



NAMI

Cape Cod

The Nation's Voice on Mental Illness

Summer 2008

President's Message July 2008: LeRoy Spaniol, Ph.D.

What Would a Recovery-Oriented Program Look Like? Part III

In the last two issues of the newsletter I discussed the "recovery vision" and several components of a recovery-oriented program. In this issue I will discuss further components of a recovery-oriented program based on research, professional practice, family experience, and the lived experience of people with mental illnesses.

Availability of Primary Health Care

Consumers of mental health services die an average of 25 years earlier than the general public (Everett, Mahler, Biblin, Ganguli, & Mauer, 2007). Unfortunately, many medical problems of people with mental illnesses go undetected. And their health is further complicated by lack of attention, ignorance, poverty, and neglect. As Lauren Spiro Director of Public Policy, National Coalition of Mental Health Consumer/Survivor Organizations has said in a recent presentation at the 2007 National Wellness Summit for People with Mental Illness (Spiro, 2007):

Each individual's life depends on the society they live in and the services and supports that are available to them. To frame the co-morbidity and early mortality rate as simply a medical issue is not only inaccurate but an injustice to everyone. The problem of co-morbidity and early mortality is an indicator of a broken system within a broken society. The coalition was formed because the survival of our brothers and sisters is being threatened by the oppressive policies, services and attitudes of the system and of society. We die young because we have no hope. We die young because our dreams have been crushed. We die young because our voice is neither heard nor understood. We die young because many of us live in poverty, and some of us live on the streets. We die young because our physical health needs are routinely ignored, often because any problems we have are attributed to our mental illnesses.

Clearly, attention to basic health needs is critical in a recovery-oriented program as well as attention to other aspects of the person's life that threaten their health and wellness.

Interventions for the Psychosocial Impacts Prior To, During, and After the Acute Onset of the Illness

The onset of a mental illness is a trauma for the whole family, including the person with the illness. And with trauma comes shock, disorientation, panic, denial, and shattered lives. In addition there are the reoccurring traumas of living with a mental illness in our society. For example:

- People have to live with the daily impact of prejudice and discrimination.
- They often live with hopelessness and despair. People live with the perceived impossibility of recovery.
- They quickly lose faith in the mental health system.
- They are believed and come to believe that they are unable to have normal roles such as student or worker,
- There is often a long-period of recuperation that may last several years.

(cont. on page 2)

NAMI FAMILY-TO-FAMILY EDUCATION PROGRAM

Two Locations: Wellfleet and Centerville

Free for family members, partners, and friends of individuals with:

Major Depression, Bipolar Disorder (Manic Depression), Schizophrenia, Schizoaffective Disorder
Borderline Personality Disorder, Panic Disorder and Obsessive Compulsive Disorder
Co-occurring Brain Disorders and Addictive Disorders

This series of **12 weekly classes** is structured to help caregivers understand and support individuals with serious mental illnesses while maintaining their own well-being. This course provides the following: family response to the trauma of a mental illness; diagnosis and common symptoms; medications and their side effects; brain biology; how to cope with crises; self-care; the inner experience of having a mental illness; recovery from mental illnesses; community resources; and advocacy. The course is taught by a team of trained NAMI family member volunteers who know what it's like to have a loved one struggling with one of these brain disorders. **The NAMI Family-to-Family Education Program is free.** Over 80,000 people in the U.S., Canada, and Mexico have already completed this course. We think you will be pleased by how much assistance the program offers. We invite you to call for more information.

Wellfleet Classes Start: Thursday, September 4, 2008, 6:30- 9:00 p.m.

Wellfleet Council on the Aging, 715 Old Kings Highway, Wellfleet, MA 02667

Teacher: LeRoy Spaniol, 508-349-2475

Centerville Classes Start: Friday, September 5, 2008, 6:30-9:00 p.m.

Our Lady of Victory Parish Center, 230 S Main St. Centerville, MA 02632

Co-Teachers: Annette and Paul Foraste, 508-775-4636

**This course is for caregivers only.
Pre-Registration is required.
Course is limited to 24 persons.**

**This NAMI Family-to-Family Education
Program is sponsored by NAMI Cape Cod and
by the Mass. Department of Mental Health
through a special grant to NAMIMASS**

- PRESIDENT'S MESSAGE (cont. from page 1)
- People experience plateaus with the appearance of no progress followed by periods of integration and consolidation. Their normal developmental phases are interrupted.

Thus, many of the distresses people feel do not come from the illnesses but from the reoccurring traumas of living with a mental illness in our society. Interventions such as peer support groups, therapy, education, skill building, goal setting, and patience on the part of providers and families are required that support and understand the often extreme emotional responses to living with a significant and potentially long-term illness.

Respect People and Their Unique Process

Each person is unique and individual. No path is the same. Learn from the experiences of people with psychiatric disabilities. Assume people can learn how to lead their own lives. Given the information, skills, and support people can make life decisions. "Taking charge" is an important turning point in the recovery process. This is clearly evident in many research studies and from the recovery literature

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NAMI CAPE COD HAS ANOTHER SUCCESSFUL WALK

NAMI WALKS FOR THE MIND OF AMERICA, held on May 31, 2008 was a successful celebration for all the participants. Thanks to all our supporters, NAMI Cape Cod continues to be among the top fund raisers in the state.

Dear Members and Friends of NAMI Cape Cod,

Congratulations and THANK YOU for continuing your commitment to NAMI as Cape Cod once again has been among the top fund raisers. A special thanks to David M., Mary G., Madge Z., and Charlie and Cindy Sumner for being team Captains for our four teams, in addition to our Cape Cod office team. Our Affiliate, as of 6/24/ 2008, has raised over \$18,000. A special recognition is extended to the Sumner family for raising over \$5,000; Regina Aldhurst and Brian Ramsay for raising over \$3,000 each; and LeRoy Spaniol and the Cape Cod office for raising over \$8,000.

We also wish to thank our neighbor, Bob Samson at the Professional Driving School, at 5 Mark Lane, Hyannis, for their continued support.

Charlie Manning, Walk Director

NAMI Cape Cod

President's message (Cont. from page 3)

People, in their recovery process, tend to experience some variability in growth within the various developmental dimensions i.e., vocational, social, educational, emotional. People will show variability from others and within themselves over time. This variability can be a function of barriers or facilitators to growth such as quality of personal contact, opportunities, treatment interventions, resources, personal drive, resilience, personal successes, and other factors. It is interesting to note that level of achievement on the various developmental dimensions is not solely or simply related to level of symptoms but also involves successfully engaging a wide variety of barriers and facilitators to recovery. People can have symptoms that they are managing or struggling to manage successfully and still be growing in their recovery.

Value the Importance of Relationships and Connectedness

Personal stories of people with mental illnesses reveal a pervasive loss of interpersonal connectedness, loneliness, and isolation, yet a profound longing to be connected in meaningful ways to others (Davidson & Stayner, 1997). Yet people become so shocked by the illness, prejudice, and discrimination that they feel they cannot act on their own desires for contact. Providers, families, and peers can find opportunities for people to interact. Connecting can be very healing to the body and to the mind. Providers need to teach skills for selecting, building, maintaining, and repairing relationships.

Examples of rebuilding connections are:

- Oneself: Provide opportunities for building confidence/self-esteem through meaningful roles. Loss of "roles" devastates a person's sense of value and meaning.
 - Others: Provide skills and opportunities for developing sustaining friendships and intimacy. Loneliness is a major problem for people with mental illnesses. Foster an atmosphere of a recovery community.
 - Broader environment: Provides opportunities for social programs, volunteering, and work that help people feel a part of the community and connected to others.
 - Meaning and purpose: While developing larger meaning and purpose is helpful (e.g., spirituality), people also need to identify their own personal purpose in life. A personal purpose often involves activities or relationships which make people feel useful and valued.
- (Cont. on page 4)

PRESIDENT'S MESSAGE (CONT. FROM PAGE 3)

Value Involvement

Listen to what people say they need and want. Encourage people to be involved in all the decisions that affect their lives. They are their lives to live. Assume that people can participate in decisions that affect their lives, even when it does not appear that they can. Listening can seem to be a fairly simple skill. Yet our projections of what we think people need often get in the way of hearing what we are being told. To be listened to is to be respected.

Include Rehabilitation and Skill Building

Education and skill building are critical interventions. Focus on strengths. Help people to build a life. The tendency historically has been to focus on pathology. Focus on strengths builds up confidence and self-esteem. It provides an opportunity to be successful. Individualized goal setting provides assistance in setting personal goals and the steps to achieve them. Setting and working toward goals is an important part of the recovery process. Without ongoing goal setting programs are at risk of becoming sheltered workshops or social clubs and people are at risk of languishing in hopelessness. Rehabilitation provides skills and opportunities for developing job skills, finding work, maintaining work, developing a career, and continuing one's education. People with psychiatric disabilities have been found to be working at all levels of employment (Russinova, Wewiorski, Lyass, & Rogers, 2003).

Involvement of Family Members

Providers need to value family involvement and understand its importance in order to assertively reach out to family members. Programs can establish policy for family involvement, develop guidelines, train staff, and supervise staff in implementation (Bogart & Solomon, 1999). Program can encourage a collaborative alliance among all parties. Providers need to involve families in the planning, implementation, and monitoring of all interventions. Shared decision making can reduce the isolation and tension the various participants often feel. Decisions that are made are more likely to meet the needs, aspirations, strengths, and limitations of those involved. And, crises are more likely to be avoided or interrupted. Providers need to believe that families do not cause mental illnesses and that there is a substantial research supporting family involvement as useful to recovery. When family members are involved, people do better.

The Active Presence of Recovered People at All Levels of the Treatment and Rehabilitation Process

People need models and mentors, i.e., other people with a psychiatric disability who have succeeded in their lives. The active presence of recovered people is common practice in recovery programs for people with other disabilities. People who are more fully recovered can and do serve at all levels of mental health programs from directors to peer professionals. Programs are also being entirely run by peers. Peer support or modeling can be an important factor in helping people to cope, to feel that they are not alone, and to have hope for their own recovery.

REFERENCES

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NAMI CONNECTION RECOVERY SUPPORT GROUP

National Alliance on Mental Illness has started something new: NAMI Connection Recovery Support Group for persons with mental illness. The program will follow the same format nationwide so that a person with mental illness can find out from the NAMI.org web site the location and time of a NAMI Connection Recovery Support Group and participate nationwide. The groups meet weekly year round for ninety minutes, and are facilitated by persons who have mental illness themselves, and who have been trained as facilitators by NAMI National or NAMI Massachusetts trainer teams. Facilitators know how to encourage the group to make room for all in the group to listen to all, short-circuit personal sagas, and engage the group in subjects of collective interest, encourage collective thought, and circumvent griping by identifying common ground for real discussion among group participants. To encourage open discussion, only persons with mental illness, not anyone else without mental illness, are permitted to attend. In early May 2008, Brian Ramsay, Colin Walsh, Madge Zecker, and Paul Foraste from NAMI Cape Cod were trained in Boston by a team from NAMI National. We are currently setting up the weekly meeting location. Another training of facilitators by a team for NAMI National will be held in the Springfield, MA area in the fall of 2008. NAMI Cares is another monthly support group for the mentally ill. If a NAMI Care person desires to switch over to NAMI Connection, that is fine. If a NAMI Care group desires to continue without change, that is fine also. (See page 7 for date, time, and place)

By Paul Foraste

Legislative Breakfast Advocates for Mental Health Treatment for Children and Adolescents

NAMI of Cape Cod, in conjunction with Mass Society for the Prevention of Cruelty to Children and Cape Cod Hospital's Kids and Teens Assessment Center, hosted a Legislative Breakfast on May 16th in Hyannis. The meeting was to foster awareness that the current system is in crisis and failing to provide adequate treatment for children, adolescents, and their families. The discussion revolved around SB2518, An Act Relative to Children's Mental Health, which is currently before the Legislature. This bill provides for early screening for behavioral health issues, and creates a system to engage the schools in early intervention through funded training and support resources. It also encourages collaboration with pediatricians and other community professionals. Finally, the bill funds payment for services in the community, allowing children to remain in their own homes wherever possible.

The meeting was attended by over sixty people, including Rep. Sarah Peake and delegates from Sen. President Therese Murray, Sen. Rob O'Leary, and Rep. Demetrius Atsalis. The speakers included Laurie Martinelli, Director of Mass NAMI, Matt Noyes from Health Care for All, Dr. Tony Dingmann from KTAC, and Ray Tamasi, from Gosnold. The program was excellent and the family stories profoundly moving.

Advocacy is an important mission for NAMI Cape Cod. By remembering the obstacles we have overcome in securing effective treatment for our loved ones, we can be essential in the fight to hold the medical system accountable to improve treatment and recovery for those newly stricken with biological brain illnesses. Please contact your Legislator and ask him/her to support this bill. By Suzanne Sullivan

NAMI Cape Cod Annual Business Meeting

The Annual Business meeting and Speakers Program was held on May 29, 2008 at the Lorusso Conference center at Cape Cod Hospital. Chris Ebel introduced the Committee members for summaries of the past years work.

Chris Ebel completed an Outreach project by compiling many resources of information for NAMI members in packets to be distributed to area Churches, Psych Centers, psychologists' offices, etc. to get the **WORD OUT** that NAMI Cape Cod is available to make referrals for families and friends of those with mental illness.

Paul Foraste spoke about the new NAMI Connection groups that are being formed, as part of NAMI's commitment to supporting recovery for consumers. This new support group is in addition to the other support groups offered at NAMI Cape Cod.

Stella Thomson informed the members that our Membership drive for this year had been completed, with many new members joining online. The work done this year includes a new database system, which helps us in mailings and keeping our member list constantly updated.

New information has also been added on our website, and members were encouraged to visit our website, www.nami.org/sites/capecod and offer their comments or questions. The calendar on the website will list upcoming events, as well as all support group days, times, and locations. We also have volunteers in the office from 10 AM to 1 PM most week days to answer your calls and concerns.

Charlie Manning spoke to encourage all present to support the Annual Walk for the Mind of America.

Suzanne Sullivan informed the group that NAMI Cape Cod, in conjunction with other groups, held a very well attended Legislative Breakfast in May.

A question was asked about our Annual Budget, and we hope to print that in our next newsletter.

LeRoy Spaniol then introduced the evenings' speakers, **Donna Wilber and Lenny Mulcahy**, who presented information on the **Recovery Education Center at Boston University**. They described it as a continuing educational program providing courses to enhance the self-directed recovery of people with psychiatric disabilities. People register as students at the Recovery Education Center and are assigned an advisor who guides the students in selection of courses related to their self-determined goals. All materials, resources, and support are provided to ensure the successful completion of the courses and the goals of the students. Readiness development courses are available to students who are not yet ready to choose their goals.

The Recovery Education Center is guided by the non-negotiable values of hope, personhood, choice, self determination, and respect. People who have been diagnosed with serious mental illnesses are invited to collaborate with staff, many of whom self-identify as recipients of mental health services, to begin the process of recovery and healing from the many consequences of a psychiatric disability. Services are delivered using education as a framework because education immediately gives people a valued role—that of a student, rather than a patient, consumer, client, or a diagnosis. Recovery is an expectation at the Recovery Center.

The Recovery Education Center is not a traditional clinical environment, but maintains the highest ethical standards. The Recovery Education Center shares power with students, has high expectations, and learns with students as the Recovery Education Center supports their quest to be full citizens as healthy adults.

Will Power

If you would like to make a lasting contribution to the mental health of residents of Cape Cod, please consider a bequest to our grassroots organization that has made many strides in recent years in advocacy, education, and support of the families and friends of those with mental illness.

A bequest in your name to NAMI Cape Cod will be a gratefully acknowledged legacy.

**NAMI Cape Cod
at the Barnstable
County Fair**

On the weekend of July 18-20, 2008, NAMI Cape Cod will have a table in the Community Booth. Please stop by to say hello, and find out more about us. There will be information and pamphlets available.

ANNOUNCEMENT**NAMI CONNEC-
TION RECOVERY
SUPPORT GROUP**

MEETINGS WILL BE HELD EVERY THURSDAY NIGHT BEGINNING JULY 31, 2008, FROM 5:30 PM—7:00 PM AT THE NAMI CAPE COD OFFICE, 5 MARK LANE, HYANNIS, MA 02601. FOR MORE INFORMATION, CALL PAUL FORASTE AT 508 778 4636. (Related article on Page 5)

Annual Meeting (Cont. from page 6)

Donna and Lenny emphasized that recovery is a paradigm shift that offers an approach to wellness inherently different from traditional treatment. Recovery, in fact, is not a “treatment” in that it is not a service being executed by an outside party. The recovery process is initiated and carried out by the person with a psychiatric disability. It offers a way for people to take control of their life, to move beyond the consequences of their mental illnesses, and the effects of prejudice and discrimination. The preferred method of encouraging and supporting this change is through an educational process, which is available to people who are interested in recovery, their supporters, providers, and care givers.

In the context of recovery, the role of the person with a psychiatric disability is significantly expanded beyond that of waiting to be cared for, to that of learning how to take charge of his or her own healing process. People with psychiatric disabilities are seen as a “whole person” instead of a “collection of symptoms.” They are no longer “cases to be managed,” but rather, are the key informants in their quest for wellness. The educational approach avoids positioning the person in a “patient role” and focuses on each person’s inherent strengths, abilities, and capacity to learn new skills for living and for developing personal growth, mutuality, and recovery.

NAMI CAPE COD STRATEGIC PLANNING It is our hope at NAMI Cape Cod that we can partner with Boston University and develop a Recovery Education Center on Cape Cod. We are currently forming a planning committee and are interested in people who have a commitment to education as an important aspect of the recovery processes of people with mental illnesses. Contact LeRoy Spaniol (508 349 2475) if you are interested in serving on this committee.

NAMI.ORG/SITES/CAPECOD

508-778-4277

Hyannis, MA 02601

5 Mark Lane

NAMI Cape Cod

The Nation's Voice on Mental Illness



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Support Group Schedule

For Friends and Family of People with mental illness:

First Wednesdays of the month—Christ the King Church Parish Center, off Rte 151, Mashpee 7-9 PM. Contact Charlie Bacher at 508-778-0650

First Thursdays of the month—First Congregational Church, Main St., Chatham 7-9 PM. Contact Chris Ebel at 508 778 4277

Fourth Tuesday of the Month—The Senior Center, 415 Old Kings Hwy, Wellfleet. 6:00-8:00 PM. Contact LeRoy Spaniol at 508 349 2475.

For People with Psychiatric Disabilities

First and Third Wednesdays of the month—Louis Gordon Office Facility Meeting Room, 1100 Rte 134, Dennis 6:00-7:30 PM. Contact Karen at 508-385-5078

Last Saturdays of the month—Federated Church, Main St., Orleans 10:00-11:30 AM. Contact Carolyn at 508-255-8521 or Linda at 774-722-3323.

MISSION

NAMI Cape Cod serves to advocate for improved services and laws governing the care of people with mental illness, to support and educate families and individuals on their path to recovery, to educate all people on the nature of mental illness.