



# NAMI

# Cape Cod

The Nation's Voice on Mental Illness

MAY 2008

## ***PRESIDENT'S MESSAGE :***

LeRoy Spaniol, Ph.D., President, NAMI Cape Cod

### **What Would a Recovery-Oriented Program Look Like? Part II**

In the last Newsletter I discussed 1) the Recovery Vision and how to keep that "good news" alive. 2) Several essential components of a recovery-oriented program including the need to strongly affirm recovery in the Mission Statement of the program and the importance of a climate of hope and expectation for recovery. In this issue I will discuss further components of a recovery-oriented program. This information comes from a variety of sources including research, professional practice, family experience, and the recovery experience of people with mental illnesses. Through these complementary perspectives we will understand how people with psychiatric disabilities change, and, how positive or negative internal and external factors influence these changes.

**Affirm Key Recovery Values** The explicit affirmation of key recovery values is an important component of a recovery-oriented program. These recovery values need to be articulated in the policies of the program; providers should be trained in the theory and implementation of the values, and should receive ongoing supervision to develop their own expertise in implementing the values. These key recovery values include:

**Participation.** People need to be involved in all aspects of their treatment and recovery processes. The 2003 President's New Freedom Commission on Mental Health report stated that: "Nearly every consumer of mental health services...expressed the need to fully participate in his or her plan for recovery" It must be assumed that people are able to participate even when it doesn't look like they can. Encouraging participation may take persistence and patience on the part of the helper. Participation can grow over time as people develop confidence in their ability to act in their own interest.

**Self-determination/choice.** People have the right to

be in the center of decisions that affect their lives. Choice empowers people because it gives them some control over their lives. Choice, even when it involves failure, builds a sense of possibility rather than a sense of impossibility. In the Report of the 2004 Consumer Direction Initiative Summit, *Transforming Behavioral Health Care to Self-Direction* (SAMHSA, 2004), the term "self-directed care" was defined as a system that is "intended to allow informed consumers to assess their own needs . . . determine how and by whom these needs should be met, and monitor the quality of services they receive" (Dougherty, 2003). A general principle is that self-determination is essential to everyone's mental health and well being and is often regarded as a basic human right (Adams, Grieder, Nerney, 2005).

**Empowerment.** Empowerment means the person is able to say "I can" rather than "I can't." Empowerment is built through achieving success in life's many tasks, even small ones. As successful experiences accumulate, peoples' sense of empowerment gradually grows. Loss of power is a loss of one's ability to act in one's own interest—this is a loss of belief in oneself. Loss of power is also the loss of one's sense of agency and vitality—the inability to experience oneself as an active and vital agent. People with psychiatric disabilities often experience themselves as having no power, no real choices. Power is further lost through the severing of our connections. When our connections are broken, we feel powerless and despairing (Lifton, 1996). There are a variety of forms of power. The power that is healing, that is more than oneself, that can move another person, is acquired through our relationships. It is power with people not over people. It is a power acquired through reconnecting with oneself, others, our environments, and meanings in life. It is a power acquired through a deepening of (CONT. ON PAGE 2)

## **NAMI WALKS FOR THE MIND OF AMERICA**

On May 31, 2008 thousands will join together on Artisan Park along the Charles River to walk for the Mind of America. This vital walk for families, individuals, and the general public will raise awareness that recovery from mental illness is possible with adequate treatment. You are invited to become part of this historic walk. To learn more , turn to page 3 of this newsletter.

**PRESIDENT'S MESSAGE (cont. from page 1)** program.

our capacity to experience life fully and directly without being overwhelmed or intimidated. It is a power acquired by coming alive (Mack, 1994).

**Growth potential.** It is important to see people's growth potential regardless of current difficulties or disabilities. Their growth potential may appear small at any given moment but it needs to be seen as an important opportunity for developing confidence and empowerment. Getting hope from others and having others show confidence in you is reported by many people with mental illnesses as an important turning point in their lives. Hope can be contagious and can plant a seed of promise, a new potential perspective, in a person who is distraught and despairing (Deegan, 1995).

**Community focus.** Providers need to facilitate integration into community life by providing opportunities for the development of multiple roles to discover and create an identity that is separate from and greater than the illness such as a student, worker, volunteer, neighbor, friend, and one who can enjoy life. The identity of "patient" is very debilitating and needs to be actively countered by providing opportunities for new identities through acquiring the ordinary roles in life.

**Whole person/family centered.** People need to be treated as whole human beings, with natural responses to a profound trauma, and with a deeply felt connection to their family regardless of their current relationship. People with mental illnesses and their family members are not to be diminished or dehumanized in any way by their need for help.

**Recovery as an expectation.** It is clear from the research and many personal accounts by people with mental illnesses that most people with serious mental illnesses recover. By recover we mean that people can work, have a social life, have an intimate relationship, live in housing of their choice, have an identity separate from the illness, and contribute to their community. We also know that there are many factors that enhance the recovery process—and some that inhibit it (Davidson, Harding, & Spaniol, 2006; Davidson, Harding, & Spaniol, 2005). We can not promise people that they will recover but we can say that most people have recovered and that with assistance they have a good chance of having a life that is satisfying, fulfilling, and contributing. Because we currently have no way of accurately predicting who will recover it is important to assume that the person we are helping has the potential for recovery.

*Policy example: Providers will affirm in their practice the above recovery values essential to our recovery-oriented*

**Provide Acute and Ongoing Psychiatric Care:** There are a variety of interventions and resources that have been shown to be helpful in a person's recovery process. These include crises intervention which is necessary to care for someone with an acute onset of a mental illness or for periodic crises that arise in the recovery process. Inpatient/outpatient treatment is required to help stabilize a person in a crisis and to assist with the re-entry into his or her community. Assertive community treatment involves actively reaching out to people in need of special assistance in coping with the debilitating and persistent nature of mental illnesses and co-occurring disorders. Respite facilities provide an opportunity for people to resolve crises without hospitalization. Transitional and supported housing provides residential options as people are released from hospitals. Case management helps people to maintain themselves in the community and to rebuild their lives. A Hot line provides a regular opportunity where people in crises can talk to another human being about their current concerns or worries. A Warm line helps people who are lonely or isolated to connect with a compassionate listener.

*Policy example: The program will make available, assist in developing, or connect to in the community the above essential elements of acute and ongoing psychiatric care. Future additions of the Newsletter will cover additional components of a recovery-oriented program.*

## REFERENCES

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## NAMI Walks for the Minds of America

### Join our Walk and Celebration

You are invited to join friends, neighbors, and your entire NAMI family in the celebration of the growth of social acceptance and recovery from Mental Illness on Saturday May 31, 2008. Support NAMI Walks for the Mind of America, be a part of supporting the recovery of those with a mental illness. The best way to become involved is to join us on the bus leaving at 8:00 AM Saturday morning, May 31<sup>st</sup>, from the Park and Ride parking lot on Route 6 at the Sagamore Bridge. The bus will travel to Artisani Park along the Charles River in Boston to walk for the "Mind of America." If you are unable to join the celebration, you may pledge a donation by sending a check to your local affiliate at NAMI Cape Cod, 5 Mark Lane, Hyannis, MA 02601, or you may go type in the following link [www.nami.org/namiwalks08/MAS/CCDONATE](http://www.nami.org/namiwalks08/MAS/CCDONATE). We wish to thank all who have already responded so generously. Call the NAMI Cape Cod office (508 778 4277) for more details.

## ***LOBBY DAY AT THE STATE HOUSE***

NAMI Mass Lobby Day was held on April 16 at the State House. Traveling from Cape Cod to the State House were Chris Ebel, Charlie Manning, Paul Foraste, Terri Rodriguez, Baybridge clubhouse members Bonnie, Dave, Scott, and Cove clubhouse members in a separate van. We heard talks from Massachusetts legislators; Laurie Martinelli, executive director of NAMI Mass; and Dr. Ken Duckworth, medical director of NAMI National. Toby Fisher then gave the attendees advice on lobbying.

The participants fanned out to lobby at the offices of our senator, our representative, the Senate President, the Speaker of the House of Representatives, the Majority Leader, and the Chairman of the Ways and Means Committee. We advocated maintenance funding for the Department of Mental Health (adjusted up for inflation), not level funding (no adjustment for inflation). Also we lobbied for H4276, improvement in children's mental health services. Another issue we urged was passage of S434 and S438, insurance coverage for the medication which the psychiatrist thinks is best for the mentally ill patient. Restricting access to mental health medications and medical treatments, especially for those with acute illness, can easily require more costly inpatient treatments and emergency services in the long run. Also we encouraged our legislators to support H1313, which would require mentally ill inmates be treated in residential treatment units, not solitary confinement. Another cause that needed our support was jail diversion: Incarceration of the mentally ill is detrimental to both the individual who does not receive proper treatment, and taxpayers who must pay the cost of unjust imprisonment. Jail diversion has been shown to be an effective way to provide appropriate treatment for the mentally ill and ensure a safer community. We also lobbied for safe and affordable housing for the mentally ill. Of the roughly 20000 chronically mentally ill individuals, over 3645 are waiting for residential placement.

**Paul Foraste**

***LEGISLATIVE BREAKFAST – Friday, May 16<sup>th</sup>***

NAMI Cape Cod, together with the Massachusetts Society for the Prevention of Cruelty to Children and the Kids & Teens Assessment Center, will sponsor a Legislative Breakfast on Friday, May 16<sup>th</sup>, 2008 from 10 am-12 noon to support SB2518: An Act Relative to Children's Mental Health. This bill will directly benefit children and adolescents with mental health needs and their families. The bill emphasizes community based services and expands insurance benefits to ensure high quality, coordinated care.

The breakfast will take place at the conference room at MSPCC, located at 208 Breeds Hill Road, Independence Park, Hyannis, and is free to all. Laurie Martinelli, Director of NAMI Mass, will be a featured speaker. We urge all NAMI members to attend and bring all your friends. So much family heartbreak can be prevented with early and effective treatment. Call Sue Sullivan, 508-385-2485, with questions.

**NAMI and HealthCentral.com Announce  
The First Annual Mental Health and Creativity Contest**

Have you or a loved one been touched by mental illness? Has your experience inspired you to write, paint or express yourself in other creative ways? NAMI and HealthCentral.com invite you to share your creative works with the community in our online Mental Health and Creativity Exhibit. All written works and still visual arts are welcome and will be showcased, including: poetry, prose, digital images of your artwork or photographs. Select works will be chosen and featured at the NAMI National Convention on June 13-16, 2008

<http://www.healthcentral.com/bipolar/creativity-exhibit.html>

***Office Progress Report:***

We are now able to email our newsletter to our members. We also are still sending the traditional way—the US Postal Service. Please notify us BY EMAIL if you would like to receive your newsletter this way. Otherwise, we will continue to send by mail.

Our next project is to update our local affiliate website: NAMI-CapeCod. We hope to report this accomplishment in the near future.

## ***“LIFE CARE PLAN”TOPIC OF SPEAKERS MEETING***

Patricia Freedman, Executive Director of Planned Lifetime Assistance Network of Massachusetts, Inc., (PLAN of Massachusetts), spoke on April 2, 2008, at the Cape Codder Hotel in Hyannis on the subject of developing a “**Life Care Plan**” for a family member with a disability. The title of her presentation was “Planning with a Purpose” and covered all aspects of developing a plan for a family member of any age with a disability.

PLAN of Massachusetts is a non-profit corporation founded in 1982 under the name “MARC Trust, Inc.” and adopted its current name in 2004 when it became affiliated with the National PLAN Alliance (NPA). The website for PLAN of Massachusetts is [www.planofma.org](http://www.planofma.org) and contains extensive information on the organization and the services they provide. The website for NPA is [www.nationalplanalliance.org](http://www.nationalplanalliance.org) and provides information on the national level.

Some of the topics covered in the presentation included the components of a **Life Care Plan** and the steps involved in its development, the role of government benefits, financial planning and estate planning, the use of supplemental needs trusts and the utilization of a pooled trust, and the services provided by PLAN of Massachusetts.

Copies of a **Life Care Plan** were made available for review by those in attendance, as well as the **MARC Special Needs Pooled Trust** and the **PLAN of Massachusetts Third Party Special Needs Pooled Trust**.

The **Life Care Plan** is a detailed written document based upon a standard format with essential information for understanding the current and future needs of the family member with the disability. It includes important medical and financial information and addresses the physical and emotional needs of the individual as well as everyday activities that may be taken for granted such as transportation, fixing meals, paying bills, etc. It also takes into account the financial assets available, including public benefits.

A good **Life Care Plan** will specify the key elements of your family member’s current lifestyle that are important to maintain in the future. In other words, what you and your family member want in the future and the supports that will likely be needed to make this happen, especially when the family is no longer able to provide the care. Through the planning process, you will be able to establish how to maximize the likelihood that the wants and needs of the future for your family member are met.

Two pooled trusts are administered by PLAN of Massachusetts with individual trust accounts in the pooled trusts for each family member client. The **MARC Special Needs Pooled Trust** is funded with assets of the person with the disability who receives government benefits, while the **PLAN of Massachusetts Third Party Special Needs Pooled Trust** is funded with assets that are provided by the families or other third parties to benefit the person with the disability. Each trust has unique characteristics in regards to the preservation and utilization of the assets in the trust while protecting the family member’s present and future entitlements to public benefits.

Copies of the booklet titled “**Special Needs Planning Guide for Families**” were also made available to the meeting attendees. The booklet provides an overview of the life planning process to help families take the important first steps towards planning for the future. Five separate chapters cover the basic topics including one chapter on the key timelines, where certain stages in a person’s life involve changing needs and require specific action steps.

Two additional books were discussed as excellent sources of additional information. The first book is titled “**Legal Planning for Special Needs in Massachusetts: A Family Guide to SSI, Guardianship, and Estate Planning**” and can be reviewed at the website [www.disabilitiesbooks.com/legal\\_planning\\_fcsn/content.htm](http://www.disabilitiesbooks.com/legal_planning_fcsn/content.htm). It should be noted that although some of the materials are specific to Massachusetts, most of the strategies are valid in any state and will get readers on track wherever they live.

The second book, “**The Special Needs Trust Administration Manual: A Guide for Trustees**” can be reviewed at the website [www.disabilitiesbooks.com/special\\_needs\\_trust/index.html](http://www.disabilitiesbooks.com/special_needs_trust/index.html).

For an overview of all the books offered by DisABILITIESBOOKS, Inc., one can go to the website [www.disabilitiesbooks.com](http://www.disabilitiesbooks.com).

It was noted during the meeting that because each family’s situation is different and the fact that this is a complicated planning process with the laws changing on a regular basis, you should seek an attorney who has specific expertise in the field of special needs trusts. PLAN of Massachusetts currently has approximately 240 clients, with approximately one-half of the clients having a disability related to mental health. The typical value of a client’s trust account is in the range of \$50,000 and the total trust assets under management is approximately \$11 million with investment management services provided by Cambridge Appleton Trust, N.A.

PLAN of Massachusetts has their offices at 1301 Centre Street, Newton Centre, MA 02459 and can be reached at (617) 244-5552 for additional information, including copies of informative literature and the life care planning documents. PLAN of Massachusetts staff are also available to discuss establishing a Pooled Trust for a person with a disability.

*National Alliance on Mental Illness*

*offers Education and Support for Families*

**Family to Family Education Program: This is a 12 week course sponsored by the National Alliance on Mental Illness (NAMI).**

It is designed to educate family members in understanding and supporting their mentally ill relative, while maintaining their own well-being. The course is taught by a team of trained volunteer family members.

Two classes will be offered this fall, one in Centerville on September 5, 2008, 6:30 – 9:00 PM, and one in Wellfleet, dates to be announced. Please call 508 775 4636 for more information.

There is NO COST to participate. Registration is required.

**USEFUL WEBSITES:**

National Empowerment Center: [www.power2u.org](http://www.power2u.org) A consumer-run national center for advocacy and change. Lots of information on consumer issues.

National Foundation for Depressive Illness: [www.depression.org](http://www.depression.org) Information on depression.

Anxiety Disorders Association of America: [www.adaa.org](http://www.adaa.org). Information about treatment of anxiety.

Bipolar Information Network: [www.moodswing.org](http://www.moodswing.org). Information on bipolar illness.

Health and Mental Health Resources: [www.athealth.com](http://www.athealth.com): Information on all health and mental health issues from a professional and consumer perspective.

NAMI Cape Cod

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HAVE YOU RENEWED YOUR MEMBERSHIP? IF SO, THANK YOU. IF NOT, PLEASE TAKE A FEW MINUTES AND RENEW TODAY!

\$35 FAMILY OR INDIVIDUAL MEMBERSHIP

NAME \_\_\_\_\_

ADDRESS \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

TELEPHONE: \_\_\_\_\_

EMAIL ADDRESS: \_\_\_\_\_

SEND CHECKS TO NAMI CAPE COD, 5 MARK LANE, HYANNIS, MA 02601

## *Mindfulness and Mental Health*

*Stella Thomson, MSW, LICSW*

*The first time I can recall hearing anything about mindfulness practice and well-being was sometime in the 1970s when Maharishi Mahesh Yogi was coming to town to speak about Transcendental Meditation. I was barely a teenager and wanted to go, but my parents seemed pretty clear that I was not going to be allowed to spend an evening with a bunch of “hippies”, and thoughts couldn’t possibly have anything to do with wellness, anyway. Here, these many years later, there has been (and continues to be) much research done on the subject, and, lo and behold, there is a very clear relationship between our thoughts and our wellness; but can mindfulness practice help us maintain our mental well-being as well? The research says, “Absolutely.”*

*Mindfulness is really about focusing on the present moment, listening to that inner dialogue that goes on constantly just below our everyday awareness, and becoming aware that we are not our thoughts, detaching from them, and changing the thoughts we have.*

*As we begin to listen to our inner dialogues, we begin to find the roots of our anxiety and depression. We find the way we think about others and ourselves and how we perceive the world in general. For example, if our inner dialogue is constantly telling us that we are not good enough, rich enough, thin enough, smart enough, kind enough, that we never do anything right and the world is not a safe place, we can’t help but have some constant anxiety and depression.*

*As we continue to listen to our inner dialogues, we become increasingly better at interrupting those thoughts and asking, “Where did that thought come from?” We begin to realize that many of our thoughts came from somewhere outside of ourselves and are not really our thoughts at all; this is when we can begin to change them.*

*How do we do that? First, we must listen to the dialogue non-judgmentally and understand our thoughts as just thoughts, neither good nor bad, but just thoughts; this is how we can begin to detach from our thoughts and just let them go. We acknowledge the thought, neither trying to push it away nor hold on to it, but simply acknowledge that we had the thought, and let it go. Sometimes it can be helpful to use some type of visual imagery – perhaps writing the thought on a balloon and allowing it to be taken away by a gentle breeze, or placing the thoughts in a small boat and letting the tide take them out to sea. As we free ourselves from the thoughts we are now able not to choose to have, there is now space in the inner dialogue for the thoughts we do want to have. The thoughts that tell us that we are good enough, have enough, are able to manage our weight in healthy ways, are kind to others, are able to do many things the way we choose to do them, and are able to choose to behave safely in the world.*

*Resolving those underlying causes of anxiety and depression in this present moment, and making a regular practice of this allows us to develop good habits of thought. Good habits of thought in the present moment lead to good habits of thought in the future. As present moments add up, our future becomes brighter and healthier.*

*Why not start making a practice of listening to your own inner dialogue and creating the wellness you want in your life? There is definitely a connection between our minds and our bodies!*

NAMI Cape Cod  
5 Mark Lane  
Hyannis, MA 02601

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, 6-8 PM, Contact LeRoy Spaniol at 508 349 2475 **THIS IS A NEW GROUP**

#### 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.

### *NAMI Cape Cod*

#### *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.