

**“Recovery Across the Lifespan: Unique
Aspects of Recovery for Older Adults”**

By

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This is a pre-conference paper prepared for the Recovery Conference scheduled for Dec. 16-17, 2004, at the Doubletree Hotel in Rockville, Md.

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Recovery from a mental illness is a journey!

This is a document on “Recovery Across the Lifespan” with emphasis upon the aspects of recovery for older adult consumers. For purposes of this paper, older adult is defined as a person 60 years of age or older.

This will be a report basically non-medical in nature, since others have written about the geriatric psychiatry evidence-based needs. It is based on my experience as a mental health consumer since 1974 when I was diagnosed with bipolar disorder, a local support group's facilitator and a leader for the Depression and Bipolar Support Alliance (DBSA) and the National Alliance for the Mentally Ill (NAMI) for 16 years. In addition, I have held numerous volunteer and advocacy positions during the past 26 years in state and national organizations and government agencies. I have been a member of the Older Adult Consumer Mental Health Alliance (OACMHA) for five years.

I was particularly proud in 2002 to receive the “Lionel Aldridge Award for Exemplary Consumer Leadership.” It is the highest consumer award given by NAMI, and I received it at the 2002 National NAMI Conference in Cincinnati, Ohio.

However, none of my education and volunteer experience completely prepared me for my role as an “older adult consumer.”

Covered below are some of my observations and suggestions regarding unique aspects of recovery for older adult consumers who have suffered a severe mental illness (SMI) during their lifetime.

I. Older persons -- a population at risk

The population aged 60 and older is this country's fastest growing age group. It is projected that it will represent 25 percent by the year 2020. Such a rapid growth results in ever increasing demand for mental health services because it is at such high risk of physical and mental health problems.

-- 10 to 20 percent of this population have mental health problems that warrant professional intervention.

-- 10 to 15 percent of older people have clinically significant depression.

-- 2 to 3 percent are diagnosed with Major Affective Disorder or Bipolar Depression.

-- Suicide rates among the elderly are even higher than in the younger age group.

-- Existence of major psychological illness in the weeks before suicide highlights the necessity for active mental health outreach and case finding services for the elderly.

-- Severe senile dementia affects approximately 5 percent of the population 65 and over. By age 80, this rate increases to between 15 to 20 percent.

-- Up to one half of persons with dementia are affected by coexisting depression or psychosis.

-- The prevalence of mental disorders and behavioral disturbances in elderly nursing home residents is estimated to be more than 75 percent.

-- Older persons require the same mental health services as younger persons, including diagnostic services treatment planning, crisis intervention, psycho-therapy, etc., but these services must be tailored to their specific needs and circumstances. They also need specialized facilitative and support services such as outreach, home visits and transportation services. Comprehensive case management strategies are essential to facilitate their interaction with other community-based organizations and services.

Clearly, the older population requires immediate and special attention to be paid to its mental health problems and service needs. (1)

II. Myths about Mental Health and Older Adults

There are several myths concerning older adults and mental health. In order to improve access to appropriate mental health care for older adults, these must be addressed.

Myth 1: Older adults are like everyone else. Therefore, they don't need specialized adult services.

The nation's mental health system is geared toward people who recognize they have a problem, seek out help, and hope to recover for work, family, etc. Many older adults don't fit into those categories. They don't seek help because they don't always know what is wrong except that they feel bad. Instead of going to a mental health center for help, they trust their primary doctors, many of whom are not confident about dealing with mental illness, or many older adults just don't seek help. Some may lack transportation to centers.

Older adults need people that understand older adults' specific psychological needs, complex physical problems and service supports. Older adults are more likely to have more than one problem. Unfortunately, people over 60 often know very little about mental health services available and where to access them. And most mental health workers have no idea how to reach out to older adults.

Myth 2: Older adults aren't overlooked; their doctors take care of them.

While one in five adults has a serious mental health problem, only one in twenty gets help. In older adults, the signs and symptoms of depression, anxiety and other mental illnesses are often entangled with physical problems. As one older adult says, "Mental illness in older adults has many masks." It can look like stomach problems, lack of energy, irritability, the flu, grief, loss of weight, lack of sleep, etc.

Therefore, many older people don't know what is causing them to feel bad. A survey by the National Mental health Association shows that 68 percent of adults over 65 know little or nothing about depression, so when they go to their doctor, they only discuss physical problems. Doctors miss diagnosing depression 50 percent of the time. In one study in Chicago, 80 percent of the people who committed suicide had seen their primary care physician within a few weeks before they died.

Myth 3: Depression is part of the aging process and, therefore, is no reason to think they will get better.

This is ageism. People expect older adults to be depressed or disoriented because of their age, their loss of family and friends or their sense of purpose. Doctors often confirm this myth by saying things like, "I would be depressed, too, if I were in your shoes." This just confirms the notion that

nothing can be done and those older adults should just accept feeling bad. No wonder older adults have the highest suicide rate of any age group. The truth is that older adults can be helped through counseling and medication and people over 60 have the same rate of recovery as younger people.

Myth 4: If you haven't had problems until now, you are safe.

Late life depression is more common than you might think. Many older adults become vulnerable to depression and other mental illness in connection with other physical ailments. Stroke, alcohol abuse, Parkinson's, cancer, arthritis, diabetes and Alzheimer's can all cause symptoms of clinical depression. Older adult caregivers are at an even greater risk for depression.

Myth 5: The effects of mental illness on older adults aren't really that bad.

Even though few older adults with mental illness are violent, the effects of the illness in people over 60 are just as deadly and costly to society. Older adults commit suicide at the highest rate of any age group. Every day, 17 adults over 60 commit suicide. For those who continue to live with mental illness, there are serious consequences. Older adults with mental illness are more likely to have physical problems and will spend two to three times more trying to deal with those problems and stay sick longer. People with depression are more likely to have strokes, heart problems and need nursing care early.

Myth 6: The present system is doing all it can to help older adults.

There are few mental health programs nationwide that have all the necessary components to serve older adults in their communities. Where these programs do exist, they have been overwhelmed with participants. The need for these programs is great. Medicare doesn't really help and actually discriminates against those with mental health problems. Medicare only pays 50 percent of the cost of outpatient mental health treatment, but pays 80 percent for physical health treatment. This adds to the present stigma and results in more expensive inpatient treatment. It is time for mental health parity in Medicare. (2)

III. Older adults as a separate and distinct culture and diverse community. The need for allocations and national standards.

It's apparent to the author after working as a volunteer mental health advocate for 26 years that older adults have been a minority culture but don't have a major mental health advocacy organization to advocate for the older adult population.

Issues specific to the older adult culture include retirement, fixed incomes, high suicide rate for white men over age 85, lack of geriatric-trained professions, and comorbidity of physical and mental health problems. Depression often co-occurs with other medical illnesses such as cardiovascular disease, stroke, diabetes and cancer. Because many older adults face such physical illnesses as well as various social and economic difficulties, individual health care professionals often mistakenly conclude that depression is a normal consequence of these problems -- an attitude often shared by patients themselves. These factors conspire to make the depression under diagnosed and under treated. (3)

Improved and increased collaboration between area aging agencies and local community mental health is needed to overcome the existing fragmentation of the mental health services system for older adults. Consumer access must be improved through education and the use of geriatric evidence-based practices to overcome age-related access barriers, stigma and denial. (4)

IV. The future years as “baby boomers” become “elder boomers” and the impending public health crisis

At least one in five people in the United States suffers from a mental disorder. By 2030, the number of people with psychiatric disorders in the over-65 age group will equal or exceed the number with such disorders in younger age groups (age 18 to 29 or age 30 to 44). Despite the growing requirement for mental health services for older people, there is a substantial unmet need.

Older adults with mental disorders are more likely than younger adults to receive inappropriate or inadequate treatments. Among the greatest challenges is the “expertise gap” that affects clinicians practicing in routine settings. This gap is the result of inadequate training in geriatric care and a failure to incorporate contemporary research findings and evidence-based practices into usual care. (5)

V. Twelve principles proposed by the Older Adult Consumer Mental Health Alliance (OACMHA) on which to base the mental health aging and treatment systems.

Recognizing the unique physical and mental health needs of older adults, OACMHA has proposed 12 principles, which are reprinted from Mental Health Weekly with permission from Manisses Communications Group Inc., on which the mental health aging and treatment systems should be based. The core principles are: (8)

1. Equality. All persons with mental health problems have equal access to treatment regardless of age, diagnosis, and the chronicity, severity or age of onset of the illness.
2. Recovery-focused care. Recovery, wellness and maximized quality of life are possible at any age and are the goal of prevention and treatment.
3. Self-determination and choice. Throughout the course of treatment, older adults with mental health problems (and their family caregivers when appropriate) are involved in all aspects of their treatment planning, including choice of providers, medications and treatment options.
4. Early identification and diagnosis. Medical examinations, mental health evaluations and psychosocial assessments of older adults by public and private health care and social service providers that include screenings for mental health disorders that are common among older adults.
5. Individualized, holistic care. Evaluation and treatments address older adults and their diverse needs in an individualized, holistic, non-fragmented manner, through timely delivery of services that are linguistically, culturally, ethnically and age-appropriate.

6. **Coordinated services.** Mental health, substance abuse, primary care, and aging service systems operate as one integrated and coordinated system at the federal, state and local level.
7. **Comprehensive community services.** Mental health and primary care systems and services include prevention, targeted outreach, early intervention, in-home treatment, recovery and aftercare services, with transportation services available as needed.
8. **Aging in place.** The need or change in level of need for mental health services does not precipitate an individual's move from the home environment. Every effort is made to allow individuals to maintain relationships with families, friends, peers and community supports and to include family caregivers in the decision-making process, when appropriate.
9. **Geriatric workforce capacity.** State officials promote and provide resources to maintain an adequate supply of multi-disciplinary geriatric mental health specialists who are specifically trained and have expertise in delivery of service to older adults.
10. **Sufficient standards.** Only service providers that meet required standards of care that include appropriate benchmarks and accountabilities are eligible for service contracts with and reimbursement by the publicly funded mental health system.
11. **State responsibility.** State and regional mental health authorities dedicate resources to maintain at least one full-time staff person responsible for developing and implementing a coordinated system of care that addresses the total health needs of older adults who have mental health problems, including degenerative brain disorders such as Alzheimer's and other dementias.
12. **Public education.** To counter misinformation, ignorance and stigma, federal, state and local mental health and aging authorities and organizations provide comprehensive community education regarding mental health, substance abuse and aging.

VI. The role of stigma in recovery for older adults

Initiating and supporting a public education campaign is important to address stigma and also educate consumers, family members, providers, and the public on the identification and the promise of effective treatments for mental health problems in older adults.

However, older adults must first overcome the self-stigmatization they often lay on themselves. Once I came to realize a mental illness was essentially a brain disorder, could be treated medically and it was similar in nature to other medical illness such as diabetes and hypertension, and after I quit "beating up" myself and quit trying to hide my mental illness, I could comfortably communicate to others and in public about my illness. I found a giant step forward was taken in my recovery when I quit stigmatizing myself. I actually found most people really didn't care about my mental illness unless they were also afflicted. Peer support groups were very helpful in this transformation.

VII. Sustaining recovery and improving coping skills. The importance and need to establish older adult consumer peer support groups.

Peer support groups:

- can help consumers understand and stay with their treatment plan and avoid hospitalization.
- provide a place for mutual acceptance, understanding and self-discovery.
- help consumers understand that a mental illness does not define who you are.
- give consumers the opportunity to benefit from the experiences of those who have “been there.” (6)

A “Later Life Group” support group for older adults is now operating in Colorado Spring and is facilitated by DBSA Colorado Springs. A portion of their information brochure follows:

“Mood Disorders in Later Life: the Growing Need for Senior Self-Help Support Groups”

I. Defining the need in your community

A. Demographics

1. Population percentage comprised of senior citizens
2. Number of senior support systems already in place
3. Number of retirement and assisted living facilities

II. Starting up your chapter’s “Later Life Group”

A. Group Dynamics

1. Start with your own pool of facilitators
2. No need to reinvent a new set of guidelines
3. Consider adding a professional advisor who specializes in geriatric psychiatry or geropsychology

B. Selecting a meeting place

1. Senior centers
2. Churches
3. Community centers

C. Advertising your meeting

1. Kick off with an initial public presentation
2. Utilize news media (local, senior and e-mail publications, Web sites, etc.)
3. Promote with flyers, specialized brochures, etc.

III. Maintaining growth, increasing visibility, and building credibility

- A. Directory listings, news media interviews, newspaper articles
- B. Get involved! Spread the word! Senior, health and informational fairs, etc.
- C. Assessing needs of group members through questionnaires/ surveys. (7)

New Hampshire's State Mental Health and Aging Consumer Advisory Council.

History

The State Mental Health and Aging Consumer Advisory Council was formed in 1998 following the first National Advocacy Consumer Forum. The three New Hampshire representatives to that Forum became the founding members of this group. They brought the idea of forming an advisory council dedicated to the needs of older adults with mental illness to the Division of Behavioral Health, Office of Consumer Affairs. The Council now consists over 50 members and continues to grow.

Purpose

The purpose of the groups is to act in an advisory role to the Division of Behavioral Health in its efforts to better understand and meet the mental health needs of New Hampshire's older citizens and their families. The group meets monthly to exchange information, study the issues and develop recommendations for change. Activities are organized into the following areas: Outreach, Education, Advocacy and Support. The Council members have participated in a number of projects and activities including: the Block Grant review process, the state annual Aging Conference, Real Choice Best Practice Conference, letters of support for grant proposals to CMS and SAMHSA, and networking with aging organizations such as AARP and OACMHA.

During the years, the Advisory Council has identified several areas related to mental health services that need to be addressed. These include:

- Caregiver and family supports
- Transportation
- Peer support programs
- Consumer education
- Public awareness and elimination of the stigma related to mental illness
- Substance abuse and medication misuse (increased awareness and services)
- Outreach to seniors at risk
- Improved communications between primary care physicians, psychiatrists and caregivers
- Seclusion and restraints

Existing peer support programs provide older adult mental health peer support outreach. New Hampshire has 15 peer support sites with most of them being under a 501-C3 not for profit status. They serve adults including older adults. This is now a very mature system with most of these sites being developed in the 1990s.

Peer support through these types of centers make a difference for seniors. Aging in place is important for most and this service can assist someone not only remain in their home but to have a good quality of life within their community. There are opportunities not only how to deal with their own recovery but to be there for others and engage in meaningful relationships. I have heard from older adult consumers say how important and meaningful their participation in these activities were to them.

Facts

- A. In 2000, more than 12 percent of Americans were 65 years or older.
- B. By the year 2020, one in six, or more than 16 percent, will be 65 years or older.
- C. In 2002, 4,989 older adults received mental health services through the 10 regional mental health centers in New Hampshire, a 16 percent increase since 1999.
- D. In New Hampshire, over 7,600 residents are living in nursing homes. Of those, about two-thirds have "some kind of mental disorder."

Membership

- A. Consumers
- B. Family members
- C. Community organizations
- D. State agencies

VIII. Concise finale

As stated at the beginning of this paper, recovery from a mental illness is a journey. The road for the journey can be very bumpy but ideally the consumer will find the journey becomes smoother as education, coping skills, a support group and good and timely medical treatment is provided.

Recovery may be necessary several times during a lifetime. Hopefully, complete recovery will be attained but sometimes less must be accepted.

An acceptable quality of life must be attained, including food, housing, clothing, socialization and volunteer work or paid employment.

And above all, maintain a positive, hopeful attitude, avoid suicide attempts and get help and support when you need it. Recovery can be complex like a puzzle. Put all of the pieces together in the proper order and the final product is better.

Addendum

Recovery: Pieces of the Puzzle

By Charlie Ross,
Lawrence, Kansas
November 2004

There are pieces of recovery from mental illness as I have experienced them in my own life. They are not meant to be strictly sequential, though to some degree they are listed that way. Nor are they considered to be discrete steps that are started and then finished before the next one is begun. Rather, they may require stops and starts and redoing over and over again through the process of recovery. Each of these stages of recovery may require days, weeks, months or years for different people in differing circumstances. Together, they comprise a very long journey; one that essentially takes a lifetime, for successful recovery from mental illness is an ongoing endeavor of the brave and noble realist.

Discovery

learning that something is “wrong” about or within yourself.

Identification

learning what it is that is wrong.

Understanding

Learning what the illness is all about.

Acceptance

Deciding/ choosing to accept changes to get better.

Stigma conquering

Overcoming prejudices and stigma to ask for help.

Doctor search

Finding and approaching the appropriate physician for help.

Medication search

Experimenting with meds to control symptoms under doctor’s direction.

Medication optimization

Settling on an effective med regime and making occasional changes as changes in symptoms warrant under doctor’s supervision.

Therapy discovery

Realizing the need to address secondary, psychological “injuries” from illness that are not directly corrected by medication.

Doctor matching

Possibly need to change doctor if medication regime fails to control symptoms for too long a period.

Therapy identification

Learning, possibly with help from the therapist, what specific problems or issues you would like to resolve.

Therapy acceptance

Finding your own reasons for doing the work to change; discovering willingness.

Therapist search and match

Finding a counselor you can be open and honest with and whose style and skills complement your needs so that you can identify and realize your objectives.

Therapy education

Learning how to function and succeed during and in-between therapy sessions.

Therapy success and maintenance

Enough of the major problems and issues are conquered and you develop survival and coping skills sufficient for stable, independent future life. You have learned to face and overcome problems in your life as they come.

Other recovery-related health issues

All other areas of life related to recovery, such as diet, exercise, substances, etc., are identified and realigned to ensure the best possible recovery and life.

Independent recovery

Having found effective medications and learned how to adapt them with doctor's guidance to maintain stability, and having learned in therapy the skills required to identify and manage life's challenges, problems and success, you may rejoin your interrupted life and pursue a rewarding future.

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