortening or even eliminating the need for institutional care. In the early 1960s the MHD addressed itself to developing a total system, beginning with existing components: three psychiatric hospitals (OSH, Dammasch and Eastern), two training centers for the mentally retarded (Fairview and Eastern), several child guidance clinics and a lone alcohol outpatient clinic.

After 80 years of focus on institutional treatment, Oregon launched into implementing the concept that persons diagnosed as mentally ill could be better treated in their own communities. For the past 25 years the target has been to decrease the use of state hospital beds and to provide local alternatives.

#### **LEGISLATION**

#### **Deinstitutionalization Beginnings**

Historically, the first national legislation dealing with the mentally ill in the United States was passed in 1922. Child guidance clinics were established at this time. In the 1930s the federal government funded the building of mental hospitals. These were the first federal funds used for mental health. The National institute of Mental Health was established in 1946, marking the first federal involvement in taking responsibility for mental health issues.

Several factors led to the trend labelled deinstitutionalization. A major factor was a significant increase in the number of people in mental hospitals. By the 1950s the number of patients in hospitals throughout the U S. averaged 560,000. As a result, treatment and care of the mentally ill began to shift from reliance on state hospitals back to treatment closer to home using community based mental health programs.

Among other factors affecting this trend was a reaction to reported abuses occurring in the state hospitals. For example, Deutsch in *The Shame of the States* (1948) reported on the appalling conditions in the institutions. Concern for the civil liberties of the mentally ill along with those of other minority groups was part of the civil rights movement of the Kennedy era. In addition, advances were being made in the treatment of the mentally ill. As indicated earlier, drugs had been discovered that masked or altered patient's symptoms, allowing them to live in society. And finally, economic factors influenced the trend. The use of the federal systems of Medicaid, Medicare and Supplemental Security Income made it possible for states to depend increasingly on federal funding to pay for services for the mentally ill.

These several factors combined during the 1960s and 1970s to impact legislation affecting the mentally ill. The system for delivering treatment was altered. The number of patients in mental hospitals decreased from the high of 560,000 to a low of 140,000 in 1974-75. The average daily population (ADP) of Oregon psychiatric hospitals in 1959 was 4,909. By 1979, the utilization of these institutions was decreased 86 percent to an ADP of 1,100. The 1984 85 ADP for Oregon psychiatric hospitals was 550.9.

In 1955, President Eisenhower signed the Mental Health Studies Act. This Act designated a Joint Commission on Mental Illness and Health to study the need for increased services for the mentally ill. The result of this study culminated in the 1961 report Action for Mental Health, which recommended the reorganization of care for mentally ill persons, with a shift from the utilization of hospitals to care in the community.

#### 196Os Legislation

In response to these changes at the federal level, the Oregon legislature established the Mental Health Division in 1961, and in 1962 the 11 child guidance clinics in Oregon were targeted as the focus for development of community care programs.

Nationally, the 1963 Mental Retardation Facilities and Mental Health Centers Construction Act (Public Law 88-164) provided for establishing Community Mental Health Centers (CMHC). The goal of this federal legislation was to empty the hospitals and shift the care of the mentally ill to local centers. Federal funds were allocated to individual centers to help them accomplish this task. Oregon developed only a few such centers. In Eastern Oregon, Lane County, and in the 1970s in Clackamas County. Multnomah County, encouraged by the success in Clackamas, created centers in north/northeast and in the west ar 1 southeast portions of the county.

#### 1970s Legislation

In 1973, several important pieces of legislation were passed by the Oregon legislature. SB 448, the Community Mental Health Programs Act, set up three regions statewide combining the programs of communities and state hospitals. Each hospital served a catchment area, utilizing the Oregon State Hospital, Dammasch, and Eastern Oregon Hospital.

A structure for counties to establish comprehensive mental health programs in three program categories was created. The areas were Alcohol and Drug (A&D), Mental and Emotional Disturbances (MED), and Mental Retardation and Developmental Disabilities (MR/DD). These programs provided services of two types. (1) basic services including outpatient services, aftercare for persons hospitalized in state institutions, training, consultation and education, and prevention services, and (2) services that were alternatives to state hospitalization including 24 hour emergency care, day and night treatment services, local alternatives in housing, and inpatient care in community hospitals. Funding formulas included a 50/50 state-county match for mental health dollars.

Also in 1973 the legislature passed SB 510 Provisions of this bill extended constitutional protection to the mentally ill by a change relating to the involuntary commitment laws. (see also section on Commitment). The hearing procedure for the mentally ill became an adversarial judicial proceeding with an emphasis on due process. The State had to prove in court not only that the person was mentally ill, but that the individual was dangerous to self or others or unable to provide for basic needs. Another provision changed the commitment of the afflicted person from the jurisdiction of the state hospital to the jurisdiction of the Mental Health Division. This allowed for treatment either at the hospital or in the community at the direction of the MHD.

By the late 1970s, the failure of the national movement to create community mental health centers to help the chronic and severely mentally ill became apparent. Local treatment tended to be provided for those mentally ill persons who were viewed as "healthy but unhappy." Community center personnel and professionals tended to avoid providing treatment for patients classified as "difficult mentally ill persons." In response to these circumstances, the Carter administration, in 1978, appointed a President's Commission on Mental Health. The goals of this group were to encourage states to create programs targeted to serve the chronic and seriously mentally ill who had been hospitalized, similar goals to those of the Community Support Program established by the National Institute of Mental Health in 1977. Under that project, Oregon received a four year grant in 1977 to "study, plan, and improve, community services for mentally ill people."3 As a result, 12,000 chronically mentally ill (CMI) persons in Oregon were identified and community support demonstration projects initiated.

Somewhat in tandem with the grant project, the 1977 Oregon legislature adopted three laws affecting emergency holds in counties and relating to persons with mental defects who were in the criminal justice system. The Community Corrections Act

represented a breakthrough in developing a system to serve those classified as mentally ill and as sex offenders, and the Psychiatric Security Review Board (PSRB) was established. Moving towards increased state funding, the counties were no longer required to pay for emergency holds at the state hospitals, and the Mental Health Division was required to reimburse counties for up to 50 percent of the costs for emergency holds in locally approved facilities.

#### 1980s Legislation

On the national level, the findings of the President's Commission on Mental Health led to the passage of the Mental Health System's Act (Public Law 96-398) in 1980. This legislation served as the impetus for action on the federal, state and local levels for improved services to the chronically mentally ill. Also released in 1980 was a draft of the National Plan for the Chronically Mentally Ill by the Carter administration. This document served and continues to serve as a resource for federal, state, and local governments whose objectives are to plan policy governing the care and treatment of the chronically mentally ill population.

In 1979, the legislature had mandated the creation of a task force to study the needs of the CMIs, and the governor had convened the State Task Force on Mental Health which completed its study by 1981. This study resulted in the passage of an omnibus mental health bill, Local Mental Health Services Act, under which Oregon's system still operates. The bill, HB 2404, categorized treatment for the mentally ill according to a priority system. The three priorities were defined as providing these services. (1) for those persons who are in immediate risk of hospitalization . . . or pose a hazard to the health and safety of themselves or others (Priority I), (2) for those persons who are least capable of obtaining assistance from the private sector (Priority II), (3) for those per-

#### LEGISLATIVE TIMELINE FOR MENTAL HEALTH

	National	State
1922	Child guidance clinics established	
1930s	Psychiatric hospitals built using federal funds	
1937	,	Child Guidance Extension Act
1946	National Institute of Mental Health established	
1955	Mental Health Studies Act	
1961	Action for Mental Health	Mental Health Division established
1963	Mental Retardation Facilities and Mental Health Centers Construction Act	
1973		Community Mental Health Centers established
		Community Mental Health Programs Act established A&D. MED and MR/DD (SB 448)
		Involuntary commitment law changed (SB 510)
		Group Care Homes bill passed (HB 3056)
1977	Community support program established by NIMH	Community Support Grant
		Emergency Holds legislation
		Community Corrections Act
		Psychiatric Security Review Board
1978	President's Commission on Mental Health	,
1979		Governor's Task Force on Mental Health appointed
1980	Mental Health System's Act	··
1981	Omnibus Reconciliation Act	Local Mental Health Services Act (HB 2404)
	Alcohol. Drug Abuse, and Mental Health	Hospital/Community Shift Project mandated
	Services Block Grant initiated	Senior Services Division established
1983		Testing and evaluation for organic diseases or conditions affecting psychiatric behavior legislation
1985		Trial visit and conditional early release legislation
		Task Force on Civil Commitment convened



sons who are experiencing mental or emotional disturbances but will not require hospitalization in the foreseeable future (Priority III).

In addition, the services to be provided by the community mental health programs were changed. The basic and alternative services created in 1973 remained for the Developmentally Disabled and Alcohol and Drug programs. Other services were mandated for the Mentally and Emotionally Disturbed program, encompassing a comprehensive list, using the Priority categories, providing 100 percent state funding for MED, but adding "within the limits of available funds." The result was a limitation of the MED service system.

Finally, this omnibus bill required the Mental Health Division to create a pilot project to "develop a plan for shifting state hospital resources to community programs through county projects to reduce hospital usage." Thus in 1981 a Hospital/Community Shift Project was started and Clackamas, Multnomah and Wasnington counties were approved for funding to carry out their plans. The money saved through reducing staff and patients at Dammasch was to be diverted to each county for expansion of their community support and crisis respite services. The five southern counties—Douglas, Jackson, Josephine, Lane and Linn—implemented the project later with the goal of reducing ADP at Oregon State Hospital and Dammasch Hospital from 264 to 224 beds. Later the project was adopted statewide which resulted in each county having a designated number of hospital beds available for its use.

The state hospital system was revised as a result of the 1981 mental health changes which affected the sizes, roles and functions of the three institutions. The Senior Services Division, under the Department of Human Resouces, was established at the same time. Foster homes which housed mentally ill persons were transferred to the jurisdiction of the Mental Health Division. Residential care facilities for the mentally ill had been transferred from Adult and Family Services Division to the MHD in 1979.

Nationally, under the Reagan administration, the Omnibus Reconciliation Act (Public Law 97-35) of 1981 was passed Major changes in human services programs occurred as a result. The service provisions of the Mental Health System's Act of 1980 were eliminated, thus ending direct federal support of Community Mental Health Centers However, the ''patients' rights'' portion of the Act was kept and serves as a ''model bill of rights'' for the mentally ill.5 The Alcohol, Drug Abuse and Mental Health Service Block Grant was initiated also as a result of the Reconciliation Act, allowing federal funds to come to the state

Two significant additions to the Oregon 1981 Mental Health Services Act were enacted by the 1983 legislature. The first statute requires that a person committed to the care of the Mental Health Division should be appropriately tested and evaluated to identify as present any organic diseases or conditions that could cause or exascerbate the psychiatric symptoms. If so, then a total treatment program would be used, including treatment of the disease or conditions. The second change modifies the commitment law, providing for conditional early release of persons involuntarily committed because of mental illness. These trial visits can be granted by the MHD to a person deemed appropriate for outpatient care in the community.

#### STATE MENTAL HEALTH DIVISION

The Oregon Mental Health Division began operations on July 1, 1962 as an agency of the Oregon State Board of Control. When the Board of Control was abolished and state government reorganized in 1969, MHD became a separate entity responsible to the office of the governor. All duties, functions and powers of the Board of relating to mental health were transferred to the Division.

Subsequent reorganizations led to the 1971 establishment of the Department of Human Resources, and since then the MHD has been administered through that department with the Mental Health Division administrator serving as an assistant department director.

1973 is considered by the Mental Health Division as the turning point for mental health programs in Oregon when the most significant changes in service delivery since the Division's inception were developed and implemented. At that time the community mental health clinics, community mental retardation programs, alcohol and drug programs, hospitals for the mentally ill and training centers for the mentally retarded and developmentally disabled joined forces on a regional basis. The comprehensive community mental health program that resulted provided for the building of a true system of hospitals and local programs to service the mentally ill, those with developmental disabilities and those with substance abuse problems.

Today the Mental Health Division is responsible for administration of state mental health programs and laws, directing services for MED and DD persons, and having custody of persons committed to its care by the courts. Following the 1985 legislative session, the alcohol and drug program was transferred from the MHD to a new Office of Alcohol and Drug Abuse Programs with the Human Resources Department. There remains a close relationship between the programs, however, particularly at the community level when diagnosis can be complicated by the similar symptoms of mental illness and substance abuse, and alcohol and drug programs remain closely interrelated with local mental health programs. The Division also is responsible for coordinating and promoting community mental health programs in cooperation with local governments, developing cooperative programs with private groups, assisting community general hospitals to establish psychiatric services, and helping to achieve better community awareness about mental health. (see Table 1)

#### State Institutions

Dammasch State Hospital, Eastern Oregon Psychiatric Center and Eastern Oregon Training Center, Fairview Hospital and Training Center and the Oregon State Hospital are operated by the Mental Health Division. As a result of the 1981 legislation, the Eastern Oregon facility became a smaller institution while Dammasch now serves an area encompassing 75 percent of the psychiatric population of the state. Treatment at the three psychiatric hospitals and at both training centers includes medication, behavior manangement, and re-orientation to practical functioning. The central, west and south counties are served by Dammasch at Wilsonville, while Eastern at Pendleton services the eastern and some central counties, and Oregon State Hospital at Salem receives patients from Marion, Polk and Linn counties Oregon State Hospital primarily serves as a multi-specialty institution providing geriatric, correctional, forensic, and child and adolescent patients with appropriate services for the entire state. In 1984, Dammasch opened a locked intensive care treatment ward for dangerously mentally ill patients transferred from the Salam facility.

The forensic psychiatric program is for patients who are dangerous and found guilty except for insanity and are under the jurisdiction of the Psychiatric Security Review Board (PSRB). Persons found to be incompetent to stand trial in criminal cases also are housed in this unit. The correctional program provides services for inmates with mental or emotional disturbances and substance abuse problems, and the geropsychiatric unit is for the elderly and operates an outreach consultation service to community programs. Severely disturbed young people are treated in the child and adolescent treatment unit which has secure areas for children and youth and where a school program also is operated.

The mental health programs in corrections provide treatment for criminal offenders through community mental health programs in some Oregon counties, at the three state correctional facilities, and at Oregon State Hospital. The Mental Health Division and the Corrections Division coordinate services, establish policies and procedures, and utilize a joint policy board of key managers to guide program development. Psychiatric Security Review Boards operate within communities to provide counseling and monitoring of former prisoners with mental health problems, who are living in localities around the state. The PSRBs generally operate through the local mental health division with close liaison to local correction programs.

There are 34 community mental health programs (CMHPs) which provide services in all 36 Oregon counties. One is operated by the Warm Springs Tribal Council, five are private, nonprofit organizations under contract to county governments, and the remainder are operated by county governments. The state and counties work together to plan, design and develop programs and policies. Services are provided through an intergovernmental agreement with the Mental Health Division. As indicated, if the CMHPs do not offer a service directly, they sub-contract with a local provider to supp'y it. In some counties, the state contracts directly with service providers, and when local services are not appropriate to a person's needs, services at state institutions are available. During 1984-85, some 44,150 mentally ill and mentally retarded people were served in community programs.

The State Mental Health Advisory Board, authorized by statute. studies the problems of mental health and advises the Mental Health Division about policies with respect to state mental health programs. The State Developmental Disabilities Planning and Advisory Council was established by executive order in response to federal law. This group advocates for persons with developmental disabilities, advising the governor, legislature and state agencies on all matters relating to Oregon's DD population. The Mental Health Division acts as liaison between the Council and other state agencies and is responsible for Council administration. The State Advisory Council on Mental Health Services was formed in response to the Federal Community Mental Health Centers Act. It advises the Office of Programs for the Mental or Emotionally Disturbed and the Division on administration of the state plan for services to the MED population. All county mental health programs have local advisory boards. For the most part, such state and local

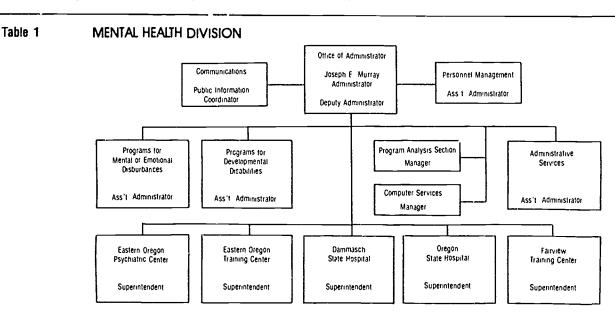
boards have members from both provider and citizen groups, and many have members who have been clients of the mental health system.

Planning for the treatment needs of Oregon's mentally il!, the service delivery system and the fiscal resources necessary to fund the community programs and state institutions is a major responsibility of the Mental Health Division and its program offices. In preparing for the 1987-89 biennium, the Division asked each of the Community Mental Health Programs for an assessment of needs to provide services to chronically and severely mentally ill persons who might request such services (and the total number of Priority I persons in the area). The MED and DD providers, along with the local mental health advisory groups and community advocates reviewed local programs, the service delivery system and identified the unmet needs of their communities to provide the Division with data for planning and budget building. All county programs are required to give the Mental Health Division an annual plan for local mental health services delivery and are encouraged to participate in long-range planning. These plans vary from simple contracting-out for small counties to complex documents from urban areas. The state is now initiating the critical mass concept for the provision of community treatment programs based on the information provided by the county plans and needs assessment surveys. (see section on Critical Mass)

While changes in the definitions for persons in the mental health system (eg, chronically mentally ill) occur very slowly over time, the changes in organizational structures and programs within the system are in a state of ongoing revision. The Mentally Retarded/Developmentally Disabled (MR/DD) program, while making no changes in the types of persons included, became simply the Program for the Developmentally Disabled (DD) as of July 1, 1986. Over the years, the descriptions of services to be provided, while not changing significantly overall, have ranged from "essential" to "basic" to "critical mass."

#### COMMUNITY MENTAL HEALTH PROGRAMS

Since 1962 Oregon has operated under the concept that most persons diagnosed as mentally ill, mentally retarded or developmentally disabled, and those with substance abuse problems can best be treated and managed by community based support services. The State Mental Health Division was established to





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implement this concept, working with the local community mental health programs. The target has been to decrease the use of state hospital beds and provide local alternatives. As these programs have been implemented, state hospital bed use has declined approximately 60 percent from the 1973-74 level.

#### Structure

The structure of community mental health systems is determined at the state level. As legislation dictates, each county must have a community mental health program which includes all services for

- 1) the mentally and emotionally disturbed (MED)
- 2) the mentally retarded and developmentally disabled (DD)
- 3) alcohol and other drug abuse problems (A&D)

Community mental health programs (CMHPs) are responsible for providing local needs assessment, planning, program design, operating or subcontracting for services, services coordination, monitoring service delivery, program evaluation, quality assurance, fiscal control and accountability.

All local programs are the responsibility of the county board of commissioners, the county court or the tribal council (when on tribal lands). Services are provided primarily through a combination of direct service delivery by the county and contracting with other agencies for specific services. Rural counties usually provide services directly except for developmentally disabled programs which are by contract with the local school district. Most counties provide at least minimally the spectrum of services listed in the statutes for community programs. Urban counties are highly focused and limited to serving the chronically and severely mentally ill (Priority I) clients. The administration and service delivery may be organized very differently from county to county. In one case, a county contracts with another for delivery of all services. eg, Morrow County contracts with Wheeler and Gilliam Counties' joint program. A different approach is employed in Crook county where the entire mental health program is operated by contract with the Lutheran Family Service of Oregon. There are differences among the counties both in their array of services and in the levels of funding support for those services.

Each county system uses its advisory board to assist in identifying the needs and desires of the community served. Preparation of the county plan and budget recommendations also are part of most advisory board responsibilities along with review and evaluation of services and determination of the community concensus regarding mental health.

Continuity of care and assurance of quality for each program are required by the Mental Health Division from each community mental health program. Although carried out in a variety of ways, all counties maintain a quality assurance procedure as part of their staffing pattern. Continuity of care is maintained and evaluated through team meetings, client chart review and consultation. Assurance of quality is maintained by clinical supervisors through reviewing client files and discussions with caseworkers. Review staffs meet periodically, at least quarterly. The review usually consists of two parts: a records review conducted by clerical staff and a quality of treatment review conducted by professional staff. Records to be reviewed are chosen using a random selection process. Care is taken that they are representative and from appropriate categories and in appropriate numbers to comply with federal regulations and Oregon Administrative Rules which apply to client standards. Areas reviewed include caseload, appropriateness of service, treatment plans, continuity of care and adequacy of records.



All services at the local level necessarily begin with the screening and evaluation phase (which includes diagnosis), followed by treatment, case management or hospitalization when local programs are not appropriate to meet the individual's needs. The goal for each client is to reach a point where the person does not need further services and is able to function independently, although complete independence is not a realistic goal for some persons.

The community mental health program serves as the primary source of access to services within the local area. Access also may be through outreach services and sometimes schools. There has been a shift statewide since 1973 toward subcontracting many of the services to private and nonprofit agencies. The services most generally contracted out include residential care facilities. counseling services, some crisis services, semi-independent living facilities, halfway houses, rehabilitation services, and community treatment programs for alcohol and drug abusers. The subcontracting process is carefully carried out and involves several steps, including acceptance by the state. The contract includes requirements of quality assurance, fiscal monitoring and site review. In most service agencies, executive directors will have degrees and/or extensive experience in the social science or human behavior fields. Programs often carry requirements for professional staff credentials, but since the funding for mental health contract services is often at a minimal level, attracting and keeping qualified staff is a continuing problem.

Certain components are common to all county mental health systems, but there are great variations due to the tremendous difference in Oregon county sizes and needs. Community mental health care services for mentally or emotionally disturbed persons (MED) include the following state defined services:

- 1 Community Support Services which incorporate the programs to provide case management, outreach, medication management, structure and support for daily living, development of residential alternatives, and vocational opportunities and training.
- Community Treatment Services are provided following assessment and evaluation of an individual's mental health needs and include medication management, counselling by psychiatric staff, therapy on an individual, group or family basis, and consultation of various kinds.
- 3 Community Crisis Services are designed to provide necessary and appropriate programs for an individual in crisis within the community and include stabilization of the person's condition, medication as necessary, therapy or respite home care, community hospitalization, state hospitalization (alternative), and precommitment services such as screening and evaluation, investigation and hearings.
- Psychiatric Security Review Board (PSRB) is for persons who have committed a crime and are determined to be guilty except for insanity. They are treated at the Oregon State Hospital for varying periods and some are then placed in local communities on conditional release. Local PSRB programs are responsible for evaluation, supervision, case management, psychotherapy, and medication. Not all counties have taken on the responsibility of PSRB clients.
- 5. Residential Services at the local level include several categories of adult group homes which provide such services as training, supervision, supportive care, medication management and 24 hour support. Foster homes serve five or fewer clients and provide 24 hour supervised living opportunities. Semi-independent living programs provide 10-40 hours per week of services and supervision of clients at their home, halfway house, apartment or enhanced room and board.



Community mental health services for mentally retarded and other developmentally disabled people (DD) include work centers, parent training, preschool programs, residential training and care homes, adult foster care, semi-independent living, and case management. Of the 26,000 Oregonians with mental retardation status, most can live outside of institutions if basic support programs are provided. About 9,800 persons have more serious problems and need special support systems for all their lives.

There is sometimes confusion about the different kinds of services provided for the different mental health clients in MED, DD and A&D. While all categories have residential facilities, they provide very different types of services based on the needs of those in the programs. DD clients often require very long-term housing while substance abuse clients will be in residential programs only for a few weeks or months. Outpatient programs for MED clients include socialization, vocational and educational training while DD clients use sheltered work programs and activity training centers. Because of the differing levels of program services, allocations for the different community support, treatment and residential client slots vary in amounts.

The 1987-89 needs assessment for community mental health programs includes data from counties containing about 80 percent of the state's population. The major needs identified were categorized according to the types of persons needing services and how these services might be funded under existing funding categories. The chronically mentally ill were identified as the largest group of persons needing additional services. Others identified included children, adults and elderly. Community treatment services for adults and residential services for adults were the most frequently requested services. Following closely in number

of identified needs were the community support services for the CM!s and crisis services. There were requests for precommitment services not currently funded by the Mental Health Division. (see Table 2)

#### **FUNDING**

Prior to the 20th century, the cost of caring for mentally ill persons was borne within the community. At the  $\epsilon$  id of the 19th century when state mental hospitals we a developed, the cost still was considered a local responsibility. Gradually states took over complete responsibility for institutional costs and local care declined. In the 1960s, the federal government entered the fiscal picture with passage of the Mental Health Centers Act, Medicare, Medicaid and the various kinds of disability legislation. With the advent of federal dollars and deinstitutionalization, states began the shift to community programs requiring local match funds to provide the basic services outlined in state legislation.

#### **Local Programs**

Both programmatically and fiscally, 1973 is seen as the beginning of a new era for mental health programs in Oregon. The legislature approved a MHD budget of \$85 million for the 1973-75 biennium, an 18 percent increase over the previous biennium and the largest in the Division's 12-year history. This budget approval and the legislation designating community mental health programs set the direction for Oregon's mental health system. The legislation required that each local program must provide specific 'basic

Table 2	OREGON ADULT MENTAL	HEALTH SYSTEM	1: AVAILABILIT	Y OF SERVICE	ES - 1984-85		
Counties	Adult Population-1984	Priority (		Priority II		Priority III	
		est:	served:	est:	served:	est:	served:
Baker	11,921	179	64	393	183	1,216	0
Benton	53.539	803	445	1,767	199	5,461	54
Clackamas	176,337	2.645	1,555	5.819	350	17.986	89
Clatsop	24,705	371	188	815	97	2.520	13
Columbia	25,570	384	122	844	70	2.608	7
Coos	45.202	678	228	1.492	149	4.611	ò
Crook	9.245	139	88	305	50	943	1
Curry	13,258	199	91	438	176	1.352	Ċ
Deschutes	45.705	686	312	1,508	91	4.662	69
Douglas	65.228	978	822	2.153	193	6.653	9
Grant	5.873	88	67	194	86	599	Ŏ
Harney	5.212	78	50	172	44	532	40
Jackson	99,336	1.490	761	3.278	365	10.132	3
Jefferson	8.213	123	97	271	83	838	7
Josephine	44,919	674	516	1.482	115	4.582	13
Klamath	42,195	633	277	1.392	299	4.304	167
Lake	5,453	82	38	180	29	556	45
Lane	200.031	3,000	1,195	6,601	65	20.403	35
Lincoln	28,966	434	196	956	162	2.955	181
Linn	65.293	979	549	2,155	160	6,660	14
Malheur	19,628	294	213	648	96	2.002	29
Marion	153.272	2,299	1,292	5.058	316	15,634	22
Mid-Columbia Area (Hood River, Wasco, Sherman counties)	30.015	450	314	990	296	3,062	0
Morrow	5,127	77	47	169	39	523	1
Multnomah	432,677	12,734	5,543	14,278	851	44,133	391
Polk Polk	32.985	495	252	1.089	141	3.364	55
Tillamook	16,501	248	91	545	127	1,683	45
Umatilla	42.853	643	495	1,414	55	4.371	0
Union	17.414	261	108	575	150	1.776	1
Wallowa	5,449	82	113	180	47	556	3
Washington	187,337	2.810	1,284	6.182	1,507	19.108	592
Wheeler-Gilliam	2,575	39	18	85	13	263	0
Yamhill	40,164	602	359	1,325	187	4.097	5 <b>5</b>

Source: Mental Health Division, County Needs Assessment Data, April 1986



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services", funded on a 50/50 state/county match basis. Also provided was the option for counties to provide certain services as alternatives to state hospitalization, after the basic service requirement was satisfied. These services would receive 100 percent state funding. At this time the requirement that each county submit an annual plan detailing the services to be provided by the allocated state funds was established.

The 1977 legislature allocated funds for case management for adult mentally ill persons who had been involuntarily committed to the Mental Helath Division. These funds for coordinating adult services were allocated to community mental health programs on the basis of the number of committed persons residing in each county and reflected the state's recognition of the need for follow-up monitoring of persons discharged from the state hospitals. As a result of this limited funding and its use, both the MHD and community mental health programs recognized the value of case management for the chronically and severely disturbed, and increased funds for coordinating services were requested in the 1979-81 biennium.

#### Corrections Funding

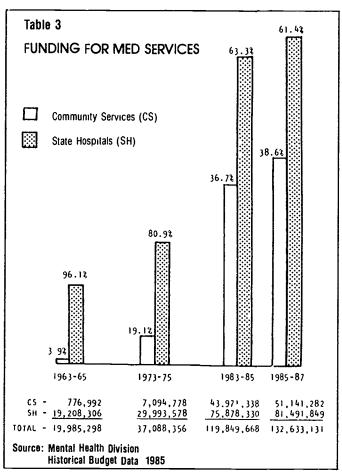
Legislation in 1977 enabled the Corrections Division and the Mental Health Division to cooperatively provide mental health treatment to persons in the criminal justice system. Funding was provided for services to mentally disturbed offenders and sexual offenders and for the outpatient re-entry program for correctional clients with substance abuse problems. The funds were divided equally between the two division budgets, and the mental health services made available at the community level were to be reimbursed at 100 percent. Accompanying this funding was the establishment of the Psychiatric Security Review Board (PSRB) which treats and evaluates PSRB clients locally through the MED budget. Some counties use correctional funds only for special programs and other counties receive no corrections money. The local Community Corrections Advisory Board allocates the dollars for treatment services or diversion.

#### Changes in the 1980s

Following the report of the Governor's Task Force on Mental Health, the 1981 legislature enacted major changes in the state's mental health system, including the elimination of the 50/50 state/county match for funding community services. The state was given the power and authority to set standards, and the responsibility for up to 100 percent funding (subject to the availability of funds). Counties stopped or reduced their local funding for programs, resulting in heavier reliance on the state at a time that coincided with the entrenchment of the recession in Oregon and reduced spending at the federal level. In addition to legislating the services to be provided and the priority order for those to receive services, the new laws provide for the shifting of hospital funds to community programs. The Mental Health Division was directed to develop a plan for shifting state hospital resources to community programs through the hospital/community shift projects. The Emergency Board in 1982 funded Clackamas, Multnomah, and Washington county projects, and the Division opted to use only "funds in hand" These funds were developed through treatment team reductions at Dammasch and start-up funds of \$1 1 million provided by the 1981 legislature. The additional funds needed to finance the projects through June 1983 were contingent upon maintaining a reduced Dammasch average daily population of 275. Since its onset, the shift program has provided some dollar additions to community programs and enhanced the quality of life for some clients who have been discharged, but communities still lack adequate residential, crisis inpatient facilities, and screening and evaluation services due to insufficient

funding. With increasing numbers of more chronically ill persons needing hospitalization, it has not been possible to keep the Dammasch population under 300.

Nationwide, the problems with the hospital-community shift and mental health funds include (1) vast dollars are not saved by deinstitutionalization, (2) inflationary pressures and a more disabled population have raised the costs of care; (3) hospital costs have not declined even though hospital populations have, and (4) continued high institutional costs have affected the amounts of funding available for the community services necessary to keep persons out of the hospitals. (see Table 3)



Adding to the mental health funding problem in the 1980s was the federal Omnibus Reconciliation Act of 1981 resulting in new state block grant programs which reduced by 25 percent the federal funding for mental health programs in Oregon in 1982-83. Based on federal guidelines, the state was to determine the allocations to each program area. This increased the power of the Mental Health Division with the shift of all federal funds from local to state jurisdiction. All block grant funds were allocated approximately equally between community support and crisis/respite services. With the elimination of the local match requirement, state funds can be used only to meet state priorities. Priority II clients can be served only after all Priority I clients are served unless they live in rural areas where private resources are not available, when private resources are not affordable by the client. or the county is granted a waiver by the Mental Health Division. Priority III clients usually cannot be served with state funds.

Reacting to the state's financial deficit, the reduction of federal funds and the redefining of services and priority clients, the Mental Health Division presented further changes in funding for the 1983-85 biennium. The broad grant-in-aid program established in 1961 was discontinued. Reduced local funds which had been used to supplement state-funded services further limited the availability

of services. However, the elimination of basic services except for chronically and severely mentally ill persons allowed the expansion of community support, crisis and residential services to those clients. The hospital-community shift continued, and the need for a comprehensive community/institutional mental health system plan became clearer. (see Table 4)

#### 1985-87 Mental Health Budget

The 1985-87 budget priorities for the Mental Health Division were directed by the following policies:

- Assure safety of mentally disabled persons who are unable to provide for themselves or would come to harm without state intervention.
- Assure adequate food, shelter, medical care and a safe, humane environment for those persons committed to state programs and admitted to community residential programs.
- Provide necessary services that are appropriate, effective, efficient and oriented toward the enhancement of the individual's ability to function independently of services.
- Promote mental health; prevent, intervene in, and treat alcohol and drug abuse; and reduce the incidence of mental disability.
- 5. Provide effective management of mental health programs.
- 6. Make maximum use of private, federal and other funds.

#### Table 4 THE 1985-87 BUDGET AT A GLANCE

\$339 million total for the Mental Health Division

\$185.2 million in State General Funds

\$112.6 million in Federal Funds

\$ 41.2 million in other funds

State-operated institutions - \$174 9 million

Community contracts - \$146.3 million

MED programs - \$51.2 million

A&D programs - \$23.6 million

DD programs - \$67.6 million

Administration - \$ 3.9 million

Nationally there is a trend to seek combinations of funding for mental health programs, including public (state, federal and local) and private sector sources. While professionals differ as to whether keeping patients in institutions is cheaper or more expensive than treating them in community settings, there is general agreement that an array of services is needed. Urban centers face special challenges in developing effective community-based programs. Portland, as one of 60 U.S. cities with more than 250,000 population, will be eligible to apply for a portion of the \$28 million in grants and low interest loans being made available in November 1986 by the Program for the Chronically Mentally III, sponsored by the Robert Wood Johnson Foundation and the U.S. Department of Housing and Urban Development. Eight grantees will be selected for a five-year program which will fund projects aimed at consolidating and expanding services for the chronically mentally ill. The National Conference on State Legislatures also has identified private programs in cities around the country which fund services in cooperation with public agencies. United Way funds often are allocated to agencies which provide mental health counseling ser-

#### Critical Mass

One of the Oregon budget concepts for 1987-89 is that of "critical mass." Having enough of the right kind of community services for people who are at risk of admission to a state mental institution is described as critical mass. It is the community mental health program capacity needed to serve all Priority I adults are in need of service and probably will seek service. This

definition assumes that the services are optimally organized and managed. Service includes (1) community crisis services, (2) community support services, (3) community treatment services; and (4) community residential services as defined in current standards and proposed for funding in the next biennium. Critical mass is the current refinement of such concepts as alternatives to hospitalization.

"In need of service" is defined as that number of chronically or severely mentally ill who either seek services voluntarily or are brought into the service through the commitment process at any given time. The critical mass needs assessment data collected by the community mental health programs during 1985-86 has been used by the Mental Health Division to build its budget for 1987-89.

There is increasing concern that the mental health system—state hospitals and community programs—is underfunded for the high risk (Priority I) persons. Over-population has plagued the psychiatric hospitals in 1986 resulting in inappropriately high case loads and problems of decertification. Changes proposed by the Task Force on Civil Commitment which relate to the need for improved precommitment services as part of community crisis services will be included in the critical mass budget package prepared by the Mentally or Emotionally Disturbed program office for the MHD budget. The presumption is that if a county had the critical mass of services necessary for its high risk population, the local program would be able to divert more clients from state hospitalization. Counties currently without a critical mass of services available are deterred in efforts for early intervention and hospital diversion.

The 1987-89 Mental Health Division budget will include funding requests which increase the percentages of services needed for counties to reach the critical mass necessary to adequately service community clients. Some counties, in their needs assessment, have indicated they are close to critical mass. Others such as Lane, Marion and Multnomah indicated a large number of services would be needed to reach critical mass. The Division budget addresses funding to reach certain percentage levels of critical mass for the counties most in need, depending upon the ability of the legislature to provide the fiscal resources. (see Table 5)

In addition to the critical mass concept for mental health services funding, the Division's proposed 1987-89 biennial budget includes MED prevention programs, programs for the homeless, work opportunities for persons with chronic mental illness, MED intensive care residential facilities, an increase in foster home rates, direct care wage increases (primarily for subcontracting agencies), patient privacy and hospital remodeling at Dammasch, enhanced institutional treatment programs, quality assurance, state hospitals renovation, increased treatment staffing, and automation projects to provide better data and improve efficiency for patient care. Developmental Disabilities priorities include increased community support for early intervention and a new program in family support, based on individualized treatment plans.

#### THE CIVIL COMMITMENT PROCESS

Commitment of persons adjudged mentally ill is a civil process in Oregon as in other states. Of admissions to the state's mental institutions from 1979 to 1985, 63 percent were involuntary and 37 percent voluntary. (see Table 6) Of those committed in Oregon, 97 percent go to some type of hospital facility (state, community or Veterans Administration). Only three percent are assigned directly to a community mental health program or other facility such as a nursing home.

Involuntary commitments occur through court proceedings, the specifics for which are spelled out in state statutes (ORS 426). The commitment process in Oregon which was completely revised in 1973, provides for careful screening, investigation and court examination of allegedly mentally ill persons. Some mental health

Table 6

## CRITICAL MASS NEEDS ASSESSMENT for 1987-89 Budget Preparation 1985-86 Priority I Clients Only

Service Element	Present % Critical Mass Funding	Present Critical Mass Funding 1985-87		Increases Needed to reach 100% Critical Mass 1987-89	
	Units*	Units	Dollars	Units	Dollars
Community Hospital Crisis	49 8	1.482	\$1.822.860	1,496	\$1,840,080
Non-Hospital Crisis	72 3	18,548	7.363.556	7.120	2.826,640
Pre-Commitment	80 7	5.966	2.105.998	1.426	503,378
Community Support	35 6	3.407	22.581.596	6,176	40.934,528
Community Treatment adults	59 4	12,190	4.754.100	8.320	3,244,800
Adult Foster Care	47 1	329	2,214,828	369	2,484,108
Group Homes	48 3	536	4.982.656	573	5,326,608
Semi-Independent Living	34 3	453	1.953.336	868	3,742,816
*Units equates to numbers of liv	ring units and numbers of persons or slots	5			

Source: Mental Health Division, County Needs Assessment Data, April 1986

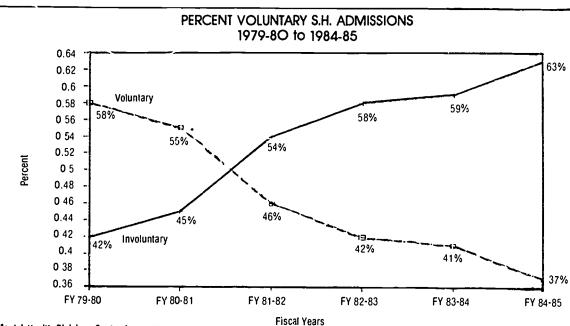
practitioners and families of the mentally ill find today's laws a block to getting treatment for persons in crisis. At issue are the rights guaranteed to clients such as access to information, right to counsel, right to monitored and planned treatment, and the right to refuse treatment sometimes at odds with the need for the protection of a person at risk and the broader rights of society. The questions raised are serious and not easily answered.

States cannot avoid the economic and human costs of mental illness. However, the involuntary commitment laws for both the mentally ill and the substance abuser are often inadequate and ineffective in the task of procuring proper treatment for these individuals.6 While the populations of mental institutions have decreased dramatically since the 1960s when community treatment programs were initiated, not all formerly institutionalized individuals have found life better outside. The lack of community resources—of least restrictive alternatives for the treatment of the mentally ill and of inpatient crisis facilities—has prompted increases in institutionalization during the 1980s. The American Psychiatric Association states that the true rights of the mentally ill are not served by laws so complex that they sometimes work against the treatment needs of the patient, "Patients' rights to freedom are not synonymous with releasing them to the streets where they cannot take care of themselves."7

#### Constitutional Issues

The state has two basic powers that enable it to hospitalize a mentally ill person who is reluctant to enter voluntarily. The first is police power or the right of the state to protect its citizens from harm threatened by a "dangerous member" of that state. The second power involves the state's role as the "parent" of its citizens with the right to act in the citizens' best interests. These two powers have been traditionally used in formulating criteria upon which involuntary commitment decisions can be based. The requirement that a person be dangerous to others is a major commitment criterion for adults in all U.S. states except New Jersey. The Oregon statute reads: "Mentally ill person means a person who because of a mental disorder, is either: (a) Dangerous to self or others; or (b) Unable to provide for basic personal needs and is not receiving such care as is necessary for health or safety." (ORS 426,005)

There are constitutional issues raised by use of the involuntary commitment process. One due process question concerns the justness of taking liberty away because of an individual's *potential* dangerousness to others Another question rises from the sometimes inappropriate "punishment" of the mentally ill through involuntary civil commitment. This may be particularly evident



ce: Mental Health Division, September 1985

11

during emergency commitment proceedings when an actual or threatened act of violence generally prompts the formal commitment action. Also troubling is the question of what constitutes a "danger to others." And states are currently debating whether or not an individual's dangerousness to property constitutes grounds for commitment A major question in the state's role of protection relates to whether or not the person "in need of treatment" receives and is helped by the services in the system.

#### Changes in Commitment Laws

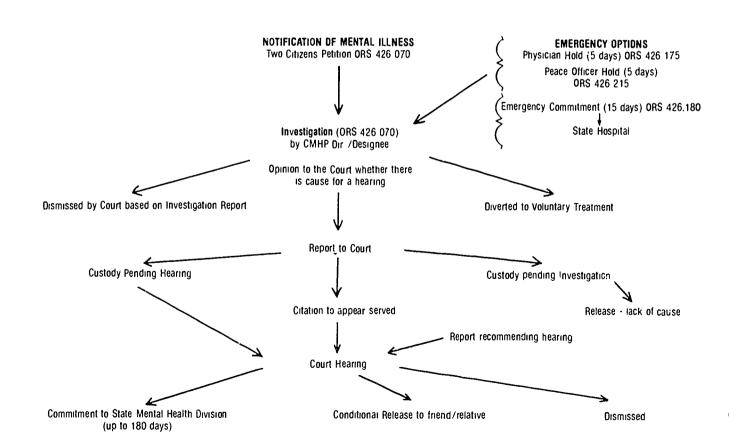
Through the middle of the twentieth century the opinion of one person was often cufficient to get another person committed. For adults this power was generally vested in a physician. Due process questions raised by denial of one person's liberty based on the *opinion* of someone else as well as the rising tide in support of human rights and the strong movement to community programs as alternatives to hospitalization led the Oregon legislature in 1973 to change the involuntary commitment law. Since then, persons have been committed to the Mental Health Division rather than to a specific state psychiatric facility, and courts are permitted to allow mentally ill persons to participate in treatment programs on a voluntary basis. Time limits are placed on commitment, and patients committed to the Division must be given a statement of guaranteed rights. (see Table 7)

The deinstitutionalization movement provided the greatest push toward revision of state commitment laws, particularly the introduction of 'least restrictive' language into the state citatutes and the practices of the state mental health system. As the debate

over the proper way to approach revision of civil commitment laws accelerates, there appears to be a nationwide concensus among mental health professionals, consumers and families on certain points. (1) the courts must be able to determine whether or not civil commitment is, in fact, appropriate for a given individual, (2) the commitment process must be just, (3) the procedural elements of a commitment law should guarantee individuals adequate due process during the admissions, treatment and discharge periods, and (4) involuntary commitment is only part of a state's mental health service system. Model legislation and guidelines for the commitment of mentally ill adults have been developed or are under development by the American Psychiatric Association, the Mental Health Law Project, and the National Center for State Courts.

Thirty-four states have reviewed or have revised civil commitment laws within the last several years. In 1985 Hawaii expanded its commitment criteria to include "gravely disabled" individuals, and Arizona liberalized its laws by striking all references to conditions or indicators of mental illness with the new law stipulating only that, as a result of mental illness, the person's "continued behavior can reasonably be expected . . . to result in serious physical harm." Kentucky strengthened the due process protections of those considered for involuntary commitment along with making it easier for mental health practitioners to provide treatment and evaluation. North Carolina revised its 1973 legislation to make it significantly easier to commit a mentally ill person. Washington substantially changed its commitment laws in recent years, particularly broadening access to the mental health system in emergency situations.

Table 7 CIVIL COMMITMENT PROCESS



Source: Lane County Mental Health Division, 1986



67

#### Substance Abuse and Commitment

One of the continuing problems in Oregon and other states is that the system cannot appropriately respond to persons with alcohol or drug dependency who are a danger to themselves, to others or unable to care for basic needs, but who are unwilling to seek care voluntarily. Oregon psychiatric hospitals are not equipped to treat substance dependent persons, and the current philosophy from the Office of Alcohol and Drug Abuse Programs is that such individuals are more appropriately treated in communities.9 The problem is that most community resources are at capacity or have waiting periods which make them inaccessible as a crisis resource. While the commitment statute wasn't written to exclude substance abusers, the behaviors of persons with mental disorders are more readily accepted as within the dangerous definition, while the same dangerous behavior by a drug dependent person often results in diversion to the criminal system or dismissal as intoxication. Inebriation can be a symptom of a more serious problem. Currently little is being done to diagnose and/or track persons with possible dual diagnosis.

Since 1982, ten states have considered or passed legislation relating to the commitment of substance abusers. Arizona has established separate criteria for chronic alcoholics which allows for use of previous admissions evidence, and Texas has eliminated commitment of substance abusers to the state mental hospitals and is developing community-based detoxification and residential programs. Nebraska delineates separate commitment procedures for chemically dependent persons as do Minnesota and North Dakota. While the Oregon Office of Alcohol and Drug Abuse Programs recognizes the need for a process to deal with involuntary commitment of the substance abuser for treatment, the problem was not identified as a budget priority for 1987-89 so that additional resources necessary will not be available in the foreseeable future. The Civil Commitment Task Force agreed that given the number of issues it had to address relative to involuntary commitment, the substance abuse commitment procedure would not be discussed because of inadequate time.

#### Task Force on Civil Commitment

Efforts by advocate groups for the mentally ill, a rising population at the state mental hospitals despite growing community programs, and a broader understanding of the involuntary commitment process problems led the 1985 Oregon Legislature to establish a Task Force on Civil Commitment. The Task Force was charged with reviewing the current process and procedures regarding involuntary commitment and making recommendations for revision to the 1987 legislature. The 15 members of the Task Force are broadly representative of the groups interested in the commitment process. Included are family advocates, physicians, a legislator, a county mental health program director, a judge, a legal defender, an ACLU representative, a psychiatrist, a county commissioner, an examiner, a representative of the state courts, and, as chair, the director of the Program Office for the Mentally or Emotionally Disturbed of the Mental Health Division.

Panels of persons concerned with various aspects of civil commitment presented testimony to the Task Force, and surveys of attitudes regarding the commitment process were sent to additional representatives. Families, judges, examiners, investigators, district attorneys, mental health program professionals, physicians, psychiatrists, legal defenders and members of the Multnomah County Task Force on Potentially Dangerous and/or Chronically Mentally III Persons were participants on the panels and the surveys. Testimony presented indicated a wide range of inconsistencies within the commitment process as it is applied in the circuit courts across the state. While the court hearing is con-

sidered an adversarial situation, judges conduct such hearings in settings ranging from very formal in a courtroom, to very informal in a hospital room. In some instances the investigator and/or a district attorney is present, but in most instances this is not the practice Medical evidence is not allowed nor the introduction of prior mental illness related events. Emergency commitments, when secure holding facilities are not locally available, result in transportation of mentally ill clients to state hospitals a distance from their homes, and often a return trip for the hearing. There are different interpretations of "dangerous" and differences within the various statutes of the number of days allowed between initial holds and hearings.

Members of the Task Force discussed at length the issues presented by panel members, by the public, written testimony of professionals and others, as well as current journal articles and statistics. Issue lists were developed in the categories of statutory change, process change, and resources. The issues within each category were ranked as (i) very important; (2) important; or (3) a good idea but not critical to the process. While grappling with the issues, the Task Force addressed the philosophy of an ideal commitment process and adopted the following statement:

The civil commitment process will only function effectively within a mental health system that assures the availability of quality statewide resources for evaluation, treatment, outreach and support in a prompt and continuous manner. The Task Force on Civil Commitment of Mentally III Persons recommends the following Goals for Civil Commitment.

- 1 To ensure the well being of mentally ill persons;
- 2 To ensure that civil commitment occurs uniformly across the state in a comprehensible and expeditious manner that respects the dignity of all concerned.
- 3 To encourage as appropriate to the mentally ill person's needs the provision of services in the person's community in a manner that minimizes disruption of the person's life, property, social supports, and source of income.
- 4 To encourage mentally ill persons to seek treatment voluntarily;
- 5 To protect the mentally ill person's civil rights at every step in the commitment process, and
- 6 To ensure that involuntary treatment takes place in the least restrictive setting possible

#### Multnomah County Task Force

The Multnomah County Task Force on Potentially Dangerous and/or Chronically Mentally III Persons met from the Fall of 1985 through March 1986. Its final report makes recommendations for legislative changes and resource needs which are identified as follows: (1) guaranteed necessary treatment to all persons who are committed; (2) involuntary commitment with appropriate treatment for last-stage alcoholics; (3) criminal case diversion for mentally III persons: (4) no broadening of the commitment criteria currently in use without additional resources; and (5) hearings for commitment in two-party cases to be held within five judicial days. The Multnomah Task Force supported the concept of "dollars following the client" and better allocation of state funds on the basis of percentage of mental health clients served.

## Recommendations of the Civil Commitment Task Force

While there were gradations of opinions within the Task Force regarding current commitment criteria, the final report which has been forwarded to the legislature and the governor, contains significant recommendations for changes in the commitment process and recognition of the importance of increased fiscal resources in mental health treatment services. A summary of the report follows:



- Extend the current commitment criteria to include those persons who are (a) chronically mentally ill, as defined in ORS 426.495(2); (b) have a history of two state hospitalizations in the last three years, and (c) are in an episode of mental or physical deterioration likely to result in danger to self or others or unable to provide for basic personal needs.\* This statute amendment addresses the issue of early intervention.
- Restrict the use of emergency commitments to reservations for land-based tribes of Native Americans which extend into two or more counties, effective January 1, 1989.\* This statute change addresses the issue of inappropriate emergency commitments.
- Standardize the length of detention for all types of emergency holds to five judicial days, including time between citation and hearing and notice of trial visit revocation hearing.\* These amendments address the confusion caused by variations in detention times for physician, peace officer, and mental health holds.
- 4. Allow investigators to interview all parties believed to have pertinent information and to have access to inedical records for current involuntary, per-hearing detention, give responsibility for investigation of police holds to community mental health program where custody taken.\* These amendments address the issues of timely and fully informed investigations regarding alledgedly mentally ill persons.
- 5. (a) Allow only circuit court judges with probate jurisdiction to commit to the Mental Health Division with notice given by community mental health director;\* (b) request Supreme Court Chief Justice have bench book prepared to aid judges in more consistent interpretation of commitment statutes; (c) allow investigator's report and medical records to be used as evidence in hearings;\* (d) require judge to appoint one Mental Health Division certified mental health examiner with examination to occur prior to hearing, and grant immunity to examiners.\* These changes address issues of inconsistency.
- 6 Allow the Mental Health Division to place committed persons in outpatient treatment and require the Community Mental Health Program to establish conditions for such treatment, including revocation \* These changes address commitment issues.
- Provide protection from liability for case manager when person on trial visit causes damage. Statute will be amended if Attorney General rules staff members are not currently protected.

\*Indicates change in statute is necessary. Fiscal impacts of changes are included in Mental Health Division budget proposals.

Many states are moving in the direction of easing judicial safeguards and broadening commitment standards.10 They are rocusing less on confrontational, formal commitment procedures and more on adaptable courtroom procedures that increase cooperation among all parties to the process. Such efforts include more intensive pre trial investigation, review and settlement of charges that have led to the commitment action, pre-hearing screening which allows for referral to alternatives to hospitalization, and comprehensive testing which could rule out the possibility of organic or substance abuse problems masquerading as a mental illness. Oregon is among the leaders in having instituted this last procedure following 1983 legislative action. However, this testing procedure is being implemented currently only at the state hospitals. Involuntary outpatient treatment, although it requires additional resources, is either in place or being given serious consideration by seven states.



The medical records of the mentally ill in Oregon are protected as are those of any patient. Doctor and staff members are not free to divulge information to others without the written consent of the patient. In the case of patients over the age of 18, family members are included in those from whom information is withheld

With the mentally ill, this provision can present some special problems. At committal hearings the alleged mentally ill person's medical records cannot be used as a basis for committal. Neither can the family of the hospitalized patient seek information about the nature of the disease or what treatment is being administered unless the patient gives permission.

If the patient is resentful of the family's role in committal, the result may be refusal of permission to examine records. This serves to isolate the family from the patient. It also can prevent the family from playing a role in planning for the patient's discharge and in making responsible plans for life outside the hospital.

Because of the stigma attached to mental illness, there are strong arguments favoring the confidentiality laws. Problems arise, however, when needed information about a client's psychotic episode is not available from medical records. Under the current commitment procedures, the investigator in the case of an allegedly mentally ill person may not talk with family members or others knowledgeable about the person's condition unless permission is given, nor can medical records be cited in the report to the court.

#### PROBLEMS IN THE SYSTEM

#### Homeless and Mentally III

Only recently has the public become aware of the burgeoning number of homeless people and of the number of mentally ill among them who are almost totally isclated from mental health services of any kind. Pinpointing this vulnerable group in precise numbers is difficult because of their mobility, their relegation to freeway underpasses, obscure city hallways, and cardboard shacks at town's edge. What sets them apart from other homeless, the nature of their illnesses, makes them wary of contact and conversation. While these factors make accurate censustaking a problem, individual studies nationally, although differing in settings and methodologies, are beginning to piece together some working estimates.

The estimates of the total of homeless persons nationally, including the mentally ill, range between two and three million, depending upon how "homeless" is defined. For instance, is a migrant family homeless? Some reports place the percentage of mentally ill among the homeless at 25 to 50 percent." Other studies cite a figure of up to 70 percent. According to the National Coalition for the Homeless, nationwide there are 300,000 chronically mentally ill within the homeless population. One study shows that about 15 percent of the nation's chronically mentally ill are homeless and that once homeless, only 15 to 30 percent will receive any kind of mental health assistance. In Oregon there are an estimated 1100 mentally ill among the homeless. This figure is based on a formula which puts total homeless in the United States at 1.379 percent of the population, with 30 percent of those being mentally ill. The formula was devised as part of a major research study on the homeless by the Massachusetts Association for Mental Health, and it is used by the Mental Health Division in planning for proposed services to the homeless mentally ill.

Several factors contribute to the rise in the homeless population overall. Significant among them was the inadequate orchestration, including unrealistic planning and funding for the community systems, of the deinstitutionalization movement of persons from hospitals into community systems. To a major extent, those local



systems were not adequately in place before the clients arrived in the community. Many at-risk persons were and are lost in the transition from hospital to community. In addition, each year nationwide some 150,000 mentally iil persons become legal adults. They may or may not have had prior contact with mental health assistance, hospital or otherwise, and lack completely even the avenue of deinstitutionalization as a means of getting into local community systems. This situation also holds true in the area of the developmentally disabled. Thus it is that the ranks of the homeless mentally ill bulge in the 20-35 year old portion of demographic curves. 12

No easy answers present themselves for changing the plight of the homeless mentally ill, and potential remedies clearly require a public commitment to provide adequate funding. As human beings they need housing, food and clothing as basics, plus at least minimal medical attention. Rather than developing a new service delivery for such persons, it makes sense to tie into the existing community mental health systems from which they are cut off at present. Outreach staff could go into the alleys, shelters and soup kitchens to build non-threatening relationships and bring the homeless mentally ill into treatment services. Oregon has a modest effort going in the Burnside area of Portland. The Mental Health Division's 1987-89 budget request includes funds for expanding identification and service to this population.

#### Housing

Additional residential alternatives for clients in both the MED and DD systems have been identified as a continuing need for more than a decade. In order to maximize treatment in local communities, appropriate housing must be available in a variety of forms—group homes, semi-independent facilities, halfway houses, supervised apartments and foster homes.

Statewide there are approximately 525 MED foster homes. Adult foster homes are administered on a different basis from that for housing provided by subcontractor agencies. The foster home contracts directly with the Mental Health Division, but the county mental health program is responsible for case management and inspection, and is liable for the enforcement of regulations. Reimbursement to MED foster home providers for basic room and board is considerably lower than for other residential care facilities. Another difference occurs in the reimbursement through "service fees" for needed extra services to residents. The maximum in fees allowable for foster homes for the elderly in the Senior Services Division is double that for MED clients even though some marginally functioning MED clients require a high level of care and assistance.

In addition, the escalating premiums for the liability insurance required of foster home providers threaten the workable status quo of the system. It is conceivable that as many as half of the MED foster homes may be forced to discontinue their operation if these problems are not addressed and resolved. The 1987-89 Menta! Health Division budget addresses the situation by requesting increased funds to reimburse MED foster home providers at a higher level than currently.

In a press release October 24, 1984 Multnomah County Auditor Anne Kelly Feeney criticized the state for not adequately funding community mental health programs. She stated that residential services are a key factor in reducing use of state hospitals but that state and county officials had not chosen to give residential services the same priority as other programs. She estimated that 50 percent of the people in Dammasch from Multnomah county wouldn't be there if they had appropriate support and living arrangements in the community.



Some critical problems and gaps which have been identified by specific county mental health program directors and professionals include the lack of crisis care. The provision of crisis services is one required of all local programs. Each county has some crisis response system it may be a highly visible hotline/crisis line telephone operated by trained personnel, or simply a number which will reach local police, the county sheriff or local hospitals. Not all counties have arrangements within their area for secure holdings of indigent clients or persons of limited means. Local crisis holding facilities are limited. In Eugene, for instance, such persons must be transported by the sheriff, shackled for safety, almost 100 miles to Dammasch Hospital in Wilsonville for holding. The client often must be returned to Eugene for a commitment hearing, and if committed, be returned to Dammasch. Establishing a better arrangement for these people who already are in a very disturbed and confused state of mind is considered of paramount importance.

It is the intent of the critical mass budget proposal for 1987-89 to alleviate a portion of the community crisis care problems, depending upon the funding level adopted by the legislature

#### **Funding**

In March 1986, the Conference of State Legislatures sponsored a Mental Health Services Funding seminar for Oregon decision makers. A major theme of the seminar was that community-based services do not cost less than institutional care since there must be a range of services provided locally, and that there will always be hospital costs for those mental patients who cannot survive outside hospitals. Additional resources are essential, and they must be focused to make patient impact and further reduce the hospital population according to the seminar leaders. Allocations should be focused in areas where local services cna develop quickly and effectively.

The critical mass concept in Oregon should have flexibility in design to respond to the diversity of Oregon geography and population, and recognition should be given to the fact that not all dollars attached to state hospital beds can be shifted to the community Community programs currently are serving twice as many persons as funded for, and yet they serve less than 60 percent of the chronically mentally ill. The problem becomes one of how to translate the dynamics of the system to the services needed with the resources available Comments from county mental health professionals supported the proportionate use of funds for certain populations.

Representative Rick Bauman, chairman of the Human Resources subcommittee of the Joint Ways and Means committee of the 1985 legislature, concluded that few in Oregon decision-making positions have much knowledge about the mentally ill. Support for programs and funding needs also has not come traditionally either from the governor's office nor the Department of Human Resources. He indicated that the legislature will make an appropriate distribution of what funds are available, but that the case for an acceptable quality of life for the mentally handicapped must be strongly made by other advocates.

The lack of sufficient funding remains the single most often cited drawback to the delivery of complete mental health services to all Oregonians in need of such services. Many populations of mentally ill are unserved or underserved. There are few programs for prevention, little help for families of the mentally ill, lack of support groups for the chronically and severely mentally ill who are working or in school, and lack of alternatives in housing. The shortage of funding at the community level also is reflected in understaffing and underfunding of both services and administration.



#### REFERENCES

- (1) Report issued by the Public Citizen Health Research Group, March 19, 1986, by Dr. E. Fuller Torrey and Dr. Sidney M. Wolfe. Summary from Mental Health Division.
- (2) Miller, G "The Future of the Chronically Mentally Ill" in The Chronically Mentally Ill Research & Services, edited by M Mirabi Spectrum Publications 1984
- (3) Briefing on "Projects to Use State Hospital Resources for Community Programs Background", Memorandum to the Honorable Victor Atiyeh, Governor of Oregon, Mental Health Division, September 1981
- (4) Report to the Legislative Emergency Board, September 1982 on "Projects to Use State Hospital Resources for Community Programs: Executive Summary". Mental Health Division 1982
- (5) Bergel & Fine. "Legislation" in The Chronic Mental Patient Five Years Later, edited by J A Talbot Grune & Stratton, Inc., 1984
- (6) National Conference of State Legislatures State Involuntary Commitment

- Laws Beyond Deinstitutionalization Mental Health Project Legislative Report, Vol. 10, #6, p.1., 1985
- (7) Richard Lamb, editor The Homeless Mentally III American Psychiatric Association, 1984, p 62
- (8) Keilitz, Ingo et al | Improving the Involuntary Civil Commitment Process in State Court Journal, Vol. 7, #4, Fall 1983, pps. 15-18
- (9) Kushnei, Jeffrey N. Testimony before the Task Force on Civil Commitment, February 20, 1986
- (10) National Conference of State Legislatures State Involuntary Commitment Laws Beyond Deinstitutionalization Mental Health Project Legislative Report, Vol. 10, #6, 1985
- (11) Lamb, H. Richard "The Homeless Mentally III" in A Task Force Report of the American Psychiatric Association, 1984
- (12) Patterson. Andrea and Rebecca Craig The Homeless Mentally III No Longer Out of Sight and Out of Mind National Conference of State Legislatures, State Legislative Report, Vol. 10, #13, December 1985

#### **GLOSSARY**

A & D. Alcohol or Drug Abuse or Dependence. A person who has lost the ability to control the use of alcohol or controlled substances or other substances with abuse-potential, or who uses alcohol or such substances to the extent that the person's social or economic functions are substantially disrupted

ADP: Average Daily Population means the number of beds occupied in Oregon State Mental Hospitals on any given day

Adult Foster Home means any certified family home or facility in which 24-hour care and services are provided for five or fewer "clients". The home or facility is the residence of the provider in whose care the adults have been placed.

Case Management means an organized service by a mental health professional to assist persons with severe mental disorders who are not able to select, obtain and use resources and services to meet their needs

**CCMP**\* Computerized Client Monitoring System is used to compile information on client characteristics, services provided, and treatment outcome, program monitoring and resources shifting are important elements

CMI: Chronically Mentally III person. An individual with a mental or emotional disturbance who (1) has been hospitalized twice or more in a 24-month period, and (2) needs residential and support services of an indefinite duration to maintain a stable adjustment in society.

CPMS: Client Process Monitoring System. A client data base of information in the Mental Health Division. Information is compiled by community mental health programs on clients in the system.

MHP: Community Mental Health Program means the organization of all services for persons with mental or emotional disturbances, drug abuse problems, mental retardation and other developmental disabilities, and alcoholism and alcohol abuse problems, operated in a specific geographic area of the state under an omnibus contract with the Mental Health Division

Critical Mass is the community mental health program capacity needed to serve all Priority I persons who are in need of service

**OD.** Developmental Disabilities By statute, a person with a disability altributed to mental retardation, cerebral palsy, epilepsy or other neurological handicapping conditions which require training similar to that required by mentally retarded individuals.

Local Mental Health Authority means the county court, board of county commissioners or tribal council (tribal lands) of one or more counties who operate a community mental health program under contract with the Mental Health Division

MMIS: Medicare Management Information System A data base system for client's medical coverage, provider information, claims for billing, eligibility and/or restrictions, maintained by Adult and Family Services Division

MED: Mental or Emotional Disturbance By statute, a person with a disorder of emotional reactions, thought processes, behavior, or relationships (excluding mental retardation, alcoholism and drug abuse or dependence) which results in

substantial subjective distress, impaired perceptions of reality, or impaired ability to control or appreciate the consequences of one's behaviour, and which constitutes a substantial impairment of personal, inter-personal, work, education or civic functioning

Mentally III Person. a person who, because of mental disorder, is either (1) dangerous to himself or others, or (2) unable to provide for his basic personal needs and is not receiving such care as is necessary for his health and safety

MR. Mental Retardation By statute a person with significantly subaverage general intellectual functioning existing with deficit in adaptive behavior and manifested during the developmental periods. Persons of borderline intelligence may be considered mentally retarded if there is also serious impairment of adaptive behavior. NIMH: National Institute of Mental Health.

DAR. Oregon Administrative Rules Regulations developed by state agencies to carry out specific responsibilities imposed on them by statute

**DRS.** Oregon Revised Statutes The codification of the legislative enactments for the State of Oregon

#### Priority Classifications for Mental Health

Priority I Those persons who, in accordance with the assessment of professionals in the field of mental health, are at immediate risk of hospitalization for the treatment of mental or emotional disturbances or are in need of continuing services to avoid hospitalization or pose a hazard to the health and safety of themselves or others and those persons under 18 years of age who. In accordance with the assessment of professionals in the field of mental health, are at immediate risk of removal from their homes for treatment of mental or emotional disturbances or exhibit behavior indicating high risk of developing disturbances of a severe or persistent nature

Priority II Those persons who, because of the nature of their illness, their geographic location or their family income, are least capable of obtaining assistance for the private sector

Provity III Those persons who, in accordance with the assessment of professionals in the field of mental health, are experiencing mental or emotional disturbances but will not require hospitalization in the forseeable future.

**PSRB.** Psychiatric Security Review Board. This board has jurisdiction over all persons in Oregon found by a court not responsible for a crime because of mental disease or defect and who present a substantial danger to themselves or others. **Quality Assurance** means a systematic procedure for assessing the effectiveness, efficiency, and appropriationess of services provided by a community mental health contractor.

Residential Care Facility means one or more buildings on contiguous property that is licensed by the Mental Health Division to provide residential care for six or more persons over the age of 16 years

#### **ACKNOWLEDGEMENTS**

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Additional copies of this report are available for \$2 from the League of Women Voters of Oregon, 317 N E Court Street, Suite 202, Salem, OR 97301 Copyright August, 1986



73

# STATE AND COUNTY FUNDED MENTAL HEALTH SERVICES

The Mental Health Division (MHD) employs over 4000 people to manage and provide services to persons with mental or emotional disturbances (MED), and persons who are mentally retarded or developmentally disabled (MR/DD). Nearly all of these employees are in the state hospitals and training centers with the remainder in MHD's Central Office.

The Central Office is located in Salem on the Oregon State Hospital grounds. It has two major service divisions—the MED Program Office and the MR/DD Program Office, and has administrative divisions such as the Office of the Administrator, Communications, Personnel Management, and Administrative Services.

The MED Program Office is responsible for planning and monitoring services for the mentally ill.

### **State Hospital Programs**

The Division directly operates three state hospitals for the mentally ill and two state training centers for the mentally retarded or developmentally disabled.

Hospitals for the mentally ill:	1987-88 <u>Patient Population</u>
Oregon State Hospital—Salem	695
Dammasch State Hospital—Wilsonville (20 miles south of Portland on I-5)	355
Eastern Oregon Psychiatric Center—Pendleton	<u>55</u> 1105

Training Centers for the mentally retarded or developmentally disabled:

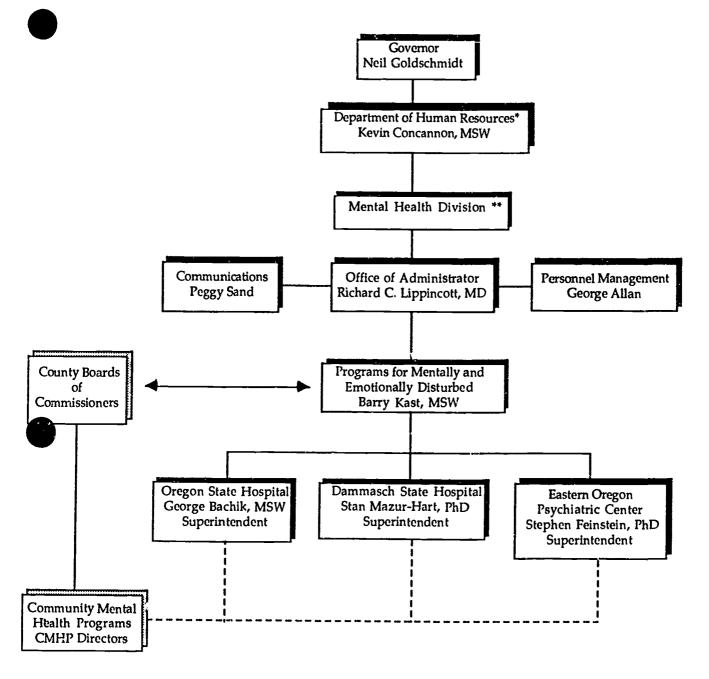
Fairview Training Center—Salem	1030
Eastern Oregon Training Center—Pendleton	<u>86</u>
· ·	1116

The state hospitals for the mentally ill have different types of programs. These are described on the following pages.

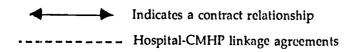


72

## STATE AND COUNTY FUNDED PROGRAMS



- \* Includes Office of Alcohol and Drug Abuse Programs, Adult and Family Services Division, Children's Services Division, Employment Division, Health Division, Mental Health Division, Senior Services Division, and Vocational Rehabilitation Division.
- \*\* Also includes programs for the mentally retarded or developmentally disabled which are not shown on this chart.





### **Oregon State Hospital (OSH)**

Oregon State Hospital, located in Salem, is primarily a specialty institution serving patients from all areas of the state. A small adult psychiatric unit also serves patients from four counties. Programs at Oregon State Hospital include:

#### Forensic Psychiatric Program (FPP)

This program is budgeted for 340 beds, including 33 beds in three transitional living cottages. It primarily serves persons who are committed to the Psychiatric Security Review Board's custody by the criminal justice system. These are persons who are found to be guilty of a crime, but who are mentally ill.

#### Child and Adolescent Treatment Program (CATP)

This 60 bed program serves severely disturbed children and adolescents from throughout the state who are extremely dangerous to themselves or others. Many of these children have already had extensive experience in out-of-home placements through the Children's Services Division. Admission to the unit is closely coordinated between the Mental Health Division and the Children's Services Division.

#### Geropsychiatric Treatment/Medical Services Program (GT/MSP)

This 146-bed program serves elderly patients with physical disorders who cannot be placed in skilled nursing facilities or intermediate care facilities because of the severity of their mental disorders and behavioral problems. The unit also serves young, neurologically impaired patients who require a skilled nursing level of service. This unit also operates 10 heavy-care medical beds which serve patients from throughout the hospital when heavy-care nursing services are needed.

#### Marion, Polk, Linn Unit (MAPL)

This 70-bed adult psychiatric unit serves adults from Marion, Polk, Linn, and Benton-counties who require general psychiatric care.

#### Correctional Treatment Program (CTP)

This 120-bed program serves inmates of the Corrections Division who meet program criteria for admission to one of four units for sex offenders, persons with alcohol and drug abuse problems, mentally or emotionally disturbed inmates, and mentally retarded or low functioning inmates lacking in social skills. This program is operated under contract with the Corrections Division and is licensed as a residential care facility.

### Dammasch State Hospital (DSH)

Dammasch State Hospital, located in Wilsonville, is an adult psychiatric hospital which is licensed for 375 beds with a budgeted average daily population of 330 patients for the 1987-89 biennium. Dammasch serves adults from all Western Oregon counties with the exception of the four counties served by the MAPL Unit at Oregon State Hospital. The population at Dammasch State Hospital has been increasing during the last two years and has consistently exceeded the budgeted population level of 330 since 1986. Due to this population pressure, voluntary admissions have been restricted since July 1986.



74



Eastern Oregon Psychiatric Center, located in Pendleton, is a small 60-bed adult psychiatric hospital serving adults from all counties east of the Cascades, except Klamath and Lake counties which are served by Dammasch. It is budgeted for a patient population of 60 and generally experiences a population slightly less than the budgeted level.

#### **Catchment Areas**

Adult psychiatric programs—Dammasch State Hospital, Eastern Oregon Psychiatric Center, and the MAPL Unit at Oregon State Hospital—divide the state into "catchment areas." A catchment area is that group of counties for which the adult psychiatric program is responsible. For example, the MAPL unit accepts voluntary admissions from a four county catchment area: Marion, Polk, Linn, and Benton counties. A catchment area map showing which counties are served by which hospital is found in the Voluntary Hospitalization section. (Chapter VII).

All the specialty programs at Oregon State Hospital (all programs except MAPL) serve a statewide catchment area.

**NOTES:** 



### Community Mental Health Programs (CMHPs)

Besides directly running the state hospitals, the Division contracts with the counties to provide services at local community mental health programs (CMHPs). These CMHPs are primarily funded by State dollars although many counties add county funds to expand the amount of service which can be provided. All counties offer services for the mentally ill, services for the mentally retarded or developmentally disabled, and services for persons with alcohol or drug abuse problems. These latter programs are funded by the Office of Alcohol and Drug Programs located in the Department of Human Resources. Alcohol and drug programs may be located in a different organization unit from the CMHP. CMHP staff are usually county employees directly responsible to the county board of commissioners. A few counties contract with private non-profit agencies to provide all mental health services; employees of these programs are not county employees. There are no state employees in the CMHPs, but the MED Program Office does ensure that state standards are met by periodic site reviews.

CMHPs offer different types of services for the mentally ill. A description of each service follows with a chart showing which services are available in each county. It is important that even though a county many offer a particular service, that service may not be accepting new patients. There are not enough dollars to provide services for all persons with mental or emotional disturbances; therefore, services are provided to the highest priority clients. This priority system is explained in the chapter "Critical Mass and Priority 1-2-3."

# DESCRIPTION OF COMMUNITY MENTAL HEALTH PROGRAM SERVICES FOR THE MENTALLY ILL

# Day and Residential Treatment Services (DARTS)

Children under 12 years of age who are severely emotionally disturbed may be eligible for these programs. DARTS provide both residential and outpatient treatment at the local level. There are currently 21 DARTS in Oregon. They are managed by the Children's Services Division. Children who cannot be managed in a DART may require hospitalization in the Child and Adolescent Treatment Program (CATP) at Oregon State Hospital.

# Community Treatment Services (CTS)—Children

Community Treatment Services for Children provide evaluation, brief intensive treatment, and less intensive long-term supportive treatment in outpatient settings.

Treatment may include medication management and frequently involves the family and other child and adolescent service agencies. These services are provided to any child or adolescent who is in need if resources are available. However, state funds are limited to children and adolescents who are identified as Priority 1. (See chapter entitled "Critical Mass and Priority 1,2,3.") Services are expected to increase client functioning to the extent that more intensive services are not required. The Legislatively Approved Budget funds services for a total of 13,465 children during the 1987-89 biennium.

# Community Treatment Services (CTS)—Adults

Community Treatment Services include evaluation and short-term outpatient treatment for individuals and families. They



76

also include long-term supportive treatment and medication management for chronically mentally ill persons who can be maintained in the community with minimal support. During 1987-89, 18,586 people who cannot afford or gain access to private services will be treated. Most of the adults treated will be helped to function more adequately in their families and places of employment, and will be maintained without requiring state hospitalization. Many will require community crisis services from time to time.

#### **Community Support Services (CSS)**

Community Support Services is an intensive long-term array of services needed to maintain chronically mentally ill adults in the community. Services include case management, outreach, medication management, daily structure and support, vocational skill development, and residential resource development. Services are provided for chronically mentally ill adults with severe mental disorders and impaired functioning in at least two of the following areas: social role, daily living, and social acceptability. Case management is also provided to all persons receiving MED residential services. Funding in the 1987-89 Legislatively Approved Budget provides the capacity to serve 4,665 clients at any one time, on a total of 9,436 clients during the biennium.

### **Dual Diagnosis Services**

All counties provide services for persons with alcohol and drug abuse problems and for persons with mental illness. The chapter, "Substance Abuse and Mental Illness" discusses the special treatment needs of

persons with both these conditions at the same time. Not all counties have developed the specialized services necessary to serve these "dually diagnosed" patients. Counties are listed as providing dual diagnosis services if they responded affirmatively to an August 1988 survey.

#### Community Hospital Crisis Services

Community hospitals provide brief psychiatric inpatient treatment and emergency holding of allegedly mentally ill persons prior to commitment hearings. These services are provided through contract with community mental health programs for children, adolescents, and adults with severe mental disorders who are likely to experience negative consequences if immediate intervention is not provided. Approximately 3,892 people will have community hospital and physician bills paid fully or in part by state funds.

### Non-Hospital Crisis Services

Non-Hospital Crisis Services provide evaluation and either referral or crisis stabilization 24-hours a day, 7-days a week. Crisis stabilization may include intensive short-term treatment, psychotropic medications, and placement in a non-hospital respite facility as needed. Services are provided for children, adolescents, and adults with severe mental or emotional problems. During 1987-89, an estimated 21,696 people will be evaluated and receive crisis services.

#### **Precommitment Services**

Services are provided for persons who are alleged to be mentally ill by citizens, police officers, physicians, health officers, or



judges, and who will not voluntarily seek treatment. These services include: 1)screening petition requests to determine the advisability of filing a petition alleging mental illness; 2) developing alternative plans of care; 3) submitting recommendations to the courts on the need for a hearing; 4) providing testimony in commitment hearings; and 5) making recommendations for disposition and treatment. Oregon statutes require community mental health programs to provide these services. During 1987-89, community mental health programs will be funded for approximately 11,608 precommitment investigations.

#### Psychiatric Security Review Board (PSRB) Services

Services are designed for persons judged by the courts to be "guilty, except for insanity" of committing a crime, who are placed under the jurisdiction of the Psychiatric Security Review Board and have been conditionally released into the community by the Board or the court. PSRB services include an initial assessment of persons for the courts and the Board to determine community treatment needs and the level of supervision required for persons conditionally released by PSRB to the community. Upon conditional release, services provided are evaluation, supervision, case management, medication management, and psychotherapy, and monthly reports to the Board on each client. In addition, some clients may receive supervised living arrangements and/or vocational skill training. The Legislatively Approved Budget provides the capacity to serve 126 PSRB clients in the community at any given time.

#### Homeless Services

Homeless services include case management; outreach; diagnostic services; daily

structure; and support and training in skills of daily living. These services are provided for severely mentally ill persons who are at risk of hospitalization, or for people in need of continuing services to avoid hospitalization. These people are unable to live independently even with community support services. The 1987-89 Legislatively Approved Budget provides services for the homeless in Marion and Multnomah counties.

#### Residential Care Facilities (RCF)

Residential care facilities provide 24-hour supervision, medication monitoring, support and training in skills of daily living. Residential facilities serve six or more residents. These services are provided for severely mentally ill persons who are at risk of hospitalization, or for people in need of continuing services to avoid hospitalization. These people are unable to live independently even with community support services. The 1987-89 Legislatively Approved Budget provides services for 530 people at any one time.

# Specialized Programs for Persons Who are Mentally Ill and Hearing Impaired

A supported housing and vocational program for mentally ill deaf and hearing impaired is being developed by the Vocational Rehabilitation Division (VRD) and Laurel Hill Center in Eugene. The program will serve VRD clients from all counties in the State. For further information, contact your local VRD office.

A second program for the mentally ill hearing impaired is located at Fir Hill Group Home, an RCF in Polk County. It has a limited capacity to serve this population. Referral is through your local CMHP.



#### **Adult Foster Care (AFC)**

Adult Foster Care Services are provided in family homes licensed for five or fewer persons. Services include training or assistance with personal care, activities of daily living, supervision of medication, supervision of behavior, prevention or stabilization of a crisis, management of diet, and health care. All persons served are severely mentally ill and unable to live independently without this level of service. The 1987-89 Legislatively Approved Budget provides 328 adult foster care slots.

Supported Housing Services (SHS)—formerly known as Semi-independent Living

Supported Housing Services include: 1) an assessment of client's functional abilities, skill deficits, strengths, and weaknesses related to community living; 2) support through regularly scheduled staff contacts; 3) assistance with activities such as funding affordable housing, moving, meals, money management, grocery shopping, transportation, etc.; 4) skill training in such areas as cooking, budgeting, self-care, housekeeping, leisure planning, etc.; 5) advocacy on behalf of the client with landlords, neighbors, etc. The 1987-89 budget authorizes 868 people at any one time.

#### **Intensive Care Facilities (ICF)**

ICFs are also known as nursing homes. Most of these facilities will accept mentally ill persons who do not have severe behavior problems and who have a medical need which requires nursing services. Residents of all counties have access to these programs regardless of whether there is a facility in their county of residence; therefore,

they are not shown on the chart of services available by the county. Referrals to ICFs are through the Senior Services Division or local Area Agencies on Aging.

#### **Supported Employment Services**

Supported Employment Services provides the on-going support needed to maintain a worker on the job when initial vocational training services provided by the Vocational Rehabilitation Division have ended. Referral to these programs is through the local CMHP. (See the chapter entitled "Entitlements.")



### Contacting a Community Mental Health Program

Some CMHPs directly provide all the service elements. Others subcontract their funds and private organizations actually provide the service. In either case, a person needing publicly funded mental health treatment should contact the CMHP directly rather than going directly to a subcontractor such as a group home. The CMHP can make the necessary assessment and refer the client to the needed service. The following phone numbers are for contacting your CMHP and arranging local mental health service. Use these numbers even when you think there may be a need for state hospitalization. CMHPs may be able to provide a local service and prevent unnecessary hospitalization.

#### **Baker County**

Mountain Valley Mental Health P. 0. Box 649 Baker, OR 97814 523-3646

#### **Benton County**

Benton Co. Mental Health Clinic 530 N.W. 27th St. Corvallis, OR 97330 757-6844

#### **Clackamas County**

Clackamas Co. Mental Health P. 0. Box 164 Marylhurst, OR 97036 655-8651

#### **Clatsop County**

Clatsop Mental Health Center 701 W. Marine Dr. Astoria, OR 97103 325-5722

#### Columbia County

Columbia Co. Fam. Counseling 161 St. Helens St. St. Helens, OR 97051 397-5211

#### **Coos County**

Coos Co. Mental Health 1975 McPherson St. North Bend, OR 97459 756-2020

#### **Crook County**

Crook Co. MH/CSS 203 N. Court St. Prineville, OR 97754 447-7441

#### **Curry County**

Curry Co. Mental Health Program P. 0. Box 746 Gold Beach, OR 97444 247-7011, ext. 277

#### **Deschutes County**

Deschutes County M.H. Day Treatment 409 N. E. Greenwood Bend, OR 97701 388-6601

#### **Douglas County**

Douglas County Mental Health 621 West Madrone Roseburg, OR 97470 440-3532

#### **Grant County**

Grant County Center for Human Devel. 166 S. W. Brent John Day, OR 97845 575-1466

#### **Harney County**

Harney Couns. & Guidance Service 415 N. Fairview Burns, OR 97720 573-8376



Hood River County MID-COL CNTR LIV HD RVR 400 E. 5th Rm 106 The Dalles, OR 97058 296-5452

Jackson County
Jackson Co. Mental Health Services
1313 Maple Grove Dr.
Medford, OR 97501
776-7355

Jefferson County Jefferson County Mental Health 530 D Street Madras, OR 97741 475-3893

Confed. Tribes Warm Springs - MED P. 0. Box C Warm Springs, OR 97761

Josephine County
Josephine County Mental Health
714 NW A St,
Grants Pass, OR 97526
474-5365

Klamath County Klamath Mental Health Program 3314 Vandenberg Rd. Klamath Falls, OR 97603 882-7291

Lake County
Lake County Mental Health Program
513 Center St.
Lakeview, OR 97630
947-6021

Lane County
Lane CMHP
1901 Garden Ave.
Eugene, OR 97403
687-3608

Lincoln County
Lincoln County Mental Health
P. 0. Box 1180
Newport, OR 97365
265-6611

Linn County
Department of Health Services Programs for Mental or Emotional Disturbance
P. 0. Box 100
Albany, OR 97321
967-3866

Malheur County
Malheur County M.H. & Counseling
1108 S.W. 4th St.
Ontario, OR 97914
889-9167

Marion County Community Support Unit 3180 Center St. N.E. Salem, OR 97301 588-5351

Morrow County Morrow Mental Health North P. 0. Box 261 Boardman, OR 97818 481-2911

Multnomah County
Multnomah County Social Services Div.
Mental & Emotional Disturbances Program
426 SW Stark, 6th Floor
Portland, OR 97204
248-3691

Mental Health Services West, Inc. 710 S. W. Second, 2nd Floor Portland, OR 97204 228-0373



Multnomah County (cont.)
Mt. Hood Community Mental Health
400 N.E. Seventh Ave
Gresham, OR 97030
661-5455

North/Northwest CMHC Inc. 5019 N. Williams Ave Portland, OR 97217 249-0066

Southeast Mental Health Network, Inc. 2020 S. E. Powell Portland, OR 97202 238-0705

Polk County
Polk County Mental Health
289 Ellendale Plaza #703
Dallas, OR 97338
370-2519

Sherman County MID-COL CNTR LIV HD RVR 400 E. 5th Rm 106 The Dalles, OR 97058 296-5452

Tillamook County
Tillamook Counseling Inc.
2405 5th Street
Tillamook, OR 97141
842-8201

Umatilla County Umatilla CMHP MED Clinics 721 S. E. 3rd Suite B Pendleton, OR 97801 276-3784

Umatilla CMHP 435 SE Newport Hermiston, OR 97838 567-2367 Union County
Center for Human Development
1100 K Ave.
La Grande, OR 97850
963-1013

Wallowa County Wallowa County Mental Health P. 0. Box 460 Enterprise, OR 97828 426-4524

Wasco County MID COL CNTR LIV DALLES 400 E. 5th, Rm 106 The Dalles, OR 97058 296-5452

Washington County Washington CMHP 1679 S. E. Enterprise Cir Hillsboro, OR 97123 681-702)

Wheeler County Wheeler-Gilliam CMHP P. 0. Box 469 Heppner, OR 97836 676-9161

Yamhill County
Yamhill County Mental Health
412 N. Ford St.
McMinnville, OR 97128
472-9371



### SERVICE ELEMENTS BY COUNTY, 1987-89 BIENNIUM

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BAKER		х	x	x	x		x	x			_			x	_	
BENTON		X	x	×	×	×	x	x	×		x			x		x
CLACKAMAS	x	X	X	x		x	x	x	x		x		x	X		x
CLATSOP		X	x	x	×	<b>x</b> -	x	x					x	x		
COLUMBIA		X	x	x	x	x	x	x			x			x		
COOS	×	x	x	x		X	_ <b>x</b> _	x	x					X		
CROOK		х	X	x		x	X	x						x		
CURRY		x	x	x		×	x	X				•		x		
DESCHUTES	x	X	x	x	x	x	x	x	x				x	x		
DOUGLAS	x	X	x	x	x	x	x	x	x				×	x		
GRANT		X	x	X		x	x	x						X		
HARNEY		X	X	X		X	x	x			x					
JACKSON	X	X	X	X	X	X	X	x	x		x		X	x		
JEFFERSON		X	x	x		x	×	x		•			x	x		
JOSEPHINE	x	X	x	x		x	x	x	x				x	x		x
KLAMATH	2	x	×	x		x	×	x					×	x		
LAKE		X	x	x		x	x							X		
LANE	X	X	X	X		X	x	X	x		X	×	x	X		*
LINCOLN	X	X	X	X		X	X	X	X					X		
LINN		X	X	X	X	x	x	x			x		x	X		
MALHEUR		X	x	X	X	x	x	x	x		x		X	X		x
MARION		x		x	X	X	x	x	x	x	x		x	X		
MORROW		x	x	x		x	x	x						X		
MULTNOMAH	7	x	x	x	×	X	x	x	x	·x	x		x	x		x
POLK	2	X	x	X			x	x	x	•	x	x	X	X	_	
TILLAMOOK		x	x	x	X		x	x						x		x
UMATILLA		x	x	x	x		x	x					x	x		x
UNION	×	x	x	x	×		×	x	x		x			×		
WALLOWA		x	x	x			X	x			X		x	x		
MID-COLUM.*	X	x	x	x			_x_	x	_x					_ <b>X</b>	x	
WASHINGTON		x	X	х	x	x	X	х	X		x			x	x	x
WHLR./GILLIAM		x	x	x		x	x	x						x		
YAMHILL		x	X	x	x		x	x	x				x	x	x	x
WM. SPRINGS		x	X	x			x						x			

<sup>\*</sup>Hood River, Wasco and Sherman Counties



Having enough of the right kind of community services for people who are at risk of admission to a state hospital is often described as the theory of "critical mass." In theory, this "critical mass" defines a certain level and variety of community mental health program services which need to be in place to maintain clients and families in the community. Clearly defining the exact levels and varieties of services is difficult.

This concept of Critical Mass is a result of the research of the 1979-1981 State Task Force on Mental Health. HB 2404 was passed in order to help community programs meet a goal of limiting state hospital admissions to those people who really need hospital treatment. Many who might otherwise be hospitalized could thus be managed in their communities. Unfortunately, Critical Mass does not exist at present due to funding shortfalls.

In order to assist CMHPs determine who qualifies for the services that are available, priorities have been established. These priorities are defined below.

### **Priority 1**

- a. A person at immediate risk of hospitalization due to a mental or emotional disturbance (M-ED problem);
- b. A person in need of continuing services to avoid hospitalization due to an M-ED problem;
- c. A person posing a hazard to the health and safety of themselves or others due to an M-ED problem;
- d. A person under 18 at immediate risk of removal from his/her home due to a M-ED problem;
- e. A person under 18 at risk of developing a mental or emotional disturbance of a severe and persistent nature.

#### **Priority 2**

A person who because of the nature of his/her illness, family income, or geographic location is unlikely to obtain services from other providers.

#### **Priority 3**

A person experiencing mental or emotional disturbances but who is not likely to require hospitalization in the foreseeable future.

### Why This Is Important

It is important to keep in mind that due to the lack of Critical Mass, only the most disabled clients, and those without tinances, are to be seen in CMHPs. Since there is insufficient funding to serve all Priority 1's, waiting lists develop. Not all the most critically mentally ill get high priority at the county level. Providers tend to work with clients where they feel there is a good possibility of some improvement. Sometimes, those with the most urgent needs "fall through the cracks" of the system. Families can contact their CMHP director to find out how their county compares in terms of percent of Priority 1 individuals served and what percent of critical mass funding is received.

This problem is not just a family problem—it is a societal problem. Families cannot take unlimited responsibility for their mentally ill relatives. There must be opportunities for chronically mentally ill persons to have gainful employment, to live independent of their families, and to have access to medical care in times of mental crisis. If society does not shoulder this responsibility, what will happen when the parents and siblings can no longer cope? For more information, contact your nearest OAMMI affiliate.



The Mental Health Division first became responsible for residential service delivery in 1979 when administrative responsibility for 29 "group homes" (i.e., Residential Care Facilities) transferred from the Adult and Family Services Division. In 1982, administrative responsibility increased as "Adult Foster Care" (AFC) homes and additional Residential Care Facilities (RCF) became part of the Mental Health Division's jurisdiction.

In 1983, the Mental Health Division created and funded Semi-Independent Living Program (SILP) services. This new service element enables M-ED clients to live in independent apartments or other community housing through the provision of support, assistance and training. SILP is now called Supported Housing Services (SHS).

As experience with residential service delivery increased, special needs became apparent. This led to the establishment of specialized nursing home placements, a "demonstration project" group home for residents who are both mentally ill and substance abusers, and a proposal for a special residential program to serve hearing impaired, mentally ill persons.

A MED Residential Task Force recently completed a report on housing program needs. As with many other categories of services, the need for residential programs exceeds the availability and low funding levels limit the intensity of service provision. A copy of this report is available at the local OAAMI affiliate or through the Mental Health Division Central Office.

Currently, the following number of slots are available (or under development) in state-funded resources:

#	Type of Program
530 Beds	Residential Care Facility
328 Beds	Adult Foster Care
868 Slots	Supported Housing Services
30	Specialized Intermediate Care Facility

### Description of Residential Programs

Residential Care Facilities provide room, board and 24-hour supervision for 6 or more residents. Each resident's needs are assessed, and services addressing them are outlined on a "Plan of Care". Facilities vary throughout the State. Some have a "long-term care" focus while others are directed at preparing residents for independent living.

Adult Foster Care Homes also provide room, board and 24-hour supervision. A "live-in" provider serves five or fewer residents in a "family home" setting. As in RCFs, AFC residents' needs are assessed with services to be provided identified on a "Plan of Care". The focus of various Adult Foster Care programs also varies; however, most serve clients who require ongoing care.



Supported Housing Services provide ongoing assistance, support, advocacy and training to persons who reside in independent housing units such as apartments and shared rental houses. They also operate in various models. Some have staff who reside on-site while others utilize visiting staff. Clients served might all live in one apartment complex, might live in clusters of units in a few larger complexes and/or might live in individual, scattered units.

Intermediate Care Facilities (ICFs) are a new category of residential program. They are established in cooperation with the Senior Services Division (which is the agency within the Department of Human Resources responsible for "nursing home" administration). ICFs provide room, board, 24-hour supervision and a minimal level of residential health care services to residents with physical health problems.

In addition to the above state-funded residential service programs, boarding homes are operated on a private, proprietary basis. In exchange for a monthly fee, residents receive room and board. These facilities are not routinely regulated by the State and vary in their quality. Services and care are not generally provided. A boarding home may look like a state-funded program on first appearance, but it is important to understand that boarding homes are both minimally funded and monitored residences and are not generally appropriate for persons with care needs beyond daily availability of room and board.

#### How to Access Residential Services

Residential Case Managers, who are on the staffs of local mental health programs, determine eligibility and facilitate placements for the 24-hour supervised programs (RCFs, AFCs, and ICFs). Supported Housing Services generally require a different

eligibility screening process. More information can be obtained by calling the local mental health agency and asking to speak to the Residential Case Manager.

### Questions to Ask Residential Service Providers

- 1. Ask for a tour of the facility.
- 2. What are the house rules?
- 3. Are medications monitored? What is the procedure?
- 4. What services are provided?
- 5. What is the goal of the program (e.g. longterm care or preparation for independent living)?
- 6. How is a resident's personal spending money managed? What must the resident supply for him/herself?
- 7. What expectations exist for residents? Is there a curfew? Can residents come and go at will? Can the resident spend the night away from the facility?
- 8. How many staff work at the Program? What are their roles? What is the staffing pattern (i.e. what shifts do staff work)? What are their credentials? Is an adult on duty 24 hours a day?
- 9. How are emergencies handled?
- 10. How are family members included in activities and service planning and delivery? Is there routine communication with family members (if the resident does/does not consent)?
- 11. How much do residents pay to participate in the program? Is there a damage deposit required? How does one get a refund when leaving the facility? Are first and last month's rent required in advance?
- 12. Is the program licensed?
- 13. What are the admission criteria? How are applications processed?
- 14. How are meals provided? Can special diets be accommodated?



- 15. Under what conditions are residents terminated from the program? What is the eviction procedure?
- 16. What are the resident's rights? How are they protected?
- 17. How is mail received and handled?
- 18. Can residents have pets?
- 19. Will the resident be expected to perform certain chores?
- 20. Is an assessment of the resident conducted? How is it done? Is the resident informed of the results? How frequently do reassessments take place?
- 21. How are services planned for residents? Are they based on an assessment?

- 22. Is there a laundry service?
- 23. What areas are open for common use? Indoor and outdoor? Television/radio?
- 24. What opportunities for social and recreational activities exist?
- 25. Is transportation (including public transportation) available?
- 26. Is there a phone available for residents' use? Any special rates? Can one make long distance calls?
- 27. Will the resident have a roommate? Are there facilities for overnight visits from friends or family?
- 28. Are there any special services or other services offered by your program?

References and Suggested Readings

Levine, I. . Developing Community Support Service Programs: A Resource Manual for Family Groups. Arlington VA: NAMI.

Uhlhorn, B. (1987). Creating a Caring Community: Developing Housing for Persons with Mental Illness. Arlington, VA: NAMI.

These and other publications are available from the local OAAMI affiliate.



There are many programs administered by state and federal agencies which provide assistance to needy clients with mental illnesses. It is often frustrating for families when they attempt to access these assistance programs. There are complex forms to be submitted as well as documents from employers, physicians, etc. The client's casemanager is trained to assist the mentally ill family member obtain the entitlements for which he/she qualifies. Use of a case manager or other resource people is adviseable as the cligibility rules listed below may change or interpretation may vary with individual circumstances.

#### STATE PROGRAMS

General Assistance (GA), Medicaid, Aid to Families with Dependent Children (AFDC), and Food Stamps are available through Adult and Family Services (AFS). You can locate the nearest AFS office by looking under Government Offices—State in the front of your phone book.

General Assistance—\$244.81° per month for a single individual

### Eligibility

- 1. Be unable to work due to disability for at least 60 days.
- 2. Present medical form available from AFS, signed by a doctor.
- 3. Demonstrate that there is no other means of support
- 4. Individuals applying for GA may possess up to \$50 in cash, and may own a car valued at no more than \$1500. Other resources are evaluated on a case by case basis.

5. After 1 year, client must apply for Supplemental Security Income (SSI), a federal program, if he/she continues to be disabled. AFS will assist clients to apply. However, if someone who applies for GA is handicapped or if the illness promises to last longer than 60 days, the applicant should apply for SSI immediately.

#### **Exceptions**

- 1. Ir.come earned in a vocational program can be disregarded. The earned income disregard shall be computed on gross earned income before any deductions. The first \$30, plus half of the next \$140 shall be disregarded up to a maximum earnings disregard of \$100 for each month of employment in an approved treatment or rehabilitation program; and a standard disregard of 14 per cent of the monthly gross earnings will be allowed to cover all work expenses, including the cost of transportation. Income earned at Sheltered Workshops is handled differently.
- 2. If an individual is living in a group home or residential program regulated by the Mental Health Division, \$30 per month personal allowance is returned to the resident. This money is returned directly to him/her unless some other arrangement has been made. For example, in some cases, residents arrange through AFS to have the home manage his/her money. Some individuals arrange for a daily allowance, others prefer to receive their money in weekly amounts. These arrangements are not automatic. They must be done through AFS using specific approved forms.



<sup>\*</sup>The figures given in this report are accurate as of September 1, 1988. Allotments and eligibility requirements change periodically. Contact your local service provider, your case manager, or AFS, VA, HUD, VRD, or the Community Mental Health Program for current information.

Medicaid—Medicaid covers psychiatric inpatient treatment at private community hospitals for short-term stays.

Eligibility

- 1. Clients eligible for SSI are eligible for Medicaid. Clients receiving GA are not eligible for Medicaid and receive medical care under the state medical program. The state medical program has a somewhat lower level of benefits than Medicaid which receives federal funds..
- 2. A case manager needs to make sure that the client has an open case with AFS.
- 3. SSI/Medicaid clients must complete re-determination if there is some unusual circumstance such as a change in disability or financial circumstances.
- 4. Clients must meet criteria for "Medically Needy Program". This means they are disabled and have medical costs due to this disability. The client will have to provide proof of medical expenses monthly. This procedure is sometimes referred to as "spending down."

### Food Stamps

Eligibility

- 1. All low income (resources of \$3000 or less if elderly or \$2000 or less if not elderly) and an annual income not exceeding \$7000.
- 2. Determination of benefit is based on income, shelter, care costs, and day care costs. Medical costs in excess of \$35 per month are paid for disabled or elderly clients.

Aid to Families with Dependent Children (Also known as Aid to Dependent Children [AFDC or ADC])

Eligibility

- 1. Single parent families and dual parent families if family can show that both parents need to be home. It is unusual that neither parent would be able to work. These situations are handled on an individual case basis.
- 2. As children reach age 3, parents are referred to the JOBS Program to help them re-enter the work force. The parent must prove disability to be exempt from this requirement.

#### **FEDERAL PROGRAMS**

Veterans Benefits (VA), Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), and Section 8 Housing are Federally funded programs. To locate the office nearest you, look in your phone directory under Government Offices—United States.

#### **Veterans Benefits**

Amounts of benefits depend on length of active duty or if disabilities are service connected.

Eligibility. Medical and monthly living benefits are available.

1. Applicants must show that they became disabled while in service. Some pension funds are available for disabilities which occur after service has ended.

There are also benefits for widows and widowers of service personnel. There are also medical benefits for those who become disabled during or after active service.

2. Apply through Veterans' Administration—1-800-452-7276.



#### Social Security Disability Insurance

Benefits come from Social Security funds. Apply through any Social Security Office.

#### Eligibility

- 1. Individuals must have paid Social Security Tax prior to being disabled or be a dependent of someone who has a Social Security Account. Exceptions to this rule apply when the applicant is under age 18 or is over 18 but has a disability which began before age 22.
- 2. Applicants must have worked in one half of the quarters during the ten years prior to becoming disabled.
- 3. There are numerous forms to be filled out. An applicant must supply hospital records and a letter from his/her doctor. A mental health case manager can help with the process. Applications are usually refused at first. It will be necessary to appeal the decision. Contact Legal Aid for assistance with the appeal process. One may also contact United States Congressmen and Senators to help with the appeal process.
- 4. If the recipient of SSDI is living in a residence program or group home which is regulated by the the Mental Health Division, he/she will receive a rebate (personal allowance) of \$51 per month. This money is paid directly to the client unless other money management arrangements have been.

#### Benefits

- 1. After two years on SSDI, clients become eligible for Medicare.
- 2. Benefit amounts depend on how much Social Security tax was paid. If the allotment is less than \$368/month, clients automatically qualify

for SSI so that the total is \$368/per month.

- 3. If an applicant is found eligible, he/she will receive a payment for the period of time since first becoming disabled minus 5 months.
- 4. If an individual is well enough to return to work, he/she may keep some of the benefits while trying to return to regular employment.

#### Supplemental Security Income

This money comes from the Federal General Budget but is administered by Social Security. When applying for SSI or SSDI, one applies for both. Applications are usually turned down the first time. A casemanager can assist clients in obtaining SSI.

#### Eligibility

- 1. Requirements are the same as SSDI but applicants need not have worked.
- 2. Applicants cannot have over \$1,900 in savings.
- 3. An individual receiving SSI can be eligible for SSDI upon his/her parent's retirement. In order to qualify for this, the individual must have been determined as disabled prior to the age of 18. If this is the case, the qualified applicant will collect benefits under the parent's account. This will not impact the parent's ability to draw on his/her own account. The individual will be eligible for Medicare following a waiting period.

#### Benefits

- 1. A Medical Card is issued which covers most medical expenses and medications. Payments for psychiatric hospital stays are limited.
- 2. The maximum one receives is \$368 per month. If an individual is receiv-

ing other income, SSI will be reduced so that the total is not greater than \$368.

3. Due to the low reimbursement rate and the large amount of paperwork, many physicians do not accept the Medical Card. (Clients must then apply for Medicaid through Adult and Family Services.)

#### **Subsidized Housing**

These are federally subsidized housing assistance programs administered through housing authorities and private developers in various counties throughout the state.

#### A. Public Housing Authorities

Public Housing Authorities are units of local government with the purpose of providing housing opportunities to lower-income households. They are the primary source of housing assistance in Oregon. Their programs are available only to persons earning no more than income levels specified by the federal government. Maximum income levels vary by area and are periodically revised. Local housing authorities can give up-to-date information on current income level maximums in the area. Persons participating in housing authority programs generally pay no more than 30 per cent of their incomes for rent and a utility allowance.

There are two main programs operated by housing authorities. One is traditional public housing in which the housing authority owns housing projects that are rented out to low-income households. The second major program is the Section 8 Existing Program. In this program,

residents find decent safe and sanitary shelter in the private market place. Residents pay no more than 30 per cent of their incomes for rent and a utility allowance. The housing authority pays the landlord the remaining amount with federal funds.

#### Restrictions

Housing authority programs are generally restricted to households earning less than 50 per cent of the area's median income. To qualify for assistance, the household must have two or more persons, or the resident must be elderly (age 62 or over) or disabled.

#### **Waiting Lists**

Almost all housing authority programs have waiting lists. It may take six months to three years to get to the top of a waiting list. Many housing authorities only take names for their waiting lists periodically so that lists do not become unmanageable.

#### Section 8 Housing

Housing authorities can supply a list of apartment buildings certified for section 8 housing.



### Housing Authorities in Oregon

Northeast Oregon Housing Authority PO Box 3357 La Grande, OR 97850 963-4497 (Serves Grant, Union, Wallowa, and Baker Counties)

Linn-Benton Housing Authority 1250 SE Queen Avenue Albany, Oregon 97321 926-4497

(Serves Linn and Benton Counties)

Clackamas County Housing Authority 13930 S Gain Street Oregon City, OR 97405 655-8267 (Serves Clackamas County)

Marion County Housing Authority 4660 Portland Rd. NE Salem, OR 97305 390-0500 (Serves Marion County outside the City of Salem)

City of Salem Housing Authority 360 Church Street SE Salem, OR 97301 588-6368 (Serves the City of Salem)

Housing Authority of Portland PO Box 13220 Portland, OR 97213 249-5591 (Serves Portland and Multnomah County)

Polk County Housing Authority PO Box 467 Dallas, OR 97338 623-8387 (Serves Polk County)

Umatilla County Housing Authority PO Box 107 Hermiston, OR 97838 567-3241 (Serves Umatilla, Wheeler, Gilliam, and Morrow Counties)

Housing Authority of Washington County PO Boλ 988 Hillsboro, OR

(Serves Washington County)



648-8511

Yamhill County Housing Authority

414 North Evans Street McMinnville, OR 97128 (Serves Yamhill County)

434-6571

Mid Columbia Housing Agency

606 E Second

The Dalles, OR 97058

296-5462

(Serves Wasco, Sherman, and Hood **River Counties)** 

Northwest Oregon Housing Authority (Serves Clatsop, Columbia, and

1508 Exchange Street

Astoria, OR 97103

325-4686

Tillamook Counties)

Coos-Curry Housing Authority

1700 Monroe

North Bend, OR 97459

(Serves Coos and Curry Counties)

Central Oregon Regional Housing

Authority

2445 Canal Blvd. Redmond, OR 97756

923-1018

(Serves Crook, Deschutes, and **Jefferson Counties**)

Douglas County Housing Authority

PO Box 966

Roseburg, OR 97470

673-6548

(Serves Douglas County)

Malheur County Housing Authority

759 Fortner Street

Ontario, OR 97914

(Serves Malheur and Harney Counties)

Jackson County Housing Authority

2231 Table Rd. Road

Medford OR 97501

779-5785

(Serves Jackson County)

Josephine County Housing &

Community Development Council

PO Box 1940

Grants, Pass, OR 97526

479-5529

(Serves Josephine County)



Klamath Housing Authority PO Box 5110 Klamath Falls, OR 97601 884-0649 (Serves Klamath and Lake Counties)

Housing Authority and Community (Serves Lane County)
Services Agency of Lane County
177 Day Island Road
Eugene, OR 97401
687-3755

Lincoln County Housing Authority PO Box 1470 Newport, OR 97365 265-5326 (Serves Lincoln County)

#### B. Indian Housing Authorities

Indian reservations are eligible for a special set-aside of housing units. Indian housing programs include both subsidized rental projects and home ownership programs. Specific information on eligibility and programs available in Oregon is available at these addresses.

Umatilla Reservation Housing Authority PO Box 1658 Pendleton, OR 97801 276-7544

Siletz Indian Housing Authority PC Box 549 Siletz, OR 97380

Warm Springs Housing Authority PO Box 177 Warm Springs, OR 97761

### C. Privately Owned and Managed Projects

There are many privately owned subsidized housing projects in Oregon. Some of these projects are owned by non-profit corporations; others are owned by for-profit entities. In these projects, residents pay no more than 30 per cent of their incomes for rent and a utility allowance. It is a good idea to be on more than one waiting list at a time. The housing authorities listed also have housing projects with subsidized rents.

#### Restrictions

Like housing authority projects, privately owned subsidized units must serve low-income households. Current income restrictions for the area are available from the local housing authority or from the housing projects. Residents must have two or more persons in the households, or, be elderly (62 or over) or disabled or handicapped. Projects listed for the elderly are often also available for non-elderly handicapped or disabled persons.



#### **VOCATIONAL SERVICES**

Vocational services in Oregon are provided by the State Vocational Rehabilitation Division (VRD), private, non-profit organizations, and some county mental health programs. To find out what is locally available, consult the local VRD or contact the local Community Mental Health Program. Look for these under Government Offices—State and Government Offices—County in the front of the phone directory.

#### Individual Programs

Individual programs vary but most share some common characteristics. Most programs use one or more of the following models:

1. Sheltered Workshops

These programs provide education, training and employment by securing subcontract work from the business community. The work is performed in the workshop. Workshops have had a history of working with people whose vocational functioning has been low. Workers receive intensive staff support and may be able to work from two to forty hours per week. Workers are frequently, though not always, paid less than minimum wage. Recently, many workshops have expanded vocational choices for people utilizing some of the other models discussed here.

2. Transitional Employment

This model secures work for individuals or groups of workers which is temporary and performed in a business (not workshop). Although the job is temporary for the worker, it

is viewed as permanent for the program so it they can continually expose clients to different types of work. Wages are paid by the employer, not the program. This model has been championed by Fountain House of New York City. Many programs have adapted portions, if not all of this model, to the special needs of their clients and business community.

3. Work Crews and Enclaves are included in the supported employment model. It is one in which an agency contracts to perform a service in the community. Workers are supervised by an agency staff person. The main difference between a crew and an enclave is that in an enclave, agency clients are performing similar work alongside nonhandicapped persons. In crews, there may be little, if any, contact with non-handicapped workers. Clients are paid by the agency and may or may not receive minimum wage.

4. Program Operated Business

In this model, an agency begins a business with the goal of generating sufficient funds to maintain it. Programs attempt to make the business profitable or at least self-supporting. Clients are trained in all aspects of the business. Some clients will graduate to similar positions in competitive settings while others remain permanently in program supported positions.



5. Supported Employment

Supported employment is a special program jointly funded by VRD and MHD. VRD funds services to train and place clients in jobs. MHD provides long term follow-up to help maintain clients in those jobs. Supported employment includes work crews and enclaves, transitional employment, program operated businesses, and individual placement. In this model, clients are placed in jobs in the community (or provided help in locating jobs), trained, and provided on-going emotional support, advocacy if needed, and training. Clients must be able to work a minimum of twenty hours per week in a nonhandicapped setting or one in which there is contact with some non-handicapped people. Once a client is in this system, he/she can access any of the aforementioned services as needed. This allows for normalized vocational experiences with support.

Funding for supported employment has been made available by the State Legislature jointly funded by V.R.D. and the Mental Health Division. There are only 100 slots for workers statewide with those slots allocated to only a dozen programs.

The most successful vocational programs offer a full range of services. They develop personalized vocational goals consistent with the client's values and skills, provide training, re-training and on-going support.

### **Work Incentive Programs**

Beginning in July, 1987, the Social Security Administration amended its rules to provide incentives to persons who continue to have a disability impairment to

return to work. These changes protect their status and therefore their entitlements to cash payments and medical coverage, until they can be reasonably expected to pay their own way and to purchase their own health insurance. Thus a person is able to retain SSI, SSDI, Medicaid, and Medicare benefits while working for an extended period of time.

Many people wishing to return to work who have a disabling condition and are receiving benefits (SSDI, SSI, General Assistance) can do so more easily than they could in the recent past. Some of the disincentives for returning to work have been removed in two of the three benefit programs. Generally speaking, people have less to fear regarding the possible loss of benefits associated with a return to work.

Clients receiving SSI and SSDI should consult the local Social Security office for information regarding any changes in the law which may impact eligibility. There have been major changes for persons receiving General Assistance which are extremely beneficial. For these persons there are a number of vocational programs which have qualified for the Income Poregard Program. This program allows persons to retain some of their earnings instead of having to pay back dollar-for-dollar earned income.

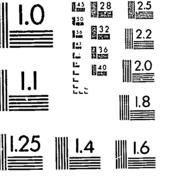
#### Questions

Questions regarding work for persons on SSI and SSDI can be addressed by the Social Security office. Questions about Income Disregard Programs can be answered by Adult and Family Service workers or by vocational program staff in your area.

<sup>\*</sup>A Summary Guide to Social Security and Social Security Income Work Incentives for the Disabled and Bling. Social Security Administration, SSA Publication #64-030 ICN 436900, July 1987.



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#### REFERENCES & SUGGESTED READINGS:

Connors, K.A., Graham, R.S., & Pulso, R. (1987). Playing Store: Where is the Vocational in Psychiatric Rehabilitation. Psychosocial Rehabilitation Journal, 10(3), 21-33.

A Summary Guide to Social Security and Social Security Income Work Incentives for the Disabled and Blind. A Social Security Administration, SSA Publication #64-030 ICN 4369000, July 1987. This publication can be obtained at the nearest Social Security Office.

**NOTES:** 

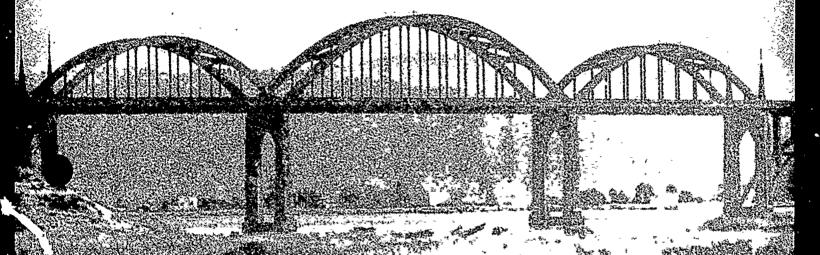


# VI. FAMILIES AND THE SERVICE SYSTEM

- •The Clients! Bill of Rights
  - Kights of Families
  - Confidentiality
- Effective Professional Collaboration with Family Support Groups

(A reprint from the Psychosocial Rehabilitation Journal)

• Estate Planning



### THE CLIEN'IS' BILL OF RIGHTS

(Adapted from the Lane County Mental Health Program).

#### THE CLIENT HAS THE RIGHT....

#### TO SERVICE

without regard to race, religion, gender, sexual preferences, ethnic background, or ability to pay.

#### • TO HIS/HER LEGAL RIGHTS

to vote, practice religion, or any other rights guaranteed by law.

#### • TO BE FREE

of physical or emotional abuse, neglect, or exploitation. from chemical or physical restraints. from arbitrary and unreasonable restrictions.

#### TO RECEIVE MEDICATION

only as prescribed by a licensed physician.

#### TO PRIVACY

to talk with any doctor, nurse, case manager, or other person. to send and receive mail which has been unopened.

#### TO MANAGE HIS/HER FINANCIAL AFFAIRS

#### TO A SAFE AND SANITARY ENVIRONMENT

 TO RECEIVE WRITTEN NOTICES OF RATE INCREASES AND EVICTIONS and to receive prompt return of security deposits and advance payments.

#### TO CONFIDENTIALITY

Communications between the client and therapists will not be disclosed to private parties without written consent from the client except when the withholding of information is in violation of a law.

#### TO PARTICIPATE IN TREATMENT PLANNING

to be informed of alternative treatment options, to be informed of treatment risks.

#### TO REFUSE TREATMENT

unless the court mandates otherwise.

#### TO EDUCATION

about illness and medications.



Institutional care for persons with mental illness was originally provided by states at state expense. The question of "rights of families" rarely came up. When the movement toward de-institutionalization gained momentum, there was an unstated assumption that care would be provided by the community, but adequate services for all those who have needed care have never become a reality. The lives of families have changed irrevocably as they have taken on more and more of the burdens of caregiving.\*

Although there has been continual growth in the area of "patients' rights" during the ensuing years, families, who have become primary caregivers by default, have no mandated rights. A vigorous family movement could change this situation. To stimulate our thinking, let's first hear the words of several NAMI leaders excerpted from a cicles they have written on the subject of the family:

#### THE FAMILIES' BILL OF RIGHTS

#### **FAMILIES HAVE A RIGHT:**

- TO EXPLICIT INFORMATION that families do not cause mental illness.
- TO BASIC INFORMATION ABOUT DIAGNOSIS, treatment plan options, and their costs, and an idea about the future course of the illness.
- TO INFORMATION ABOUT BEHAVIOR MANAGEMENT, advice and guidance about resources in the community, and the availability of peer support (AMI groups).
- TO EDUCATION that would assist in reaching a healthy level of adaption to a cruel illness.
- TO RESPECT FROM PROFESSIONALS for the expertise of the family, as well as a sharing of the power in the total therapeutic process.
- **TO BECOME APPROPRIATELY ASSERTIVE** and to overcome traditional socialization that teaches not to question authority.
- **TO BE INVOLVED** with the chronic patient as a support system and adjunctive resource.
- TO HAVE A SOCIAL ETHIC that is more concerned about a patient's welfare than costeffectiveness.
- TO A MANDATED ROLE on governance or advisory boards and a voice in mental health program planning that directly affects their lives.
- TO A NON-ADVERSARIAL LEGAL SYSTEM that is understanding of potential tragedy and helpful in attempts to prevent disaster from occurring.

<sup>\*</sup>Adapted from an article by Agnes Hatfield in *The Chronic Mental Patient*, ISBNO-8089-1649-1 entitled "The Family."



#### REFERENCES & SUGGESTED READINGS

- Hatfield, A. (1987). Systems resistance to effective family coping. *New Dimensions for Mental Health Service*, 23 (spring).
- Lefley, H. (October, 1987). Aging Parents as Caregivers of Mentally Ill Adult Children: An Emerging Social Problem. Hospital and Community Psychiatry.
- Lefley, H. The Role of Family Groups in Community Support Systems. Issue paper for the 7th NIMH-CSP Learning Community Conference, Rockville, Maryland, April 28, 1985.
- Report of the National Conference on Educational Approaches to Families of the Mentally III held February 26-27, 1987 in Arlington, Virginia, co-sponsored by NAMI's Curriculum and Training Committee. The American Journal of Family Therapy, 15(3), 1987.

**NOTES:** 



It is a fact of life that many severely mentally ill persons live with their families. or live apart but require continuous family help. Therefore, it is important that there be a trusting relationship between the family and the mental health professional for the benefit of the ill family member. Yet when professional treatment is available, families are frequently excluded from the treatment process under the principles of confidentiality. Added to that burden is the fact that professionals have often blamed families for causing the illness.

Families know the most about their relative's history of illness. They, therefore, rightfully expect to know the progress of treatment. During a crisis, when the ill person is out of control, family members are also experiencing the crisis and, at such times, need to know what is being done to help their family member.

#### THE DILEMMA

The legal principle of confidentiality is based on the privacy of information shared in the context of a client and therapist relationship. Such information is protected against disclosure to another party unless the client voluntarily indicates with whom such information can be shared. The problem arises when a family member is encouraged to assist the treatment of the mentally ill client, but the client refuses consent to share information. The mental health professional must address the legitimate need of family members to have information and cooperation, while at the same time, upholding the law and protecting the client's right to confidentiality.

#### **HELPFUL STRATEGIES**

- 1. Families should not be afraid to ask questions, share information, and give information. During the course of treatment there should be opportunities to have family meetings. This reinforces the appropriateness of professionals encouraging the client to give consent to release of information since the family is a supportive part of treatment.
- 2. Mentally ill clients are often willing to sign a waiver of the right of confidentiality if the request is made during a period of stability. But during periods of crisis, often clients are in no state to grant such a request, and those are often times when the family is most in need of information. Families should encourage mental health professionals to obtain the waiver from the client during the stable period. Then families can be a continuing part of the treatment process.

It is important to note that more than one waiver may be necessary. One should be on file with the hospitals likely to be utilized as well as with treating professionals.

3. Although confidentiality is the client's right, there is an overriding right of others to be protected. Such a situation occurs if an ill person should identify someone as a potential target of violence. If the clinician judges this threat to place the identified victim in immediate risk, he or she is bound to break confidentiality for the sake of protecting the potential victim.



This principle applies in the case of someone who says he intends to commit suicide. If such a threat is deemed to be imminent, then the therapist is not bound to preserve confidentiality. In both cases there may be a need to alert family, friends, and police in preventing a potentially fatal outcome. The right of confidentiality is superceded by the right to protection from others or oneself while in a disturbed state.

4. It is extremely important for the professional care provider and families to form an alliance based on mutual respect and cooperation. The sharing of information shows respect for the family as partner in treating an ill member. However, it is appropriate for all parties to be sensitive to the need for restricting information shared in such a way as to protect the privacy and integrity of the ill family member.

#### CONCLUSION

One of the most devastating aspects of mental illness is the sense of powerlessness it can create in families, friends, and clinicians. Family members want to offer help for their mentally ill relatives. They have information that contributes to a better understanding of the client due to their knowledge of historical facts, background data, symptoms and history, precipitating events, crisis warning signs, and much more. All of this information is crucial to good diagnosis and treatment. Having open and clear lines of communication is vital.

Hearing and responding to the family perspective is the basis for a cooperative treatment partnership to help the mentally ill relative. Although there are certain ethical and legal guidelines regarding confidentiality, the sharing of information can become a means of bridging and unifying concerned parties in treatment.

### References & Suggested Reading

Confidentiality: Information Barrier Bars Family Help for Mentally Ill. Alliance for the Mentally Ill of Tucson and Southern Arizona, 1987, 4(2).

**NOTES:** 



# Effective Professional Collaboration With Family Support Groups

# Richard T. Wintersteen Leslie Young

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Leslie Young, M.S.W., is Director of Community Support Services, Johnson County Mental

Health Center, Merrian, Kansas.

Abstract: Support groups for families of the mentally ill provide assistance for many people coping with the illness of a family member. Many groups have professional advisors who help them in various ways. Research and practice experience suggest that the roles that advisors play are different from the roles played by professionals in clinical group practice. Liaison must enhance the strength and vitality of groups. Based on research findings, guidelines for professional practice as a group advisor are presented.

The mutual help movement has emerged from needs of individuals and families facing major life crises. Such groups provide "information on how to cope with . . . problems; material help, if necessary; a feeling of being cared about and supported" (Silverman, 1980). They fill a need resulting from the common experiences of people facing disorganizing events such as serious illness or major economic or social dislocation (Gartner & Reissman, 1984; Katz & Bender, 1976; Lieberman & Borman, 1979; Gitterman & Schulman, 1986). These needs result from social distance caused by the gap between professional and client statuses, the reluctance of people to discuss such intensely personal problems in conventional social situations, and the deeply held (but perhaps inaccurate) feeling that others who have not experienced the crisis personally cannot truly understand.

Silverman (1980, p. 12) has identified several qualities that characterize mutual help groups, including these:

- (1) They develop an organizational structure, with officers, a governing body, and procedures for continuity of the organization.
- (2) The members determine all policy and control *all* (italics hers) resources they are both the providers and the recipients of the services.
- (3) Membership is limited to people who have the particular problem or problems with which the group is concerned.



- (4) Helpers are chosen because they have personally successfully overcome or resolved their problem.
- (5) There is a specific assistance program, which has evolved from the members' experiences in dealing with the shared problem.

By participating in a shared mission, members of self-help groups sense potential for power and influence (Silverman, 1980; Gartner & Reissman, 1984). Self help groups influence legislation (Berger & Neuhaus, 1977), the direction of community services (Lieberman & Borman, 1979; Piven & Cloward, 1976), and act to change stereotypes of people who lack intimate contact with the affected group (Norman, 1976; Hatfield, 1981). The increased sense of power and competence helps them to become effective advocates for patients, interact more effectively with professionals, and provide humane support for families with afflicted members.

Self-help groups differ from family groups organized and offered by professionals, including counseling and therapy groups and psychoeducational programs, in that members learn from each other, obtain leadership from among their own ranks, and value independence and autonomy. "Self-help groups are unique because their services are provided without cost, because support services are available spontaneously in times of crisis for families, . . . and because the groups exist as long as the families want them to exist" (Zirul & Rapp, 1987, p. 15-16).

Self-help groups vary in the extent to which they permit the participation of non-affected professionals. Unlike some self-help groups (for instance, Alcoholics Anonymous and other Twelve Step groups), professionals often maintain an active role with support groups for the mentally ill. Professionals often provide the impetus to launch a group, actively refer new members, and often maintain regular contact with the group. Research indicates that professional agencies and self-help groups establish positive, if not totally comfortable, relationships (Remine, Rice, & Ross, 1984; Deneke, 1983).

Potential difficulties between self-help groups and agencies include agencies minimizing the utility of groups (Remine et al., 1984), the tendency toward professional domination (Zirul & Rapp, 1987), and risks of rivalry (Powell, 1987). Equally important are the reservations that family members feel, based on previous experiences with professionals (Hatfield, 1981). These issues should not dissuade professionals and support groups from working together, but all parties must meet in an attitude of mutual understanding and respect.

### Self-Help and Support for Families of the Mentally III

The organization of the National Alliance for the Mentally III (NAMI) in 1979 has been identified as the central development in the adaptation of this modality to families of the mentally ill (Hatfield, 1981; Starr, 1982).



Family support groups provide a forum to share experiences, accumulate information, draw mutual support, and work to overcome community stigma (Hatfield, 1981).

The needs of families of the mentally ill are extensively cataloged in the literature. These include (among other things) the need for information about the illnesses and their treatment; effective coping strategies for families, and for the opportunity to express their feelings of fear, anger, grief, and confusion; and the desire to impact service systems on behalf of clients. The literature graphically describes the sense of distance and isolation from professionals experienced by many family members (Appleton, 1974, Torrey, 1983; Hatfield, Fierstein, & Johnson, 1982; Lamb, 1982). While blaming and stigmatizing attitudes from professionals seem to be waning (Wintersteen & Rapp, 1987), families still report evidence of "conscious or benign neglect" or being ignored (Zirul & Rapp, 1987). Families need information and advice, but often find professionals lacking when they turn to them (Hatfield et al., 1982; Wintersteen, 1986).

Family support groups "provide an opportunity for patients and families to express fears and concerns in a mutually supportive and understanding atmosphere since experiences and concerns are shared" (Rustad, 1984, pp. 236-237). McFarlane, Beele & Rosenhick (1983) describe multiple family meetings as a manifestation of "the time-tested value of banding together to cope with major chronic illnesses and traumatic events" (p. 244). The emergence of the self-help movement for families of the mentally ill has introduced a new dimension into the relationships between families and professionals (Hatfield, 1981).

The respondents (families with a mentally ill person) reported considerable merit to the help of friends, relatives, and groups members. In contrast, the various forms of therapy were valued little; nearly half found no value at all. These findings are better understood when needs of families are expressed. Of highest priority are understanding of the illness, practical guidance in patient management, and community resources such as housing. These are not typical functions of therapy. Self-help groups may meet these needs better (Hatfield, 1979, p. 563).

As part of a study of education in family support groups, members were asked to comment on the roles, actions, and attitudes of professionals who work with their support group. The observations of these members and information from other sources are presented here and refined as a set of principles for professionals who work with self-help groups.

#### Method

A series of psychoeducational workshops was organized by three chapters of Kansas Families for Mental Health. Each workshop was led by



a team of trainers, self-selected from the membership of the chapter. After a training process, the leaders organized workshops in the home chapters. The workshops were conducted during the fall, 1985, and others have been staged subsequently. Data reported in this paper were obtained through questionnaires and telephone interviews with each person.

## **Characteristics of Subjects**

Subjects of the study were 54 members of family support groups involved as trainers, trainees, or control group members. Women made up 70% of the subjects, and most participants were parents of the index patient. Almost all of the subjects were still actively involved with the lives of their mentally ill relative (only four subjects 7% indicated no role at all), including providing shelter (22, or 40% have their mentally ill child living with them), financial support, transportation, and other direct activities. They seem typical of the general population that make up family support groups for the mentally ill. The groups do not vary in the distribution of these roles (x2 = 5.36758, df = 10, n.s.).

#### **Findings**

Attitudes toward the Support Group

Respondents were first asked to discuss the extent of their participation in the family support group and attitudes toward it. Most were active members of the family support group in their community (see Table 1). They have been members from 1 year to over 15 years, and were active and regular in participation. They obviously valued it for their own growth and sustenance. As Table 2 suggests, they expressed considerable satisfaction with leadership and morale within the group.

Table 1
Frequency of Support Group Meetings and Attendance of Participants

	Twice A Month	Monthly	Less Than Monthly	Total
Frequency of Meetings of Participants	19 (38%)	31 (62%)	0 (0%)	50
Frequency of Attendance of Participants	16 (33%)	26 (53%)	7 (14%)	49



Table 2
Evaluation of Family Support Groups

		_	
(SCALE = 5 High to 1 Low) Issue	N	Mean	SD
How well are meetings run?	49	4.082	1.077
How is the morale of members?	49	4.388	0.909
Are your needs met by the group?	49	4.469	1.043
How important are the meetings to you?	49	4.510	1.063
How effective are the leaders? (Pretest)	49	4.388	1.057
How effective are the leaders? (Post-test 2)	46	4.065	0.854

These members recognized that they can become effective in the community and with professionals, as a group and individually (Table 3). When asked to specify the attributes that attracted them to the group, the most cited are information and support. When asked to propose priorities for further action, the list was more expansive and varied. Public information, outreach to new members, and political action were frequently reported activities.

Table 3
Members' Present and Future Group Function

Issue	Current Function	% Total	Future Function	% Total
Support to Members	50	58.2	19	16.1
Information for Members	31	37.2	14	11.8
Advocacy	4	4.6	19	16.1
Community Education	**************************************		21	17.9
Developing New Services			13	11.0
Attracting New Members			13	11.0
Monitoring Services			10	8.5
Operating Services		-	9	7.6
TOTAL	86	100	118	100.0



This point is important and instructive. Groups may go through a natural metamorphosis, in which, as the group matures, the focus moves from individual and family concerns to more action-oriented programs. There is both strength and risk in this. Families move through predictable stages of coping, and gradually turn from an inward to an outward orientation Terkelsen. 1987). As they come to accept the illness and move ahead, they need less support and more opportunities for positive action. The risk, of course, is that they may lose sensitivity to new members who still require support, information, and an opportunity to divest themselves of their strong feelings within an accepting context. For this reason, some groups have chosen to offer several different types of meetings, and to encourage active outreach to new members.

Respondents were asked to characterize their sense of power to influence services and their relative's treatment (Table 4 and 5). Subjects perceived the potential to become more powerful in the future and felt their situations to be far from weak and powerless ones. This finding is completely in line with other findings of this study, in that lay persons are showing a new sense of freedom and willingness to act.

Subjects expressed positive convictions about the potential of their groups to influence local services (See Table 6) through their commitment to public education and their intention to engage in political advocacy.

## **Professionals Working with Support Groups**

Over two thirds of respondents (38 of 53) were members of groups that had a professional advisor or liaison from a local service agency. It is notable that all but two (96%) supported the role of advisor and felt that it would be helpful to group functioning. They felt that the group advisor contributed information and served as a link to service providers.

On the other hand, it was clear that they expected the advisor to play a limited role in the group. They were highly critical of some professional advisors who had tried to dominate their group, and many said that they

Table 4
Ratings of Present and Potential Influence of Support Group on Local Services

	N	Mean	SD	. p	
Present	50	2.7400	1.332	0.000	
Potential	50	4.2000	0.969		

(Rated on a scale of 1 = Have No Influence to 5 = Very Great Influence)



Table 5
Perception of Present and Ideal Influence to Relative's
Treatment by Family Members

	N	Mean	SD	p
Present Influence	51	2.9412	0.968	0.000
Ideal Influence	51	3.6078	0.827	

(Rated on a scale of 1 = Have No Influence to 5 = Very Great Influence)

would have no hesitancy in "firing" an advisor who acted against expectations.

Group members perceived risks of professional involvement in three general areas — attempts to dominate the group, negative or patronizing attitudes toward families, and providing false or outdated information. Most members had never seen such responses, but they could envision such things occurring. In some cases, negative or unpleasant responses had taken place, making members vary wary. One group, for instance, chose to have no advisor because they were involved in an ongoing dispute with the local mental health program over allocation of resources for the chronically mentally ill.

# Table 6 Power and Requirements to Influence Local Services

A. Does your support group have the potential to influence local services?

YES

44 (96%)

NO <u>2 ( 4%)</u> TOTAL 46

B. What will your group need to do in order to have that influence?

	%'\$
Political Action/Lobbying	43%
More Members/Strength in Numbers	24%
Community Education	26%
Setting Priorities/Identifying Targets	5%
Become More Aggressive	<u> 2%</u>
	100%
TOTAL	(42)



Another group nearly failed because of the involvement of an advisor. This advisor, while well-meaning, did not understand the difference between encouragement and control. The group sat in a circle while he very carefully answered questions and shared information. There was little or no sharing between members and all communication seemed to flow through the staff member. While almost thirty people came to the first meeting, by the third the attendance had dwindled to five. By the fifth meeting only three people attended, and they were very confused and frustrated. They decided to move the meeting away from the mental health center (a location that had had associations for some prospective members) and detach from the advisor. They moved into a church hall and began to operate on their own. Within 3 months the group had grown to about twenty members.

The difference in the groups' experiences can be found in the factor of leadership. In the original format it was a professional's activity. When the group was owned by the members and leadership was allowed to emerge from within that body, the group began to meet member needs and growth occurred.

On the other hand, professionals make a positive and even necessary contribution when they understand the role that they can best play. While professionals are often instrumental in getting groups started, and sustain them by means of referrals and other support, groups work best when staff keep to a background role. Members of one group arranged things so that the staff liaison attended only about every other meeting. Their sense was that members felt more comfortable when they were by themselves. They had a positive regard for the liaison, but could not avoid the concern that their anxious or angry comments would be viewed in a negative manner. Despite the efforts of the liaison to reduce these fears, it seemed to all that the best answer was her periodic absence. In this situation there did not seem to be some subtle message that families were sensitive to. Rather, it appeared that they were responding to more generalized concerns about stigma and blaming.

Another liaison staff member very new to the field was less of a threat to the older and more experienced group members. In fact, the staff member felt that he learned more from families than they did from him (at that point in his career). He found that they could tell him more about the feelings, concerns, and coping mechanisms of families than he very learned from previous training and experience. A role in professional education lies within each family support group. Since, until recently, professional literature has neglected mental illness from the viewpoint of the family, families are the best in vivo source of information on the subject.

One family group worked out an arrangement with a local medical school to expose residents in psychiatry to the news of family members. At each support group meeting, two students attended for the purpose of



listening, not participating. While some students responded with indifference and were clearly "putting in their time," others seemed quite interested and stimulated by the experience. Only a very strong, well-organized group should perhaps attempt this strategy. Strangers observing meetings could greatly hamper the group process, unless strong leadership and group cohesion exists.

One group moved from staff to lay leadership. The group had been established by a very competent and sensitive staff member, whose organizational skills and warmth had launched it. She made the decision to transform her role, and made it clear that she was abdicating the leadership position. The members initially resisted, pointing to contributions that she had made and how comfortable they were with her leadership. When she persisted, the group formed a nominating committee, chose officers, and reorganized themselves. They gradually acclimated themselves to a new relationship with her, in which they, rather than she, were responsible for the success of the group. She did not abandon them, but neither did she allow herself to be seduced by the appeals of the members.

Some groups have been able to find professionals who also have a mentally ill family member to act as advisors. Under these circumstances, the group gains the expertise of the professional, and the concern about the advisor's attitudes lessens.

#### Discussion

This study is limited to members of just one type of support group, families of the mentally ill, but it seems likely that many of the conclusions expressed here are applicable to other client populations as well.

Working with family support groups calls for new roles for professionals who serve as liaison with support groups. One set of tasks has to do with helping family groups organize, recruit members, and become known to the larger community. Community mental health centers might designate a staff member to provide consultation and support services to teach support group in their area. A by-product of this linkage is to keep agencies aware of the needs and experiences of families, since one advantage of having a professional in attendance at meetings is that it is potentially educational for the professional community.

The role of the mental health professional then becomes one of enabler, educator, and catalyst, rather than as leader and quasi-therapist to the group. The appropriate professional role to groups identifies opportunities for education and social action, and fosters their collective determination to get on with the tasks at hand. The enhancement of such powerful efforts is a old and respected tradition in mental health professions, especially social work (Mallory, 1984; Pancoast, Parker & Froland, 1983). Social work in this mode reaches back to its roots in settlement house and



neighborhood development activities. The community in this sense is not defined by geography but by mutual need and mutual concern.

The results of this study and the work of others would suggest certain principles that apply to the relationship between professionals and self-help groups. The list that follows is intended as a guideline for practice.

- 1) The appropriate professional role is as a liaison and resource person, not as a therapist. Support group members are there for mutual support, information, and social action, but not to receive therapy from the liaison person.
- 2) A knowledge of group processes is necessary in order to understand what is transpiring and to assist leaders in carrying out their tasks.
- 3) The liaison must become familiar with the literature of self-help groups before undertaking this role, in order to keep the group focused and to self-monitor personal performance.
- 4) Ownership of the group belongs to the members, and is not the service of any agency. Leadership emerges from the group and is selected by the group alone. The group alone is responsibility for its success and failure.
- 5) The liaison can help the group by supplying information, referring new members, and offering advice as appropriate. The liaison takes no action that extends the power of this role or conflicts with the basic purpose of the group.
- 6) The liaison and employing agency should be aware of the sensitivity of members to patronizing or stigmatizing attitudes and work to eliminate them from personal or organizational behavior.
- 7) The liaison must be able to tolerate the wide range of emotions that will be expressed, without becoming defensive, internalizing the comments, or attempting to support or rationalize the mental health system or the behavior of staff. They may clarify practices or policies as an explanation for events, but should do so in a way that avoids communicating judgement on a group member's words or feelings.
- 8) The liaison should understand that professionals have much to learn from families, and should be prepared (within the limitations of confidentiality) to serve as a conduit of information to colleagues. The liaison also works with other professionals to increase their awareness of and support for the group.
- 9) The liaison is aware of talented individuals who may serve on boards or advisory committees, so long as this function does not take leadership from the group.
- 10) Since social action is one-function of self-help groups, agencies should at least be aware that the group may monitor the pro-

grams of the agency. This should be seen as a legitimate function, and the agency should neither threaten nor manipulate the group. In fact, the advisor may be aware of a policy on a local or state level that is harmful, and request intervention by the family group.

#### Conclusion

Professionals play a significant, if backstage, role in facilitating the development of the family support movement. New families can be referred to groups in their area. Support group members can be involved as volunteers in agency services and community education. Professionals use their expertise and resources to help groups acquire strength and reach out to the community.

The family support movement in mental health has made considerable gains in this decade. The evidence suggests that groups are beginning to turn their focus outward, from a concern with responding to families in pain to a concern for better provision of services for patients and attacking

issues of stigma where they find it.

Concerns have recently been raised about the continued viability and strength of the movement. Lamb, Hoffman, Hoffman & Oliphant (1986) fear that family members may abandon advocacy for patients because of observed empathy from professionals. They are concerned about the prospect that family groups may lose their commitment to the pursuit of change, choosing to bask instead in the warm new relationship that they have found with professionals. The authors call for family groups to keep their objectives focused and the membership restricted to those who are in fact relatives of the mentally ill.

The evidence of this study suggests that this warning, while appropriate, may not be as urgent as the authors suggest. Subjects place an increasing priority on their own empowerment. "We need to stand up and bark," (Anonymous). They look to new agendas featuring social and political action, and see evidence of recent success to bolster their convictions. For example, the recent changes in one state's civil commitment law are, to a considerable extent, attributable to the lobbying activities of a statewide NAMI-affiliated organization, leading a grass roots effort where visible and articulate spokespersons for the movement were local citizens in pursuit of a cause. They take seriously their role as advocates for the mentally ill.

Professionals assist this movement by fostering its growth and independence. They encourage the development of lay leaders and local priorities. They do this while realizing that the group will monitor their performance and propose areas of improvement. They do so because they recognize that over time professional agencies and support groups week the same goals and share a common commitment. They recognize the support groups



provide a resource for services that is unique to their position, their strengths, and their continuing determination to provide quality care for their loved ones.

#### REFERENCES

Anonymous. Personal communication.

Appleton, W. S. (1974). Mistreatment of patient's families by psychiatrists. American Journal of Psychiatry, 31(6), 655-657.

Berger, P. L., & Neuhaus, R. J. (1977). To empower people: The role of mediating structures in public policy. Washington, D.C.: American Enterprise Institute for Public Policy.

Deneke, C. (1983). How professionals view solf-help. In D. I. Pancoast, P. Parker, & C. Froland (Eds.). Rediscovering self-Help: Its role in social care. Beverly Hills: Sage, pp. 125-141.

Gartner, A., & Reissman F. (1984). The self-help revolution. New York: Human Sciences Press.

Gitterman, A. & Shulman, L. (1986). Mutual aid groups and the life cycle. Itasca, Il: Peacock. Hatfield, A. B. (1979). Help-seeking behavior in families of schizophrenics. *Journal of Community Psychology*, 7, 563-569.

Hatfield, A. B. (1981). Self help groups for families of the mentally ill. Social Work, 26(5), 408-413.

Hatfield, A. B., Fierstein, R., & Johnson, D. M. (1982). Meeting the needs of families of the psychiatrically disabled. *Psychosocial Rehabilitation Journal*, 6(1), 27-40.

Katz, A. H., & Bender, E. I. (1976). The strength in us: Self-help groups in the modern world. New York: New Viewpoints.

Lamb, H. R., Hoffman, A., Hoffman, F., & Oliphant, E. (1986). Families of schizophrenics: A movement in jeopardy. Hospital & Community Psychiatry, 37, 353-357.

Lieberman, M. A., & Borman, L. D., (1979). Self-help groups for coping with crisis. San Francisco: Jossey-Bass.

Mallory, L. (1984). Leading self-help groups. New York: Family Service America.

McFarlane, W. R. (1983). Family treatment in schizophrenia. New York: Guilford.

McFarlane, W. R., Beele, C. C., Rosenbeck, S. (1983). New Developments in the family treatment of the psychotic disorders. In L. Grinspoon (Ed.) Psychiatry update: The American Psychiatric Association Annual Review, Vol. 2 Washington, D.C.: American Psychiatric Press, pp. 242-262.

Norman, J. (1976). Consciousness-raising: Self-help in the women's movement. In A. H. Katz, E. I. Bender (Eds). The strength in us. (pp. 166-174) New York: New Viewpoints.

Pancoast, D. L., Parker, P., & Froland, C. (Eds.), (1983). Rediscovering self-help: Its role in social care. Beverly Hills: Sage.

Piven, F. F., & Cloward, R. A. (1976). Social advocacy type: The National Welfare Rights Organization. In A. H. Katz, & E. I. Bender (Eds.) The Strength in Us. (pp. 49-54). New York: New Viewpoints.

Powell, T. J. (1987). Self-help organizations and professional practice. Silver Spring MD: National Association of Social Workers.

Remine, D., Rice, R. M., & Ross, J. (1984). Self-help groups and human service agencies: How they work together. New york: Family Service America.

Rustad, L. C. (1984). Family adjustment to disability in midlife. In M. G. Eisenberg, L. C. Sutkin, & M. A. Jansen (Eds.), Chronic Illness and Disability through the Life Span: Effects on Self and Family. (pp. 222-242). New york: Springer.

Silverman, P. R. (1980). Mutual help groups: Organization and development. Beverly Hills: Sage.



Starr, S. (1982). National Alliance for the Mentally III: The first two years. Psycl osocial Rehabilitation Journal, 5, 3-4.

Terkelsen, K. G. (1987). The evolution of family responses to mental illness through time. In A. B. Hatfield & H. P. Lefley (Eds.), Families of the Mentally Ill: Coping and Adaptation. New York: Guilford, pp. 151-166.

Torrey, E. F. (1983), Surviving Schizophrenia. New York: Harper & Row. (The "classic" book for families, although written with somewhat of an anti-professional bias).

Wintersteen, R. T. (1986). A pilot test of the families educating families model. Lawrence KS: University of Kansas, School of Social Welfare.

Wintersteen, R. T., & Rapp, C. A. (1987). Changes in blame and stigma against families of the mentally ill: Research findings and practice reform. Unpublished paper.

Zirul, D. W., & Rapp, C. A. (1987). Working with self-help groups: An instructional module. Lawrence KS: School of Social Welfare, University of Kansas.



Parents of the mentally ill must be unusually careful in estate planning to avoid losing their loved one's governmental benefits and to prevent potential invasion of the state for cost of care.

Every situation is unique. It is poor planning for individuals to use any type of form document from a stationery store or which may be developed by a group. A form may be good enough for 60 % of the population. But you may be one of the 40% who needs a really specific and customized plan. Overlay on top of that the situation that you are in, families of people who are mentally ill. That makes your situation even more unique.

Not just any lawyer will be able to handle this sophisticated planning. This is a very specialized area. Contact your local NAMI chapter to locate an attorney with the special training needed for this task. Friends you may meet there can possibly recommend someone who has expertise in this area.

An excellent resource to help you when you interview a lawyer for your estate planning, is a book by L. Russell, Alternatives: A Family Guide to Legal and Financial Planning for the Disabled. It contains the questions to ask when interviewing a lawyer about discretionary trusts, non-invasive powers, and other issues.

#### **Terms**

There are two types of estate planning-life planning and death planning.

Guardianships, conservatorships, and powers of attorney deal with situations occurring while you are alive. Wills, and usually trusts, deal with death planning -- what happens when you die.

Guardianship deals with personal care decisions, residential decisions, and medical decisions.

Conservatorship, also guardian of the estate, handles financial property and money management decisions. With both guardianships and conservatorships, a court appoints someone to make present decisions for an individual. In some states there are special commitment procedures that apply to guardianship of the mentally ill, and give the guardian the powers for commitments to hospitals and arrange for psychiatric treatment. These decisions do require court action. These procedures take away the rights of an individual and that is why the court is involved. Typically it is an involuntary proceeding. Often times it is confrontational. It might even get into a contested trial to determine whether this person needs a guardian to make his/her personal care decisions, or needs a conservator to handle his/her money. A conservatorship can be costly to set up and to maintain, but it does provide some protection for both the ward and the fiduciary who is making the decisions. A bond can be posted to make sure that no one misuses the money. The court is available readily to call into question anything that may be done. So a conservatorship for financial matters may be an answer which should be considered in lieu of a trust.

A will is a document which is in effect only upon your death to determine how you are going to transfer assets, to whom, and what the terms of that transfer are going to be.

Note: This paper was drafted from an audio tape of the workshop on wills and trusts which was presented at the NAMI Convention in Boulder, Colorado, July 1-4, 1988. The speakers were Craig Gordon, BA, JD from Tucson, Arizona and Charles Arnold, BS, JD from Phoenix, Arizona.



A trust is a very special legal form of ownership which divides the management and control from the beneficial ownership. The traditional and most central purpose of a trust is to provide management of assets. For example, you have an individual who isn't going to exercise good judgment in how to handle property. You want to put that property into a trust and designate a trustee to be the legal owner of the property, and to exercise management and control over that property, to determine how to invest the property, and to determine how the property is going to be spent for the benefit of the beneficiary.

Non-probate transfers of funds which do not require a will or a trust are as follows: life insurance, IRA tax sheltered annuities, joint bank accounts, and joint tenancy of real estate. All of these are forms of ownership of property which are contracts with a company or a bank in which you tell that company what you want to happen with that money.

Life insurance: You pay a premium and upon occurrence of a specified event, your death, the life insurance company agrees to pay a certain amount of money to somebody. You specify that person as the beneficiary. If you specify your handicapped individual as the beneficiary of your life insurance, that money goes directly to him/ her and doesn't go into any trust no matter if you already have a trust or if you have a trust in your will. This is a trap for the unwary. All these other forms of ownership need to be adjusted as well. If you have a POD account (a payable on death account) which names a family member, when you die, that money goes directly to that family member. If that family member is not capable of managing that money him/herself, you are going to need a conservatorship.

Worse yet, if that family member is on SSI, and receiving entitlements, he/she is going to be declared ineligible for those entitlements because he/she has suddenly acquired some money.

#### Wills

A will can be written by anyone who is a competent individual. This could include a mentally ill person. Even if there has been a guardian or conservator appointed, as long as any individual meets the tests required for writing a will, he/she can write a will. The basic test is that one has to understand the nature of a testamentary document—a document that takes effect upon death and determines the ownership of property. Individuals must understand the nature and extent of their property. And they have to understand who the natural objects of their bounty are. Who is their family who would normally inherit their property? If a person understands those three things, he/she can legally write a will.

A will is revokable and can be changed at any time before a person dies. A lot of people assume that a will is going to be something that will last forever. This is not necessarily true. If one spouse dies, the surviving spouse could change the will, remarry, and have entirely different goals in mind. You may want to consider that when you are writing a will. If you have children by a prior marriage, you may want to make provision for those children in your own will instead of just assuming that your spouse is going to take care of them.



#### **Trusts**

There are three parties to any trust. The first is the trustor or the grantor, creator, the settlor. These are all names for the person who owns the money first and sets up the trust is a contract between the settlor and the trustee. The trustee has to accept the contract and the trustee then becomes bound to carry out the wishes of the settlor. The trustee can be another family members or can be a bank or any private individual that you want to trust with this authority, and who is willing to accept this authority. The trustee will then manage the property for the benefit of the beneficiary that you have specified under the terms and conditions you have specified.

There can be trusts for a myriad of purposes with all kinds of different terms in the trusts. The horizon is wide open as to what you can do within a trust. The only limit to the terms of a trust are based upon not violating any laws or public policy. Lastly, a trust is of finite duration—it cannot last forever and it will eventually end when the properties are distributed free of trust to individuals known as the remainderment. These are the people who will eventually have the property to control as they wish. They could be grandchildren, they could be other family members, or it could be charity. A trust is kind of like your own private corporation, your own private holding company to manage your money after you are gone. You set the rules as to how you want that property to be managed. Primarily it provides management; secondarily it entrols the disposition of the property for a number of generations. You can, for example, designate that the property go to your son, then to you grandchildren, and ultimately to be distributed to your greatgrandchildren. And you can specify percentages any way you want.

A third and significant advantage to a trust is there are some possible estate tax savings. You can minimize the cut that the federal government would get by utilizing a trust. Another by-product of a trust is that it doesn't go through probate. It doesn't go through the costs (the lawyer's fees, the personal representative fees, the court costs) associated with having to probate an estate. This can be an illusory savings, because to set up a trust is often just as expensive as it would be to go through the probate. It is just a question of whether you want to pay the lawyer now to set up a trust or to pay the lawyer later to do a probate. Each situation is different. There are lots of good reasons to use a trust—a living trust. Or lots of good reasons to wait and set up a trust in your will, a testamentary trust.

Living trusts—also known as inter-vivo trusts—are trusts you set up while you are still alive. You can actually fulfill all three roles. You can be the trustor to set it up; you can be trustee to manage the property yourself; and you can be the primary beneficiary of your own trust, and manage your own property for yourself. The benefit of this arrangement is that when you die, the trust continues. A new trustee, a successor trustee, is named in the trust to carry on the responsibilities of the initial trustee.

A testamentary trust is a trust that you write in your will. It doesn't take effect until you die, and then it springs into effect with the trustee named in your will.

A trust can either be revokable, that you as the trustor-creator of the trust, can change, alter, or cancel; to which you can add more property while you are still alive; or you may make it an irrevocable trust. There may be certain tax advantages or reasons to make it so that you cannot change it.



A trust can be a stand-by trust. This means you set up the trust but don't put any money in, it or put only a small amount of money it in it to be funded later by life insurance, by subsequent gifts, by bequests from your will, and/or by other people. You may want to set up a trust for your handicapped child to be funded later by an inheritance from a grandparent or another family member.

One type of trust you may hear about is called a *sprinkling trust or spray trust*. This is a trust which has multiple beneficiaries and the trustee has the discretion to sprinkle the benefits among the beneficiaries as the trustee sees fit.

A grantor trust is the trust that you set up for yourself. A trust that you are the beneficiary of and you set it up yourself. Often you can be the trustee yourself, but you don't have to be. It can still be a grantor trust with someone else as the trustee.

A charitable remainder trust is a trust which has a charity as the remainder to eventually get some benefit. This has become a very popular estate planning technique because if there is an ultimate charitable beneficiary, you can get a present income tax deduction for the present value of that future bequest to charity. For example, if you put \$100,000 in a trust with you as the beneficiary of the income. But if when you die, that property is going to go to a charity, you will get a deduction, a percentage based upon your life expectancy for the present value of that future deduction. You can do that with a disabled family member as a beneficiary as well.

A spend thrift trust is a trust which cannot be accessed by the creditors of the beneficiary. This is something you want to include in a trust for your disabled family member because you don't want any creditor, such as the state, to be able to access those funds.

An informal trust is a "trust" which is no trust at all. This is where you may give property, or mention in your will that you give this property to your son and hope and intend that he will take care of his disabled sister. But there is no legal obligation. This is merely precatory language with which you hope that he will do that but there is nothing binding upon him to do so. It is not really a trust but is sometimes referred to as an informal or a precatory trust.

#### Substituted Judgment

When we are talking about a trust we are talking about a vehicle that is created in one's lifetime. You may ask whetner a family member can act as a trustee for a handicapped beneficiary? There is no problem with asking a family member to act as a substituted judgment maker for one important reason, and that is that your family member is more aware of your wishes and presumably more able to carry out your wishes as to the continuity of care of your handicapped beneficiary than anyone else. There is a down side in the potential conflict of interest. The issues are highly personal, unique, and specific and need to be discussed thoroughly with family members and a lawyer.

#### Wills and Testamentary Trusts

A will is a document that doesn't mean a thing until you die. If things are working well for you, if your family member is well cared for by you, or if your property is in your name, and your family member who is ill and perhaps receiving some supplemental benefits is doing fine, there may be no need to create a trust that will take effect immediately. It may be more sensible to think in terms of a testamentary trust to take effect later on when that contingency happens. If that contingency is your death or the death of your spouse as well, then perhaps that is



what the document should state. A testamentary trust is a vehicle to provide for somebody's substituted judgement contained in a will that doesn't take effect until you die. It is revokable because you haven't died yet so you can change it at any time.

#### Supplemental Trusts

If you have a net worth of 2.5-3 million dollars, it is easy to set up a trust, that says, "upon my death, this money is to be used to take care of my handicapped beneficiary."

Any trust lawyer can draw up that trust. The general mind-set of trust lawyers is to have the grantor put as much money as possible into the trust so that the handicapped family member will not run short of money. However, since most of us do not have that kind of money, a supplemental trust may be the choice of trust to make. A supplemental trust is one that is intended to provide for your handicapped beneficiary without jeopardizing whatever governmental benefits may be available to him/ her because he/she has no money. A basic social security disability (SSDI) is going to be payable to your handicapped beneficiary no matter what as a result of his/her disability. But some other other benefits, allotments, entitlements, have another qualifier and that is that you have to be "povertized." You have to not have any money. Therefore to qualify for SSI (Social Security Income), you must have no more than \$1900. To qualify for Medicaid one must be virtually "broke." These requirements are contrary to the idea of putting as much money into the trust as possible. The supplemental trust is way to try to impose your thoughts and wishes upon someone to try to carry them out and do so without jeopardizing whatever governmental benefits may be available. Contrary to a regular trust, a supplemental trust tells trustees not to pay for

the basics such as the care, support and maintenance of the beneficiary as a basic trust does. (Since a trust counts as an asset, a regular trust will disqualify the family member from receiving SSI or Medicaid. The family member must then "spend down" to qualify for these benefits.) Instead, the supplemental trust can be designated to go for such optional extras as a radio, a trip, or other items which governmental benefits don't supply. There is nothing illegal or secret about the terms of such a trust. It can state "up front" that it is the intent of the document to provide for the supplemental needs, not the basic support needs, of the handicapped beneficiary. In fact, the document will further go to instruct the trustee to do what he/she can to gather those benefits to make sure that the handicapped beneficiary qualifies for everything that he/she ever will be qualified to receive, and that the trustee only use trust funds for extra items. It may be preferable in such a trust to give the power of control to a family member instead of a bank. Ideally, the trustee should become familiar with available social services to make sure that the handicapped beneficiary receives whatever services are available in the community. This trustee, in a sense, also acts as a social service coordinator.

There is some other language in the document that is terribly important to use in order to qualify property as an insulated asset, and that is the discretionary aspect of the trustee's instruction. The trustee has to be told that it is in his/her discretion as to what supplemental things the money is to purchase for the handicapped beneficiary. Another paragraph in the supplemental trust can state that in the event that this trust is determined not to be valid, or that a governmental authority is able to invade the trust and use those proceeds to either offset the cost of care previously provided



or to disqualify somebody from getting future aid, then the trust terminates and is distributed to other family members or according to whatever the grantor's wishes were. It is important to include these terms in case the laws are changed and the terms of the trust no longer apply. The original grantor will have made provisions so that the estate will be distributed consistent with the his/her wishes rather than at the whim of the state or federal government. In the case of the supplemental trust, it is better to be specific, even to the point of redundancy. It is possible to be so specific because with the exception of the state of Louisiana, the grantor is under no obligation to provide for the handicapped family member. If fact, the handicapped family member can be totally disinherited giving all the money to someone else or to a charity. In order that the funds are not totally lost for the care of the mentally ill person, the state allows you to set up the supplemental trust any way you desire.

## Who should be a trustee? How should you choose a trustee?

One may select a family member or a corporate trustee. You can have more than one trustee. Generally, whatever you want to do is going to be alright. You may wish to appoint one trustee who is capable of negotiating the available service systems and another who can lend financial acumen to the management of your portfolio. There is a new industry of private guardians and conservators developing, institutional or corporate fiduciaries who can carry out your wishes in a more sensitive way than a bank.

#### **Summary**

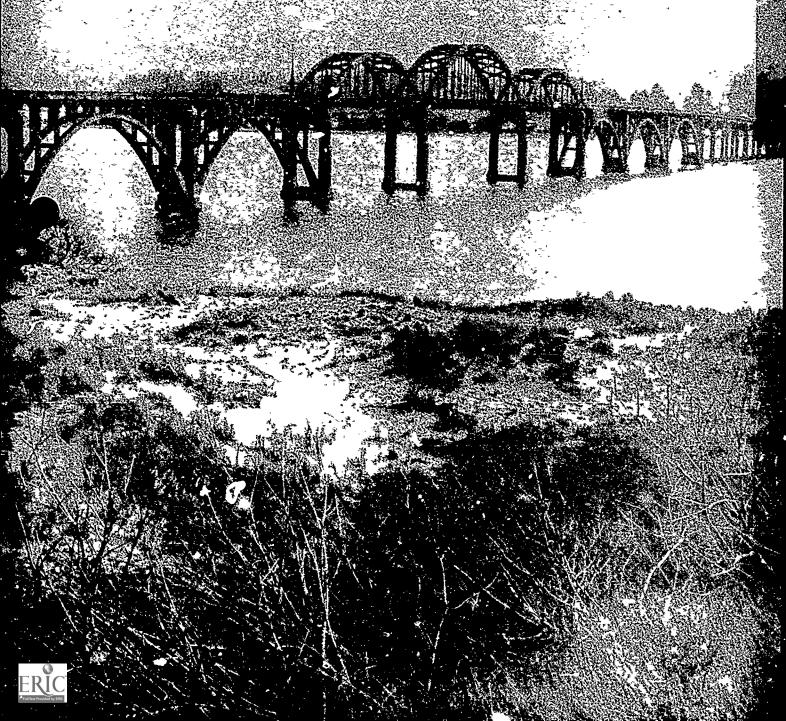
It is important to plan for your mentally handicapped family member now, whether you have funds to distribute or not. Contact your local NAMI chapter for help in finding a lawyer who is qualified to help you make these plans. Every situation is different. Arrangements you make now can be changed in the future if you decide to do so.

**NOTES:** 



# VII. VOLUNTARY AND INVOLUNTARY HOSPITALIZATION

- Psychiatric Hospitalization
   State Hospitalization
   A Family Member's Guide to Civil
   Commitment
- •The Psychiatric Security Review Board



## **PSYCHIATRIC HOSPITALIZATION**

At some point a person with mental illness may require hospitalization. To hospitalize or not is a complex decision. Each situation is unique; there is no "typical" situation on which to base a decision. Questions that a mental health professional may ask when considering hospitalization include the following:

- (a) What symptoms are being experienced?
- (b) Is there "acting-out" behavior? Is there danger to the individual or someone else?
- (c) Has behavior changed significantly in the recent past?
- (d) Is there some community program which can assist the mentally ill person without hospitalization?
- (e) Is the family no longer able to cope with the current situation on hand?

#### Types of Psychiatric Hospitals

An early decision which must be made is whether to use a state hospital, veteran's hospital, or private hospital. In 1986 there were approximately 17,050 admissions for people with psychiatric diagnoses in Oregon. These were distributed as follows:

State hospitals	4500
Veterans administration hospitals	2300
Private hospitals	
With dedicated psychiatric beds	9070
Without dedicated psychiatric beds	1180
	17,050

Note that private hospitals may or may not have what are called "dedicated psychiatric beds." Dedicated psychiatric beds are used exclusively or primarily for psychiatric care, and provide 24-hour medical and nursing service. Non-dedicated psychiatric

beds are used for all medical illnesses and may not provide a formal psychiatric treatment program.

In deciding which type of hospital to use, several factors need to be considered such as:

- (1) Is the person a veteran and does he/she meet Veteran's Administration eligibility rules?
- (2) Is the situation an emergency? Which type of hospital is closer?
- (3) Does the person have medical insurance which covers psychiatric hospitalization?

In considering financial issues, private hospitals usually charge about \$500 per day for psychiatric conditions. This does not include physician charges which are extra. The length-of-stay is usually short, often 5-10 days. It is important to know that individuals are responsible for their own cost of care in a state hospital to the extent that they can afford to pay. Charges range from about \$100 to \$170 per day depending upon the hospital and treatment program. This includes all medical care needed while the person is hospitalized. There are no additional charges. Although all the person's individual assets (trusts, insurance, cash), may be billed for cost-of-care in a state hospital, there is no parental or spousal responsibility to pay, even for their children.



#### Hospitalization in a State Hospital

Administrative Rule 309-31-210 adopted December 30, 1987 by the Mental Health Division lists the following criteria for admission to and discharge from state hospitals:

- (1) Admission Criteria:
  - (a) All admissions, voluntary and civilly committed, shall be limited to adults whose mental disorder is severe; and
  - (b) Need specialized care and/or treatment available in a state or other inpatient psychiatric hospital and not otherwise available to the patient in a community program. A patient needs hospital care and/or treatment if failure to receive it would result in serious harm.
- (2) Discharge Criteria:
  - (a) Mental disorder
    The superintendent or designee shall discharge the patient (whether voluntarily admitted or civilly committed) whose mental disorder:
    - (i) Is no longer present, in remission, or
    - (ii) Can receive appropriate care and/or treatment which is available to the patient in a community program.

However, a patient whose disorder is in remission should not be released if continued hospital care or treatment is needed to help the patient remain in remission for a reasonable time after release. There are thirty-one Oregon Revised Statutes (laws) under which a person may be admitted to a state hospital for the mentally ill. These statutes can be grouped into three types:

- (1) voluntary
- (2) precommitment holds
- (3) involuntary
  - a. civil court commitment
  - b. criminal court commitment

Voluntary hospitalization is just that. A person who voluntarily admits him/herself to a state hospital must be released within 72 hours of giving written notice of desire to be released. Parents of minors may voluntarily commit their child or guardian to a state hospital. They may also request written release of the minor within 72 hours. If the state hospital physicians feel that a person is too dangerous to self or others to be released, they may initiate a precommitment hold.

Precommitment holds are temporary involuntary hospitalizations which usually last five judicial days. Holds allow emergency treatment when a person is a clear and present danger to self or others due to apparent mental illness and will not seek voluntary hospitalization. Holds allow ime to stabilize the person, assess his/her mental and emotional state, and prepare for a civil commitment hearing if necessary. The state hospital may release a person at the end of the hold period if it appears he/ she does not require further hospitalization, or the person may be allowed to sign voluntary commitment papers and avoid a civil commitment hearing. Police officers, two physicians, the community mental health program director, or individuals may all initiate holds. If an individual, such as a family member, wants to initiate a hold, he/she needs to go to the community mental health center. (See "A Family



Member's Guide to Civil Commitment").

Involuntary commitment may be through a civil court or a criminal court. Civil courts are used when the person being committed has not broken a law or the offense is minor—for example, "disturbing the peace"—and no charges are filed. The civil commitment process is explained in "A Family Members Guide to Civil Commitment." If a mentally ill person commits a crime, his/her lawyer may choose to plead "not responsible by reason of mental disease or defect." The criminal court judge

then sends the person for a mental health examination, usually at the Oregon State Hospital. If the plea is successful, the person will be found "guilty except for insanity" and will be sentenced to the Psychiatric Security Review Board. (This process explained in the chapter entitled "The Psychiatric Security Review Board.") Contrary to popular belief, the "insanity defense" is not frequently raised. Out of 104,310 criminal court cases tried during 1987, only 85 defendants plead the insanity defense and only about 59% of these were successful.

**NOTES:** 



## STATE HOSPITALIZATION

The following state hospital programs are open to voluntary admissions of individuals who meet admission criteria:

Eastern Oregon Psychiatric Center—serves adults from 16 Eastern Oregon counties (see catchment area map)

#### Oregon State Hospital:

Adult Psychiatric Program (MAPL)—serves adults from Marion, Polk, Linn, and Benton counties

Geropsychiatric/Medical Services Treatment Program—serves statewide patients needing a nursing home level of care

Child and Adolescent Treatment Program—serves children statewide

Forensic Treatment Program—serves voluntary admissions who are dangerous offenders, and dangerous sex offenders, usually as a condition of probation

Dammasch State Hospital, serving 16 western Oregon counties, has been closed to nearly all voluntary admissions since July 1986.

For All Admissions: Purposes for hospital treatment include:

1. Safety--to keep someone from hurting themselves or others and/or to help them feel safe if they are very frightened.

- 2. To allow the doctor to quickly readjust the person's medicines and get their symptoms under control as fast as possible.
- 3. To help control the amount of stress the person's experiencing from the outside world.
- 4. To assist in understanding the kind of problems the person is having by such means as physical exams and other tests.
- 5. To provide treatment during the time when the person may not be willing to voluntarily accept help.

The hospitalization process is individualized for each patient, but include an admission-assessment phase, a treatment phase, and a discharge planning phase. During the admission and assessment, each member of the patient's treatment team (psychiatrist, psychologist, social worker, activity therapist, wurse) gathers information and completes an assessment of the patient's problems and strengths. team, along with the patient and if possible the family, develop a treatment plan, establishing the specific goals the patient should meet prior to discharge, and how hospital staff will assist the patient toward these goals.

Treatment may include medications, group or individual therapy, supervision and support in changing behaviors, recreational or occupational therapies, etc. The treatment team meets regularly with the patient and family if possible, to review progress and make any changes needed in the treatment plan.

As treatment progress is made, more attention is focused on discharge planning,



and identifying the patient's needs upon leaving the hospital.

Family Involvement in Hospitalization: The patient's family can be helpful during this hospitalization period in a number of ways:

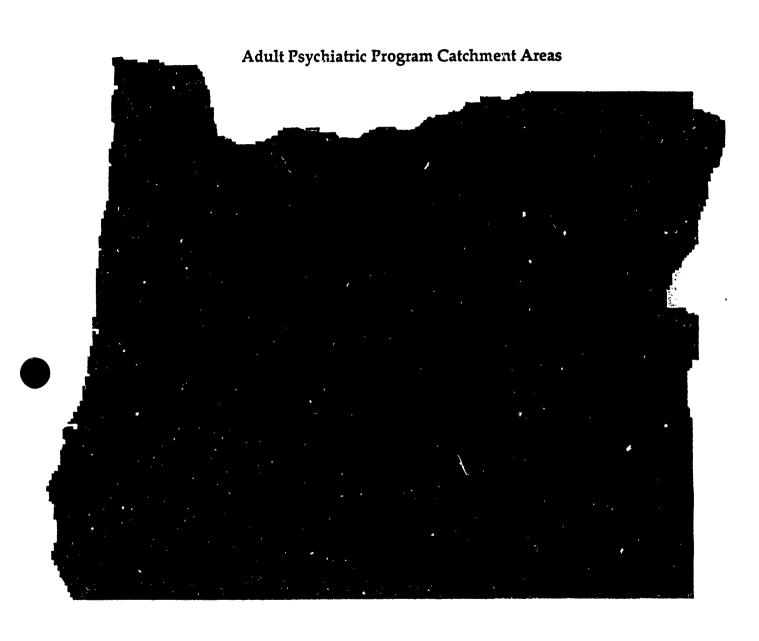
- 1. They can help explain to their family member why they must be in the hospital.
- 2. They can help the staff understand and plan treatment for their family member.
- 3. They can visit and help their lamily member feel more loved and cared for.
- 4. They can help their family member take medicine, talk about problems and do some daily activities because the person trusts them.
- 5. They can learn how to help their family member when he/she is discharged.
- 6. They can meet and talk with other families to help themselves cope better with having a sick family member.

In summary, the hospitalization process can be complicated involving decision making at several points along the way. The treatment process varies among hospitals. It is important for families to be involved in the treatment process. (See "Confidentiality.") A family experiencing the hospitalization process for the first time may need help in responding to the pressures and in making decisions. Families who have already experienced the process are willing to assist. By calling the nearest OAAMI chapter, families can get the help they need.

For further information, consult the NAMI reading list. These and other materials are available from the OAAMI affiliate.

Adult Psychiatric Program Catchment Areas On Following Page







Oregon State Hospital



Dammasch State Hospital



Eastern Oregon Psychiatric Center

## A Family Member's Guide to Civil Commitment

The purpose of this article is to assist family members in navigating the complex legal process known as civil commitment. One is confronted with a sea of legal procedure when a family member is in need of involuntary psychiatric treatment. The shores can be rocky; fraught with frustration, emotional pain and confusion. It is important to remember these points during this time:

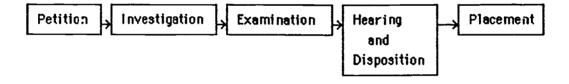
- 1. The purpose of civil commitment is to provide involuntary treatment and custody to persons who cannot or will not *voluntarily agree* to participate in mental health treatment that is required to protect the safety of the person or the public.
- 2. A person committed to the Mental Health Division retains his or her full civil rights including the right to refuse treatment. The Mental Health Division has the right to assign the person to an appropriate treatment facility without the person's consent, but must follow an involved and lengthy procedure before it can administer medication or any other medical procedure without the person's informed consent.
- 3. Civil commitment is a legal process not a clinical one. It is designed to protect the civil rights of the allegedly mentally ill person. At times, the logic of legal procedure is at odds with the logic of reasonable psychiatric intervention or the best wishes of family members.
  - Mentally ill people have a legal right to refuse treatment if they so choose, just as a person who has any other type of severe medical disorder has a right to refuse treatment. A person who is in desperate need of psychiatric treatment has a legal right to refuse treatment even though it may be in the person's best interest to participate in that treatment. The only exceptions are when a person is dangerous to self or others, or if the person is chronically mentally ill and is becoming dangerous to self or others.
- 4. The legal definition of mental illness is not the same as the psychiatric definition of mental illness. The legal definition of mental illness is composed of two parts: 1) the person must suffer from a mental disorder; this is the psychiatric definition of a mental illness; 2) in addition, as a result of that mental disorder, the person must also be one of the following:
  - a) dangerous to self or others, or unable to provide for basic personal needs and is not receiving such care as to provide for health or safety.
  - b) is chronically mentally ill (i.e. suffering from a chronic schizophrenia, a chronic major affective disorder, a chronic paranoid disorder or another chronic psychotic disorder) and has been twice civilly committed to a state hospital in the past three years and is exhibiting similar symptoms or behaviors to those that preceded one of the hospitalizations and unless treated will deteriorate so that the person will become a person described in paragraph (a) above.



130

This is a very complicated definition. Family members must remember that before a person can be involuntarily committed the person must meet the **legal definition** of a mentally ill person.

- 4. The civil commitment law gives no rights or special privileges to family members. A family member is regarded as any other member of the public. Neither love and concern for the mentally ill person, nor family ties are granted the right for special consideration in the process. The judge determines how much consideration is to be given family member's input. It is very difficult for family members to be in this position.
- 5. The mental health system has insufficient resources to provide care to all persons in need of them. Only the most severely ill persons are eligible for treatment. Even some of these people must wait on long waiting lists before they can be served. Once a person has completed the period of commitment, he/she may choose not to participate in mental health services, or these services may not be available for some time.
- 6. Civil commitment and the mental health system cannot guarantee the level of care and the degree of supervision which the family member may require.



#### An Overview of the Civil Commitment Process

There are essentially five steps in the civil commitment process. The filing of a petition with the circuit court starts the process. An investigation of the allegedly mentally ill person is then conducted by a certified investigator who is an employee of a community mental health program. The investigator then makes a recommendation to the judge concerning the need to proceed to a commitment hearing. If the judge determines to hold a hearing, the allegedly mentally ill person is examined by a psychiatrist or a certified mental health examiner. This examination is initiated prior to the hearing and may also occur during the commitment hearing. During the commitment hearing the judge hears all the evidence and makes a disposition of the case, a decision whether the person meets the statutory definition of a mentally ill person and therefore should be committed to the Mental Health Division. If committed, the Mental Health Division then assigns the committed person to an appropriate placement for care, custody and treatment.



#### The Petition

The civil commitment process begins when someone petitions the circuit court to commit an allegedly mentally ill person to the Mental Health Division for care, custody and treatment. A petition is initiated when a public petition is filed with the court or when a person is placed on a hold.

Two people file a public petition in the county where allegedly mentally ill person lives.

Any two people may file a petition with the community mental health program in the county where the allegedly mentally ill person resides. The community mental health program in turn notifies the court.

A peace officer or two-physicians at a hospital may place a hold on an allegedly mentally ill person, causing that person to be held in a holding room approved by the Mental Health Division. The community mental health program director or the director's designee, when authorized by the county governing body, may direct a peace officer to place a hold on a person. When an allegedly mentally ill person is placed on a hold then the person placing the hold files the petition with the court.

#### The Investigation

Investigation conducted by community mental health program.

The community mental health program interviews, or investigates, the allegedly mentally ill person and advises the court whether there is sufficient indication, or probable cause, that the person is mentally ill as defined by statute and whether a hearing should be conducted. The investigator must be at least fifty-one percent certain that the allegedly mentally ill person is in fact mentally ill in order to recommend a commitment hearing. Based upon the facts contained in this report, the court will determine the need to conduct a commitment hearing.

#### The Examination

Examination may occur prior to the hearing but usually occurs during the hearing.

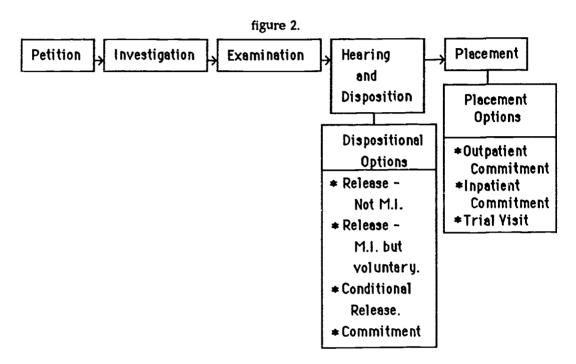
If a hearing is to be held, the court will hire an examiner, who is an expert witness, to assess the person's mental health. This examination of the allegedly mentally ill person is initiated prior to the hearing. Sometimes the examination occurs outside the courtroom or the entire examination may occur during the hearing; this depends upon how the judge wishes to conduct the hearing. The law requires the examiner to be either a psychiatrist or certified by the Mental Health Division. Only one examiner is required, but the allegedly mentally ill person or the defense attorney may request an additional examiner. There are never more than two examiners at the hearing.



#### The Hearing

The judge decides how the hearing is to be conducted; this will vary from county to county.

At the hearing the court will review all the evidence allowed by law. This includes the investigation report and the medical record for any prehearing period of detention (hold) that may have occurred. Witnesses may also be called; including family members, friends, or anyone else who may have pertinent information. Attorneys representing the allegedly mentally ill person and the state insure that both sides of the case are heard by the court.



The judge decides if the person is mentally ill as defined by statute and makes a disposition of the case accordingly. The court has four basic dispositions it can make. The person may be determined to be: 1) not mentally ill and released, 2) mentally ill but willing to voluntarily pursue treatment, 3) mentally ill but conditionally released to a caregiver (usually a family member), or 4) mentally ill and committed to the Mental Health Division for care, custody and treatment.

#### Length of Commitment

A person is committed to the Mental Health Division for a period of time not to exceed 180 days. The physicians at the hospital or other treatment facility may discharge the person from commitment and release the person from the hospital at any time they believe the person is ready. Families may not be notified of an early release. A person may also be released on trial visit which is described below.



133

#### **Placement**

The Mental Health Division assigns committed persons to their placement. Persons who are committed to the Mental Health Division are then placed in a setting that best meets the person's needs. The Mental Health Division may place the committed person in an inpatient setting, e.g. committed to a state hospital, or place the person in an outpatient setting. If the Mental Health Division, through the community mental health program director, places the person on outpatient commitment, then at the time of the hearing the community mental health program director establishes the conditions of placement. When a person placed in a state hospital has improved to the point where outpatient services are then appropriate the Mental Health Division, with the agreement of the community mental health director, may place the person on trial visit in the community.

More About the Specifics ... What To Do and What to Expect

#### PUBLIC PETITIONS.

Q: How do I file a public petition?

The following persons may file a public petition:

- Any two parties except the allegedly mentally ill person.
- Any magistrate.
- The county health officer.

Public petitions are filed with the community mental health program in the county where the allegedly mentally ill person resides. Check the telephone book for locations, or contact the Mental Health Division at 378-2460.

Oregon administrative rule requires that the community mental health program must attempt to divert the allegedly mentally ill person from commitment, if possible. This is the reason public petitions are filed with the community mental health program. The investigator will work with the persons wishing to file a public petition and the allegedly mentally ill person to voluntarily enroll the allegedly mentally ill person in mental health treatment if that is possible and appropriate. This may take some time.

Investigators are required to attempt to voluntarily enroll a person in treatment services before proceeding with an investigation.



Q: What happens when I sign a petition at the community mental health program?

Every opportunity is given the person to voluntarily participate in treatnient.

The investigator must contact the allegedly mentally ill person in three days, but has fifteen days to complete the investigation report. An extension may be granted by the court if the investigator cannot locate the allegedly mentally ill person or if a treatment option less restrictive than involuntary civil commitment is being pursued.

#### HOLDS.

Q: How do holds work in general?

A: The following applies to all holds:

Persons can only be placed on a hold if they are dangerous to self or others.

- Oregon Revised Statute 426.175 and 426.215 allows a hold to be placed on an allegedly mentally ill person if the person is dangerous to self or others and is in immediate need of care, custody or treatment for mental illness. No other commitment criteria are grounds for placing a hold on a person.
- Allegedly mentally ill persons can be held only in hospitals that have been approved by the Mental Health Division. Not every hospital is approved for this purpose.
- A physician must agree to admit the person to the hospital for the hold or the person must be released and the hold is no longer in effect.
- The hold lasts up to five judicial days. A commitment hearing must be held within five days of the commencement of the the hold.
- The hold may last less than five judicial days. The hold may be dropped before five days if the judge receives an investigation report recommending that no hearing occur and determines to release the person.
- The hold may last more than five days. The allegedly mentally ill person, the person's attorney or the attorney representing the state's interest may request that the judge



postpone the hearing an additional five days for time to prepare for the hearing.

- Once the person is admitted to the hospital on a hold, the person cannot be discharged from the hospital without the court releasing the hold. A physician cannot release the hold.
- A petition must immediately be filed with the circuit court for the hold to be complete. The circuit court is notified when a person is placed on hold by filing the Notification of Mental Illness with the court clerk. This is usually accomplished during business hours.
- It is up to the medical judgement of the physician whether or not drugs are to be administered involuntarily to the person on hold. Some physicians prescribe medication, some do not.
- The commitment hearing must be held within five judicial days of the placement of the hold. A judicial day is any day the court is in session. Usually judicial days are business days, 8 a.m. to 5 p.m., Monday through Friday. Weekends and holidays do not count as judicial days.

## Q: How does a Peace Officer Hold work?

Any peace officer may take any person the peace officer has probable cause to believe is dangerous to self or others and is in immediate need of care, custody and treatment for mental illness to a hospital which has been approved by the Mental Health Division. The hold is not complete until a physician who has admitting privileges at the hospital agrees to admit the person and the peace officer files the petition with the court.

The peace officer must see the person behave in a manner that is dangerous to self or others. The officer is not permitted to rely upon the testimony of others to establish probable cause.

Peace officers take a person on hold to the nearest approved hospital even if that hospital is in another city or county in the State of Oregon. If the hospital is more than one hour from where the person is taken into custody, then the peace officer must have a physician sign that the person is medically stable to travel to the approved hospital.



Q: How does a Two Physician Hold work?

A: Any physician, in consultation with another physician, may sign a hold at an approved hospital where the physician has admitting privileges. The consulting physician does not have to have admitting privileges, however.

Once the person is admitted to the hospital on a hold, the person cannot be discharged from the hospital without the court releasing the hold. A physician cannot release the hold even though that physician may have caused the person to be placed on the hold.

Q: Are there any other types of holds and how do they work?

A: A Director Initiated Peace Officer Hold is essentially a Peace Officer Hold. A community mental hearth program director or designee may direct a peace officer to place a hold on a person. Only community mental health program directors and the directors' designees who has been authorized by the county commission or other county governing body may be empowered to direct a peace officer to place a hold. This hold requires the director or designee to establish probable cause and to file the petition with the court.

A Warrant of Detention, strictly speaking, is not a hold. A judge can cause a person to be detained in a hospital on a warrant of detention if the judge believes the person is dangerous to self or others. Usually this occurs at the recommendation of the investigator who has interviewed the allegedly mentally ill person and has found the person to be dangerous to self or others. The investigator makes the recommendation in the investigation report but only the judge has the authority to issue a warrant of detention.

#### INVESTIGATION.

Q: Who is responsible for conducting the investigation?

A: The community mental health program in the county of custody is responsible for conducting the investigation. Only mental health investigators certified by the Mental Health Division may conduct investigations.



## Q: What is the purpose of the investigation?

A: The purpose of the investigation is to collect sufficient facts for the court to determine whether there is probable cause to believe that the allegedly mentally ill person is in fact mentally ill. The Court decides to conduct a commitment hearing based on the facts contained in the investigation report.

The Court may issue a Warrant of Detention to cause a person to be held until the hearing because of the recommendation made by the investigator in the investigation report. Therefore, another purpose of the investigation is to protect the person and the public if the person is dangerous to self or others.

The report also includes important information used by the state's attorney and the defense attorney to prepare for the case.

## Q: What is contained in the investigation report?

The investigation report includes only information pertinent to the current hold or public petition. The exception to this is if the person being investigated is chronically mentally ill and has had two civil commitments to a state hospital during the past three years, then the investigator can review medical records necessary to establish that the person meets the statutory definition for commitment as a chronically mentally ill person. Past psychiatric history cannot be included in the report except as reported by family or friends.

The report generally includes:

- a brief description of the reasons the person was placed on hold or a public petition was filed;
- a history of past mental or emotional problems, substance abuse history, and legal history as provided by the allegedly mentally ill person, family or friends;
- The names of all third parties interviewed and whether the allegedly mentally ill person consented to these interviews;
- information obtained from the admitting physician and hospital staff about the persons behavior and condition during the hold;
- information from family, friends and neighbors interviewed during the course of the investigation; and
- a mental status examination.



The report also states the investigator's opinion concerning whether the person is:

- suffering from a mental disorder
- dangerous to self or others
- unable to provide for their basic personal needs and whether the person is receiving such care as is necessary for health or safety

Family members do not have access to the investigation report. Q: Who gets a copy of the investigation report?

The statute specifies that the Circuit Court, the allegedly mentally ill person, the allegedly mentally ill person's attorney, the attorney representing the state's interests, and the examiners are the only persons who have access to the investigation report.

#### **EXAMINATION.**

Q: Who is the examiner?

A: The examiner is an expert witness hired by the court. Examiners are either psychiatrists or mental health professionals certified by the Mental Health Division to serve as examiners at civil commitment hearings. Only one examiner is required, and an additional examiner is available at the request of the allegedly mentally ill person or the person's attorney. The law is silent regarding whether a person can choose their examiner. The judge decides who will serve as an examiner.

Q: What is included in the examination report?

A: The Examination Report confirms that the person suffers from a mental disorder and that the person is dangerousness to self or others, or unable to care for self. The Examination Report includes a recommendation concerning the type of treatment best suited to assist the person to recover from mental illness and an opinion concerning whether the person would cooperate and benefit from voluntary treatment.

## HEARING/DISPOSITION.

Q: What happens at the hearing?

A: Exactly what happens at the hearings is determined by the judge. Each judge will hold the hearing in the judge's own style and



according to the judge's interpretation of the law. The basic flow of the hearing is as follows:

- The judge informs the allegedly mentally ill person of his or her civil rights.
- The attorneys and the examiners are identified for the record.
- The attorney representing the state's interests calls witnesses to present the facts of the case. Usually the investigator is the first witness called and questioned. People interviewed by the investigator including family, friends or neighbors are called as witnesses if the state's attorney desires. The physician who treated the person while on hold may be called as an expert witness.
- The defense attorney cross-examines all witnesses.
- The defense attorney may call witnesses and the state's attorney cross-examines these witnesses.
- The examiner(s) are allowed time to interview the allegedly mentally ill person in front of the judge unless the judge has allowed the examination to take place prior to the hearing.
- The examiners complete their reports and give them to the judge.
- The judge may ask questions of any witness or the allegedly mentally ill person during the hearing.
- Having heard all the evidence the judge makes a decision whether the person is mentally ill and makes a disposition of the case.

## Q: Who is required to attend a commitment hearing?

A: The commitment hearing is presided over by a Circuit Court judge. The following people required to attend the hearing:

- Allegedly mentally ill person
- Defense Attorney
- District Attorney, or other attorney appointed to represent the state's interests.
- Investigator.
- Examiner(s).
- Witnesses.

## Q: What evidence is allowed?

A: The judge determines what evidence is allowed. This point may be argued by the attorneys. Usually parts or all of the following are allowed into evidence:



- Investigation Report.
- Medical record for pre-hearing period of detention.
- Examination Report.
- Treating physician's testimony.

## Q: What are the dispositions the judge can make?

A: Dispositions available to the court are limited to these:

- Release-not Mentally III.
- Release-Mentally III but voluntary.
- Conditional Release. The conditions of placement are set by the court.
- Commitment to MHD for a period of up to 180 days.

## Q: What is the criteria for commitment?

There are two basic criteria for commitment:

- 1. Dangerous to self or others, or unable to provide for basic needs.
- 2. Chronically mentally ill and exhibiting the same behaviors as those that preceded one of two hospitalizations during previous three years.

#### ORS 426.005 states,

Commitment last

for 180 days.

- "(2) ' Mentally ill person' means a person who, because of a mental disorder, is one or more of the following:
- (a) Dangerous to self or others.
- (b) Unable to provide for basic personal needs and is not receiving such care as is necessary for health or safety.
- (c) A person who:
- (A) Is chronically mentally ill, as defined in ORS 426.495;
- (B) Within the previous three years, has twice been placed in a state hospital following involuntary commitment under this chapter;
- (C) Is exhibiting symptoms or behavior substantially similar to those that preceded and led to one or more of the hospitalizations referred to in subparagraph (B) if this paragraph; and
- (D) Unless treated, will continue, to a reasonable medical probability, to physically or mentally deteriorate so that the person will become a person described under either or both paragraph (a) or (b) of this subsection."



Q: What is conditional release and who can be caregiver?

A: A mentally ill person may be committed on conditional release if:

- The caregiver, who is a legal guardian, relative or friend, requests conditional release.
- The caregiver can care for the committed person in a place acceptable to the judge.
- The caregiver is able to care for the committed person and has the financial resources to provide the care.

ORS 426.280 (7) states, "Any guardian, relative or friend of a mentally ill person who assumes responsibility for the mentally ill person under a conditional release under ORS 426.125 shall not be liable for any damages that are sustained by any person on account of misconduct of the mentally ill person while on conditional release if the guardian, relative or friend acts in good faith and without malice."

#### PLACEMENT.

Q: What are the placement options?

The law states that the Mental Health Division is responsible for placement. Placement options at the time of the hearing include:

- Inpatient commitment to a state hospital or to a local inpatient facility. There are three state hospitals in Oregon that serve the mentally ill; Dammasch State Hospital, Oregon State Hospital, and Eastern Oregon Psychiatric Center.
- Outpatient commitment to a community mental health program; conditions of placement are set by the community mental health program director at the time of the hearing.

Once a person is stabilized at a state or local hospital the committed person may be placed in the community on trial visit under conditions of placement established by the state hospital.

Trial Visit



- Q: What happens if the person is still needing to be in the hospital at the end of their period of commitment?
- A: If the committed person is still mentally ill as defined by statute at the end of the period of commitment, then the hospital may request the court to continue the commitment for an additional 180 days. The committed person has an opportunity to contest this. If contested a recertification hearing is held before the circuit court and a disposition is made by the judge. There is no limit to how many times recertification can take place.
- Q: Can a person who is on conditional release, outpatient commitment, or trial visit be returned involuntarily directly to the hospital?
- A: No. The person must have a revocation hearing before the person is returned to the hospital against their will. Revocation hearings are initiated by informing the court that the person has violated their conditions of placement. The judge decides whether to hold a hearing.

The person, however, can be voluntarily admitted to a hospital. Once admitted on a voluntary basis, the person has the right to leave the hospital. The hospital must discharge the person within 72 hours of the request to leave. The hospital may initiate a revocation hearing or place the person on a hold if the physicians feel the person is dangerous to self or others.



Civil commitment is a very complex legal process through which mentally ill persons are provided involuntary care, custody and treatment. The process is designed to protect the civil rights of the allegedly mentally ill person. At times these protections may appear not to serve the best interests of the allegedly mentally ill person. Family members and friends, who want the best for their loved-one, are often frustrated by the legal constraints of the process and can feel alienated by it.

When a family member must pursue civil commitment on behalf of their loved-one the best place to start is the community mental health program in the county where the allegedly mentally ill person lives. The community mental health program will work with family members to help the allegedly mentally ill person to access the most appropriate treatment services available. The community mental health program will advise family members whether there is probable cause to pursue civil commitment. If commitment is not the course to take, the community mental health program will discuss the available options.

There are many intricacies of the law that may make civil commitment impossible in a particular situation. Working closely with the investigators at the local community mental health program will give family members the best opportunity to understand how the law applies in their particular situation.

Information that family members provide to the investigator for the investigation report is very important. It is the principle means by which their input reaches the judge. Family members should be prepared to testify at the commitment hearing, also. Many investigators will test the credibility or the sincerity of family members' information by their willingness to testify at the hearing. Many times the information family members have provided for the investigation report will not be allowed into evidence unless family members testify at the hearing. This may be very difficult for family members to do. However, the ability of the court to establish the facts necessary to commit the person who is desperately in need if involuntary psychiatric care may hinge on their testimony.

The legal seas of civil commitment can be successfully navigated to the benefit of the mentally ill person. It is important to understand the role each person plays in the process, the rights of the allegedly mentally ill person, and the limitations of civil commitment. The best interests of the mentally ill person must be the foremost concern of all participants in the civil commitment process.



# THE PSYCHIATRIC SECURITY REVIEW BOARD

The Psychiatric Security Review Board (PSRB) was created in 1978 by the state legislature to maintain jurisdiction over individuals who are found "guilty except for insanity" of a criminal offense. These offenses range from misdemeanors such as illegal use of a vehicle, to felonies such as murder. About 25% of the crimes committed by these individuals are misdemeanors. Persons under the PSRB jurisdiction range in age from 18-80. Most of these individuals are classified as indigent.

Courts sentence individuals who are under the Board's jurisdiction to the maximum sentence they would have received if they had been found guilty of their crime by a court. Most of the individuals under PSRB jurisdiction are placed in a state hospital (usually the Forensic Psychiatric Program [FPP] at Oregon State Hospital) for mandatory confinement and treatment. About 25% are placed on immediate conditional release in communities by courts.

Persons under the Board's jurisdiction are entitled to mandatory hearings and, in general, are represented by a state-appointed attorney. An Assistant Attorney General represents the state at PSRB hearings. Testimony is presented by treating psychiatrists and other witnesses. Written evidence is considered. The Board may commit the person to the custody of the Mental Health Division, conditionally release the client to the community with supervision and treatment, or discharge from jurisdiction.

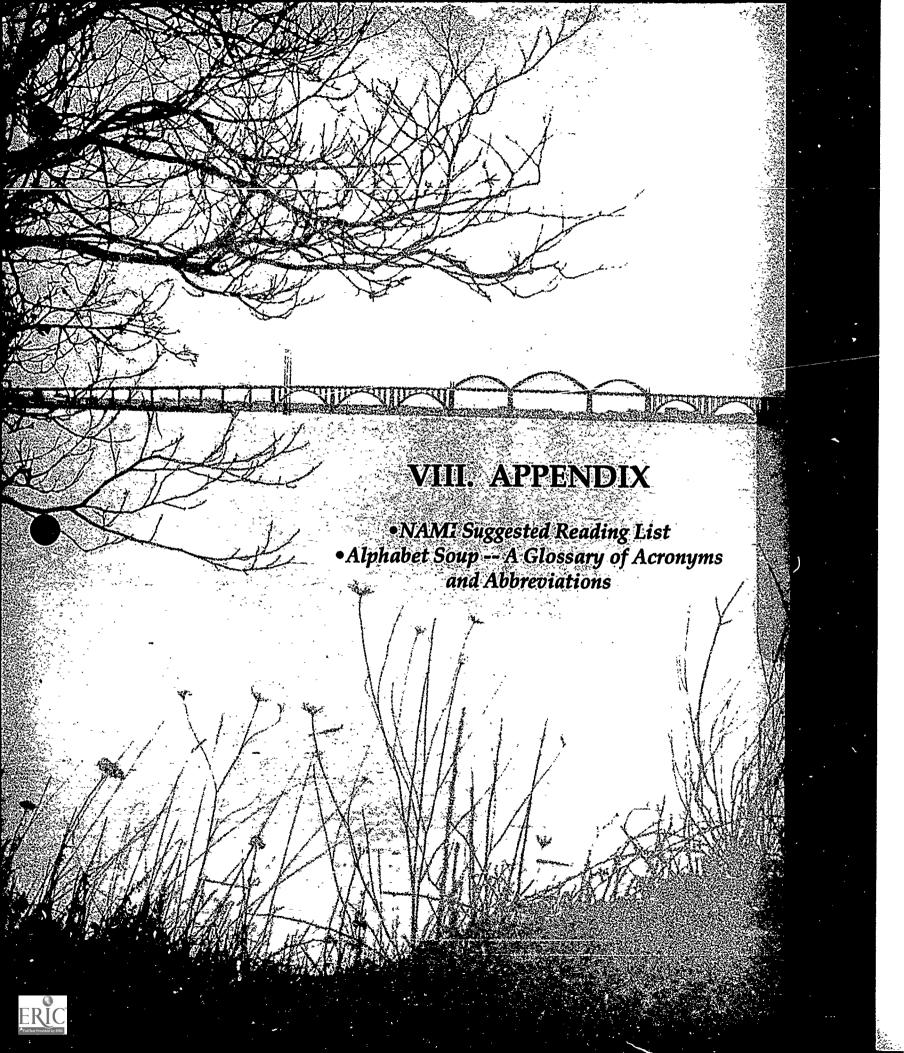
Individuals who are committed to the hospital receive treatment as do any other patients who are in the hospital. Those who are conditionally released are supervised by a designated case coordinator in the community. This coordinator may be a mental health professional or a probation officer. Client Progress Reports are filed with the PSRB on a regular basis. Conditional release orders usually require that the individual take regular medication, abstain from street drugs and alcohol, and participate in appropriate mental health services. If the conditions of the release plan are violated, or an individual experiences a decompensation in his/her mental status, the PSRB can revoke the release and return the individual to the hospital.

As of August 31, 1988, 450 people were under PSRB jurisdiction. Of these, 275 were on the units of the Forensic Psychiatric Program at Oregon State Hospital and 110 were on conditional release in the community. The remainder were in other situations, such as other state hospitals, Fairview Training Center or the Oregon State Penitentiary.

When an individual's jurisdictional time expires, the PSRB must release him/her. Also, individuals who are no longer found to be mentally ill, or if so affected, no longer present a danger to others, must also be discharged.

Family members of individuals who are under the jurisdiction of the PSRB have benefited from membership in a support and information group formed to meet the special needs of families of forensic clients. The Friends of Forensics was formed in November 1987 and meets regularly in Salem, Oregon. The group has developed an information packet for interested persons. For more information on this group, contact your local OAAMI chapter.





### NAMI RECOMMENDED READING LIST

(These books are available from NAMI)

#### Science and Research

Anderson, N. (1984). The Broken Brain: The Biological Revolution in Psychiatry. New York: Harper and Row. (Cloth, \$16.10)

#### General

Boston Foundation. (1987). Homelessness: Critical Issues for Policy and Practice. Boston: The Boston Foundation. (Paper, \$3.40)

Bouricius, J. (1987). Dealing with Drugs: Psychoactive Medications and Street Drugs: Their Good and Bad Effects on the Mentally Ill. Amherst, MA: Jean Bouricius. (paper, \$4.70)

## Depression

Greist, J. and Jefferson, J. (1984). Depression and Its Treatment: Help for the Nation's No. 1 Mental Problem. Washington, DC: American Psychiatric Press. (Paper, \$6.80)

Papolos, D. and Papolos, J. (1987). Overcoming Depression. New York: Harper and Row. (cloth, \$16.10)

## Schizophrenia

Torrey, E. (1988). Surviving Schizophrenia: A Family Manual (rev. ed.). New York: Harper and Row. (paper, \$8.50)

Walsh, M. (1986). Schizophrenia: Straight Talk for Families and Friends. New York: Warner Books. (PAPER \$3.40)

#### Children and Adolescents

McElroy, E. (1988). Children and Adolescents with Mental Illness: A Parents Guide. Kensington MD: Woodbine House. (PAPER, \$11.00)

Shields, C. (1987). Strategies: A Practical Guide for Dealing with Professionals and Human Service Systems. Richmond Hill, Ontario: Human Services Press. (paper, \$8.50)

# Families and Coping Strategies

Bernheim, K., Lewine, R., & Beale, C. (1982). The Caring Family: Living with Chronic Mental Illness. Chicago: Contemporary Books. (paper, \$7.60)

Dearth, N. et al. (1986). Families Helping Families: Living u. th Schizophrenia. New York: W. W. Norton. (cloth, \$12.75)

Garson, S. (1986). Out of Our Minds. Buffalo, NY: Prometheus Books. (paper, \$10.20)

Group for the Advancement of Psychiatry, Committee on Psychiatry and the Community. (1986). A Family Affair: Helping Families Cope with Mental Illness. New York: Brunner/Mazel. (paper, \$8.50)

Hatfield, A. (1985). Consumer Guide to Mental Health Services. Arlington, VA: NAMI.(paper, \$1.50)

Hatfield, A. Coping with Mental Illness in the Family: A Family Guide. Arlington, VA: NAMI. (paper, \$3.50)

Kantor, J. (1984). Coping Strategies for Relatives of the Mentally Ill (2nd ed.). Washington, DC: NAMI (paper, \$4.50)



147

## Legal and Financial Considerations

Russell, L. (1982). Alternatives: A Family Guide to Legal and Financial Planning for the Disabled. Evanston, IL: First Publications. (paper, § '.20)

#### Services and Facilities

Levine, I. Developing Community Support Services Programs: A Resource Manual for Family Groups. Arlington, VA: NAMI. (paper, \$5.10)

Uhlhorn, B. (1987). Creating a Caring Community: Developing Housing for Persons with Mental Illness. Arlington, VA: NAMI. (paper, \$10.00)

### For Professional Service Providers

Bernheim, K., & Lehman, A. (1985). Working With Families of the Mentally Ill. New York: W.W. Norton. (clorh, \$19.50)

Hatfield, A., ed. (1987). Families of the Mentally Ill: Meeting the Challenges. San Francisco: Jossey-Bass. (paper, \$11.00)

Hatfield, A & Lefley, H., (Eds.) (1987). Families of the Mentally III: Coping and Adaptation. New York: Guilford Press. (paper, \$17.00)

#### Personal Narratives

Kytle, E. (1987). The Voices of Bobby Wilde. Washington, DC: Seven Locks Press. (cloth, \$15.30)

North, C. (1987). Welcome, Silence: My Triumph Over Schizophrenia. New York: Simon and Schuster. (cloth, \$16.50)

Sheehan, S. (1983). Is There No Place on Earth for Me? New York: Vintage Books. (paper, \$5.90)

Shelter, H., & Straw, P., (Eds.) A New Day: Voices from Across the Land. Arlington, VA: NAMI. (paper, \$2.00)

#### **NAMI** Publications

Shelter, H. (1986). A History of the National Alliance for the Mentally Ill. Arlington, VA: NAMI. (paper, \$2.50)

## Videotape

News from Medicine: Peace of Mind. (1987) (60 min.) Atlanta, GA: Cable News Nerwork. (videotape, VHS [only], \$15.00)

When the Music Stops. (1987) (20 min.) Wilmington DE: The DuPont Company. (VHS [only], videotape and brochure, \$20.00)





ADAMHA News, published monthly by the Alcohol, Drug Abuse, and Mental Health Administration (publishes articles on current research); \$15/year. (5600 Fishers Lane, Rockville, MD 20857.)

Hospital and Community Psychiatry, published monthly by the American Psychiatric Association; \$35/year. (1400 K St., N.W., Washington, DC, 20005.)

Mental Health Reports, published biweekly by Capitol Publishing Co.; \$152/year. (1300 North 17th St., Arlington, VA 22209.) Since most affiliates cannot afford this publication, the Program Publication Committee suggests that you read this 8-12 page valuable update at your local library, mental health agency, or state hospital.

Psychosocial Rehabilitation Journal, published quarterly by the International Association of Psychosocial Rehabilitation Services and the Dept. of Rehabilitation Counseling, Sargent College of Allied Health Professions, Boston University, Center for Rehabilitation Research and Training in Mental Health; \$26/year. (1019 Commonwealth Ave., Boston, MA 02215.)

Schizophrenia Bulletin, published quarterly by the National Institute of Mental Health; \$16/year. (Supt. of Documents, US Government Printing Office, Washington, DC, 20402.P

Tie-Lines, published quarterly by the Information Exchange on Young Adult Chronic Patients (TIE, INC.); \$35/year to organizations; \$12 to individuals. (P.O. Box 278, Spring Valley, NY 10097.)

### NOTE

New information is being published all the time. Contact your local OAAMI chapter for information on new publications.

NAMI

2101 Wilson Blvd., Suite 302 Arlington, VA 22201 (703) 524-7600 Add 10% of total book order to cover shipping and handling.



# ALPHABET SOUP

# A Glossary of Acronyms and Abbreviations

There are many abbreviations which you will encounter when dealing with health professionals, hospitals, and informational material about your family member's disease. Some of these refer to technical medical terms. Others refer to names of medicines which may be prescribed. Many health professionals use these abbreviations without realizing that you may not know their meaning. You may refer to this glossary as you need or read it through. If you should encounter a term which is not in this list, do not hesitate to ask for an explanation.

AA Alcoholics Anonymous

ACSW Academy of Certified Social Workers

ACLU American Civil Liberties Union—The ACLU will intervene in cases when

the organization feels that an individual's rights or civil liberties have

been violated.

ADL Activities of daily living

AFC Adult Foster Care

AFS Adult and Family Services

AIDS Acquired Immunodeficiency Syndrome

AIMS Abnormal Involuntary Movement Scale—This scale is used to measure

the symptoms of Tardive Dyskinesia

AMA Against medical advice

AMI Alliance for the Mentally Ill

AMIP Alleged Mentally III Person—a term used to refer to a patient before he/

she has been committed to a program by a court.

ATR Art Therapist, Registered

b.i.d. twice daily

BS Bachelor of Science—Some RNs have completed a four year program and

receive a BS.



CASSP Child and Adolescent Service Program

CAT Computerized Axial Tomography as in CAT Scan. The CAT Scan is

used to examine the brain for lesions or other abnormalities.

C/ATP Child and Adolescent Treatment Program—a program at Oregon State

Hospital. A minor who is hospitalized will be placed in this program.

CBC Complete Blood Count

CCC Criminal Court Commitment

CMHP Community Mental Health Program—These programs are admini-

stered on the county level.

CMI Chronically Mentally Ill

CSD Children's Services Division

CSP Community Support Program

CTS Community Treatment Services for children provide evaluation, brief

intensive treatment and less intensive long-term supportive treatment

in outpatient settings.

DART Day and Residential Treatment Centers. These are run by Childrens

Services Division.

DD Developmentally Disabled

DO Doctor of Osteopathic Medicine whose degree is equivalent to an MD

degree and is a similarly licensed physician

DRG Diagnostic related groups—Hospitals must classify treatments into

these categories which are defined by the federal government. Medicare and Medicaid payments are dispersed according to this schedule.

DSM III R The Diagnostic and Statistical Manual, Third Edition, Revised—This

manual codifies classifications of mental illness. Your family

member's diagnosis is defined by this book.

**EEG** Electroencephalogram

**EOPC** Eastern Oregon Psychiatric Center

El: Emergency room

151



GA General Assistance—Income available from the Adult & Family

Services Division

GT/MSP Geropsychiatric Treatment/Medical Services Program—located at

Oregon State Hospital

HCFA Health Care Financing Administration

h.s. At bedtime

IM intramuscular—refers to drugs that are injected into a muscle

IV Intravenous—refers to drugs injected into a vein

JCAH Joint Commission of Accreditation of Hospitals—referred to as the

Joint Commission. The JCAH reviews and accredits hospitals accord-

ing to a specific set of standards.

LiCO3 Lithium Carbonate

LPN Licensed Practical Nurse—LPNs require specialized training in addi-

tion to a high school diploma. LPNs may dispense medications.

MA Master of Arts

MAO(I) Monoamine oxidase as in MAO inhibitors--See Medication and

**Mental Illness** 

MAPL Marion-Polk-Linn Treatment Program—a unit at Oregon State Hospi

tal which provides general psychiatric care for individuals from Mar

ion, Polk, Linn, or Benton Counties.

MD Medical Doctor—a doctor of medicine. MDs may be licensed to prac

tice medicine.

MED Mentally or Emotionally Disturbed

MHAO Mental Health Association of Oregon

MHD Mental Health Division

MMPI Minnesota Multiphasic Personality Inventory—a test used in

diagnosing schizophrenia.

MS Master of Science 152



MSE Mental Status Exam—used in evaluating the level of mental function-

ing. It is used when someone is committed against his/her will.

MSW Master of Social Work

NA Narcotics Anonymous

NAMI National Alliance for the Mentally Ill

NGI Not Guilty by reason of Insanity

NIMH National Institute of Mental Health

NIS Negotiated Investment Strategy—an agreement among providers,

counties, the Mental Health Division, and advocates.

NMRI Nuclear Magnetic Resonance Imaging—This machine produces a very

clear "x-ray" of the brain.

OAAMI Oregon Alliance of Advocates for the Mentally Ill

OAC Oregon Advocacy Center—receives federal funding as Oregon's "Pro-

tection and Advocacy System"

OBS Organic Brain Syndrome

OHSU Oregon Health Science University—the medical school in Portland.

The crisis unit there sees many chronic mentally ill people.

ORS Oregon Revised Statutes

OCH Oregon State Hospital

p.r.n. As needed, or as patient requires or requests

PHD Doctor of Philosophy—Many psychologists have completed both a

master's degree and a doctoral degree. They have clinical training and have completed research. PHDs do not prescribe medications.

PSRB Psychiatric Security Review Board

q.d. Once a day

q.h. Every hour 153



q.h.s. At bedtime

q.i.d. Four times a day

QMHP Qualified Mental Health Professional

RCSW Registered Clinical Social Worker

RCF Residential Care Facility—a group home for 5 or more with 24 hour a

day supervised care.

RN Registered Nurse—A registered nurse has attended nursing school

and completed licensing examinations.

Rx prescription

SHS Supported Housing Services - formerly known as SILP

SIL see SILP

SILP Semi-Independent Living Program—created in 1983 by Mental Health

**Division** 

SRF Salem Rehabilitation Facility

SSD Senior Services Division

SSDI Social Security Disability Insurance

SSI Supplemental Security Income

TD Tardive Dyskinesia—a side effect of some medications. Refer to the section

on Medication and Mental Illness.

t.i.d. Three times a day

Tx Treatment

VA Veterans Administration

VRD Vocational Rehabilitation Division

x times—as in medication instructions: take 3x daily