

NAMI EDUCATION TRAINING AND PEER SUPPORT CENTER EDUCATION PROGRAMS

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NAMI Education, Training, and Peer Support Center Team

We have taken steps to reorganize the Education Center so that we can continue to serve you as effectively as possible. We are historically organized by individual programs, adding a director and program center as each new program came on board. However, the things being asked of us by the field are common to all of our programs – technical assistance, advice on problems shared by each program, timely updates, data reporting, training, etc. Given this commonality, we will no longer make a distinction between family and consumer programs, or stay in our silos working separately on program issues by all of our programs. Therefore, we have decided to reorganize by function – specifically, the function of technical assistance, the function of curricula and training and the function of internal project direction.

Lynne Saunders directs Field Services (with an emphasis on family and Veterans programs). Lynne has dedicated her 20+ year NAMI career in mental illness to her deceased sister and father who were diagnosed with a mental illness, and carries the distinction of being one of the first NAMI national staff members. Lynne has appeared and shared her family story in the Family-to-Family Tribute Video. Lynne has a B.S. in secondary education from Ohio State University.

(<u>Lynne@nami.org</u>) 703/516-7971

Cynthia Evans directs Field Services (with an emphasis on consumer programs). Diagnosed with depression at age 12 and later, Borderline Personality Disorder (BPD), she was once unable to hold a job longer than three months. Now she has been gainfully employed since 1992. Prior to coming to NAMI in 2008, she was program director of a consumer-run drop-in center in Northern Virginia for five years. Cynthia is a gifted public speaker, has written more than 40 workshops on employment and empowerment for people with mental illness and others and enjoys working with others who have traveled similar paths. (Cynthiae@nami.org) 703/516-7987

Lynne and Cynthia will focus on technical assistance and support to the field across all programs, including continuing education in program leadership and management.

Teri Brister, Ph.D., is the Director of Training (with emphasis on family, child and adolescent programs). As a family member, Teri is a state trainer for the Family-to-Family Education Program, the Provider Education Program and the Facilitator Support Group Training Program. After serving as the executive director of NAMI Mississippi, she joined the NAMI National staff in July 2005 as the Regional Leadership Consultant for Region 2. She has enjoyed a 20 year career in community mental health centers in Mississippi serving in both clinical and administrative positions. Teri has a BS and MS degrees in Counseling Psychology and was awarded a doctoral degree in Public Policy and Administration from Jackson State University in 2006. She is a Licensed Professional Counselor in Mississippi. (Tbrister@nami.org) 601/829-0591

Sarah O'Brien is the Director of Training (with an emphasis on consumer programs). Diagnosed with Bipolar Disorder at the age of 18, Sarah has a special empathy for people living with mental illness and their families. She received her B.A. from Goucher College in

2001, and worked as the coordinator of consumer programs for NAMI Montgomery County, Maryland from 2004-2005. Sarah has been employed at NAMI (the national office) since 2006 and during that time has served as the Director of two NAMI Signature Programs- In Our Own Voice and Peer-to-Peer. She brings her experience in training and curriculum development to her current position.

(Saraho@nami.org) 703-516-7226

Teri and Sarah will focus on training, program content and updates, and will be responsible for repurposing existing programs into virtual formats.

Candita Wacker Sabavala is the Departmental Project Director. Prior to joining the Education team, Candita served as NAMI's Corporate Relations Manager from 2002-2007. In this role, she established and maintained relationships with key industry contacts in neuroscience research and development, marketing and public relations, and government affairs. Candita has a bachelor's degree in Communications from George Mason University. (Candita@nami.org) 703/600-1100

Candita will work with departmental directors and staff to provide project oversight and direct supervision of support staff to ensure all departmental deliverables are met.

Carmen Argueta, who is fluent in Spanish, is the Spanish Programs Specialist. Her works focuses on working with the Latino Community in the programs we currently have available in Spanish such as De Familia a Familia, Conexión NAMI, Persona a Persona y En Nuestra Propia Voz. She is also responsible for support functions across programs. (Carmena@nami.org) 703/600-1105.

Maura Bulger is the Program Coordinator responsible for support functions across programs. She is originally from Montreal, Quebec and moved to DC about nine months ago. She graduated from the University of Toronto with a BA in Canadian Studies and received her MA in European Studies from the University College Dublin. Maura decided to get involved with NAMI following her work at the Wing Lake Developmental Centre School in Michigan because she realized she wanted to help people having a hard time helping themselves. She recognizes the barriers that stigma creates when it comes to mental illness and recovery.

Blakelee Sharpe is the Program Assistant in charge of document management. She is a graduate of the George Washington University with a degree in Communication and an academic focus on public health advocacy. (bsharpe@nami.org) 703/516-7997

Marshall Epstein is the Program Assistant managing the demanding task of order fulfillment for all programs. Marshall received a B.A. degree with honors in Economics at the University of Virginia in 1983. He worked for the Internal Revenue Service from 1983-1997 as an economist and a program analyst. He has been working for NAMI from 1999 to present. Marshall is a person living with bipolar disorder and anxiety. (Marshall@nami.org) 703/516-7975.

Programs in the NAMI Education, Training and Peer Support Center

Because of NAMI's leading role in the creation of outstanding peer-directed programs in education and support, NAMI national maintains the NAMI Education, Training and Peer Support Center. This department is responsible for coordinating and expanding eight national programs, involving thousands of trained NAMI volunteers who bring these programs at no cost to families, consumers, mental health and school professionals. NAMI is unique among organizations advocating for individuals with serious and persistent mental illness for its commitment to family and consumer peer education programs which are now successfully directed by NAMI members in a wide number of community settings. These programs are described below:

The NAMI Family-to-Family Education Program is a free 12-week course for families, partners and friends of individuals with serious mental illness, taught by 3,500 trained NAMI family members and family-member consumers. Since 1991, it has graduated over 300,000 people in 49 states and the District of Columbia, Puerto Rico, Canada, Mexico and Italy, and has been translated into Spanish, Italian, Vietnamese and Arabic. The program is also offered in VA hospitals across the country. Scientific evaluation demonstrated that course participants gain a greater understanding of mental illness, cope better with the strains of illness, worry less, and feel greatly empowered to navigate the health care and political systems to get better treatment and services. The course dwells on the emotional responses families have to the trauma of mental illness; many family members describe their experience in the program as life-changing. Family-to-Family is supported by Bristol-Myers Squibb and Otsuka American Pharmaceutical, Inc.

The NAMI Peer-to-Peer Recovery Education Course is a 10-week, peer led, recovery education course open to any person with a serious mental illness. Established in 2000 in 4 pilot states, Peer-to-Peer emphasizes recovery from mental illness as a feasible, supportable goal. It also challenges the stigmas commonly associated with mental illness. Using a combination of lecture, interactive exercises, and structured group processes, the peer mentors teaching the course encourage growth and wellness among participants. Topics covered include: the biological bases of mental illness; personal and interpersonal awareness coping skills; information on addictions, spirituality and basic self-care; and advocacy. The course is offered at no cost to those who attend. Peer-to-Peer is supported by Astra/Zeneca.

The NAMI Connection Recovery Support Group Program is a weekly 90-minute support group for people living with mental illness in which people learn from each others' experiences, share coping strategies, and offer each other encouragement and understanding. Launched in spring 2007, NAMI Connection groups are facilitated by persons who live with mental illness for other persons with any diagnosis who also live with mental illness. Supported by Astra/Zeneca, the NAMI Connection program is a national, phased initiative to implement mutual support groups in communities across the country. Contact:

NAMI In Our Own Voice: Living with Mental Illness is a unique public education presentation that offers insight into the hope and recovery now possible for people with severe mental illness. Trained individuals with mental health challenges lead a brief yet comprehensive and interactive presentation about mental illness. The presentation includes a video, personal testimony, and discussion between the presenters and the audience. The testimonies put a face on mental illness while informing the audience of how people with mental illness recover and reclaim productive lives. This program has reached over 275,000 people. *In Our Own Voice* is supported by the Lilly Foundation.

The NAMI Provider Education Program offers 15 hours of in-service training to line staff at public mental health agencies, taught by a trained 5-member team of family members, consumers and a mental health provider who is either a family member or a consumer. Now active in 20 states and Ontario, Canada, the course emphasizes the lived experience of mental illness, expands compassion for the daily realities of this heroic struggle, and prepares staff members to practice a collaborative consumer/provider/ family treatment team model of care.

The NAMI Family Support Group Facilitator Skills Training Program, a weekend training workshop, provides NAMI family support group leaders with the requisite skills and knowledge of group dynamics to enable them to run support group meetings where participants are encouraged to share actively in the work of the group, and gain confidence in their abilities to cope and "work the system". NAMI offers training for state trainers in this program annually.

NAMI Basics is NAMI's newest peer-directed education program, developed specifically for parents and other caregivers of children and adolescents who have either been diagnosed with a serious mental illness/serious emotional disturbance, or who are experiencing symptoms but have not yet been diagnosed. This course contains six 2.5 hour classes, with several additional modules in the planning stage. This program has been available in the field in 2008. The development of NAMI BASICS is supported by Janssen, L.P.

NAMI Parents and Teachers as Allies is a 2-hour in-service program for teachers, helping them to recognize and identify early-onset mental illness in children and adolescents. The presentation is conducted by parents and consumers who have had to negotiate mental illness within the school system. This program is a joint project of the NAMI Education Center and the NAMI Child and Adolescent Action Center.

Cumulative Program Data as of March 2011

NAMI Family-to-Family: First piloted in 1992; became a NAMI national program in 1998

- States now in the program: 49 and District of Columbia
- Foreign countries/territories in the program: Mexico, Canada, Italy, Puerto Rico
- Total number of graduates of the 12 week course: 300,000+
- Family-to-Family teachers trained: 7,000+
- De Familia a Familia teachers trained: 150+
- Family members now graduating per year: 12,000-14,000

NAMI Provider Education Program: First piloted in 1995; became a NAMI national program in 2000.

- States now in the program: 23, plus 8 affiliate sites
- Foreign countries in program: Ontario, Canada
- Total number of provider graduates: 13,000+
- Family-to-Family team teachers trained: 1162
- Consumer team teachers trained: 1200
- Provider team teachers trained: 564
- Total team teachers trained: 3232

NAMI Peer-to-Peer Recovery Education Program: Piloted in 2001

- States now in the program: 28, plus 1 affiliate site, plus Mexico
- Total number of graduates of the 10-week course: 11,722
- Peer-to-Peer consumer mentors (teachers) trained: 2,644
- National trainers: 198
- Persona a Persona graduates: 70
- Persona a Persona mentors (US): 30
- Spanish speaking state trainers (US): 4

In Our Own Voice: Living with Mental Illness: First piloted in 1995

- States now in the program: 41
- Foreign countries now in program: 0
- National Trainers: 10
- Certified "IOOV" Presenters: 2,200+
- Audience members reached: 275,000+
- Audience members now reached every year: 50,000+

NAMI Support Group Facilitator Skill Training Program: First piloted in 1999

- States now in the program: 44
- Foreign countries/territories in the program: Virgin Islands, British Columbia, and Mexico
- Support Group trainings on the state level: 200+
- Trained support group facilitators on the state level: 3,000+

NAMI Connection: Launched in 2007

- States now in the program: 45
- Trained support group facilitators on the state level: 2,200+
- Foreign countries now in program: none
- Active Support Groups: nearly 500
- People attending NAMI Connection groups: 90,000

NAMI Basics: Launched in 2007

- States now in the program: 33
- Total number of graduates of the Basics course: 2,700+
- Trained teachers at the state level: 800
- Foreign countries now in program: none
- National Trainers: 1
- Family members now graduating per year: 1,500+

NAMI PEER PROGRAMS: BASIC PRINCIPLES

NAMI Family-to-Family Education Program

NAMI Provider Education Program

NAMI Family Support Group Facilitator Skill Training Program

NAMI Peer-to-Peer Recovery Education Course

NAMI Connection Recovery Support Group

NAMI In Our Own Voice

NAMI Basics

NAMI Parents and Teachers As Allies

- Serious and persistent mental illness is a traumatic event for families and consumers alike, and must be understood in terms of this fundamental clinical perspective.
- Families and consumers adjust to this traumatic experience over time in a predictable process of coming to terms with profound dislocation in their lives.
- ♦ In each stage of adaptation, their emotional responses reflect a natural reaction to this process of adjustment, but their needs will differ in each stage.
- Family/consumer strength, persistence and heroism in the face of this overwhelming human challenge must be recognized and validated.
- Recovery and the reconstruction of personal priorities must be the goal of treatment
- Because of their lived experience, family members and consumers make ideal teachers, and peer-directed education courses provide a dimension of emotional healing not available in any other setting.
- Peer-directed educational and support programs must be included as an integral part of mental health services and be paid for by mental health systems.

Evidence from our Spanish classes indicates that because these basic principles underlie the curriculum, the beneficial impact of Family-to-Family is trans-cultural.



You can access the latest Family-to-Family State Program Directors listing when you go to the Family-to-Family Intranet. The listing is found in the Teacher's, Trainer's and Coordinator's Corners.

If you do not have access to the Family-to-Family Intranet, you must first sign in on the NAMI Web site (www.nami.org), click on the sign-in link, then click on "Register and Join" and follow the instructions to obtain a NAMI user name and password. When you have your user name and password, send it to Marshall@nami.org. He will link you to the Family-to-Family Intranet.



The NAMI Family-to-Family Education course is a copyrighted and trademarked exemplary evidence-based program which is conducted under the auspices of the NAMI national organization. In the 20 years the program has been operating, over 7,500 NAMI volunteers have been trained to teach this free, peer-directed 12-week program in their home communities.

In order to maintain the high standards in the field which have won it a "best-practices" designation, NAMI closely controls the dissemination of the program, conducts the initial training of teachers who start the program in their home states, and centrally trains all state trainers who subsequently train teachers.

Since 1991, it has graduated over 300,000 people in 49 states and the District of Columbia, Puerto Rico, Canada, Mexico and Italy, and has been translated into Spanish, Italian, Vietnamese and Arabic. The program is also offered in VA hospitals across the country.

The course places emphasis on a trauma model of family healing, providing insights into, and resolution of, the profound distress experienced by families and their close relatives as they struggle to cope with serious and persistent mental illness. The curriculum helps caregivers not only to learn a wide range of biomedical information about serious and persistent mental illnesses, but also to understand how the lived experience of these deeply stigmatized conditions effects their relative. In addition, the course helps family members deal with the trauma of coping with this life-and-family crisis, learn how to reinstate their own life plan as an essential element of self-care, and take collective action to advocate for better treatment and recovery-oriented services for their loved one. Special workshops in communication and problem-solving impart durable caregiver skills in handling the most common concerns which arise in caring for relatives with these brain disorders.

Two scientific studies on the effectiveness of this program showed that course participants had a significantly decreased subjective (emotional) burden of mental illness, and an increased sense of empowerment regarding the system, the community and family. They felt significantly more able to cope with the mental health system and felt an increased ability to cope with their ill family member.

A third study (a randomized controlled trial) was undertaken in 2007. Funded by a 4-year grant from NIMH, it has involved over 300 family members. As of May, 2010, the RTC is completed. (These studies were conducted by Lisa Dixon, M.D., M.P.H., and University of Maryland Division of Services Research). This study will establish Family-to-Family as an evidence-based program, meeting the standards set by the President's New Freedom Commission on Mental Health (2003) and the Institute of Medicine's Committee on Quality of Health Care in America (2001).

The curriculum is updated every year to reflect advances in scientific findings, and to stay abreast of new medications and current medication protocols. These updates are then distributed to teachers in the field. Over the 12-weeks of the course, class participants collect class handouts in a notebook comprising 250 pages of useful resource information which they keep to share with other family members, and with their family member who is ill. The course is open to any family member, partner or friend, or consumer who has a first-degree relative suffering from a serious and persistent mental illness (schizophrenia, bipolar disorder, major depression, co-occurring brain and addictive disorders, borderline personality disorder, post traumatic stress disorder, panic disorder, and obsessive compulsive disorder).

More than three-fourths of the states in the Family-to-Family program have been successful in securing ongoing funding from state departments of mental health. The reputation of the effectiveness of this program is now so strong that state systems are endorsing the benefits of a "partnership in education" with NAMI state organizations. The NAMI Education, Training, and Peer Support Center stays in close contact with each state organization running the program, offering technical assistance and consultation through conference calls with state program directors, annual master classes for teachers and ready access to its program Intranet site.

Each year, state organizations designate experienced teachers to come to St. Louis, MO to attend the national Family-to-Family Training-of-Trainers, under the direction of Joyce Burland, Ph.D., a family-member psychologist who developed the program. This three-day intensive workshop prepares these individuals to serve as state trainers, assuring that each state can train and expand its pool of teachers.

The course is open to any family member, partner or friend, or consumer in recovery, who has a first-degree relative suffering from a serious and persistent mental illness (schizophrenia, bipolar disorder, major depression, borderline personality disorder, panic disorder, obsessive compulsive disorder, post-traumatic stress disorder, and dual diagnosis).

De Familia a Familia

Latinos are "the majority minority" in the United States, and NAMI is reaching out to this population through the Spanish Family-to-Family Education Program (De Familia a Famila). In the United States, NAMI California and NAMI New Jersey are leading this effort. Each of these states has a core of certified Spanish trainers, run ongoing Spanish classes, and employ Spanish speaking staff to support outreach and program administration. NAMI California alone has trained over 100 Spanish teachers. NAMI New Jersey, in collaboration with the New Jersey Mental Health Institute, Inc., received a SAMHSA grant to bring De Familia a Familia to the Spanish population in that state. In Mexico, the growth of the program has been phenomenal, with over 1,000 families graduating since 2000.

NAMI national held the first De Familia a Familia Training of state trainers in 2003 and todate 15 states have certified Spanish-speaking trainers ready to increase the number of teachers teaching De Familia a Familia. De Familia a Familia has been a life-changing experience for Spanish-speaking families, with one class participant saying, "For me, this experience will impact my life forever. I will never forget this opportunity to be able to meet other Latinos and share my experience and pain."

Family-to-Family/Veterans Administration Project

In 2007, a three-year NAMI/Veterans Health Administration (VHA) Memorandum of Understanding (MOU) was signed at the NAMI convention in San Diego, CA. The MOU stipulates that the 49 NAMI state organizations currently offering the Family-to-Family program will be required to hold one Family-to-Family class, with certified Family-to-Family teachers in the selected VHA facility. NAMI state and local organizations will work with VHA to inform veterans and VHA staff of the availability of this program with the goal of having 51% veteran family member class participants. To date, 45 program states have launched the Family-to-Family class. The good news is that an extended 3-year MOU was signed December 2010 and additional VA hospitals and medical hospitals will be added in each of the 49 F2F program states.

A supplemental PTSD take-home module for the Family-to-Family was prepared by the Veterans Healthcare Administration, National Center for PTSD and updated in 2011. This module is available to families in Class 3 of the course and is being well received across the country as a timely resource for families of relatives with PTSD.

NAMI Family-to-Family Education Curriculum

- <u>Class 1</u>: <u>Introduction</u>: Special features of the course; learning about the normative stages of emotional reactions to the trauma of mental illness; our belief system and principles; your goals for your family member with mental illness; understanding illness symptoms as a "double-edged sword."
- <u>Class 2</u>: <u>Schizophrenia, Major Depression, Mania, Schizoaffective Disorder</u>: Diagnostic criteria; characteristic features of psychotic illnesses; questions and answers about getting through the critical periods in mental illness; keeping a Crisis File.
- <u>Class 3</u>: <u>Mood Disorders, Borderline Personality Disorder, Anxiety Disorders, Dual Diagnosis</u>: Types and sub-types of Depression and Bipolar Disorder; diagnostic criteria for Borderline Personality, Panic Disorder and Obsessive-Compulsive Disorder; Post-traumatic Stress Disorder; Co-occurring brain and addictive disorders; telling our stories.
- Class 4: Basics About the Brain: Functions of key brain areas; research on functional and structural brain abnormalities in the major mental illnesses; genetic revolution in biological psychiatry; genetic transmission of major mental illnesses; infectious and neuro-developmental "second hits" which may cause mental illness; the biology of recovery; consumer stages of recovery from brain disorders.
- <u>Class 5:</u> <u>Problem Solving Skills Workshop:</u> How to define a problem; sharing our problem statements; solving the problem; setting limits.
- <u>Class 6:</u> <u>Medication Review</u>: How medications work; basic psychopharmacology of the mood disorders; anxiety disorders and schizophrenia; medication side effects; key treatment issues; stages of adherence to medications; early warning signs of relapse.
- <u>Class 7:</u> <u>Inside Mental Illness</u>: Understanding the subjective experience of coping with a brain disorder; problems in maintaining self-esteem and positive identity; gaining empathy for the psychological struggle to protect ones integrity in mental illness.
- <u>Class 8:</u> <u>Communication Skills Workshop:</u> How illness interferes with the capacity to communicate; learning to be clear; how to respond when the topic is loaded; talking to the person behind the symptoms of mental illness.
- <u>Class 9:</u> <u>Self-care:</u> Learning about family burden; sharing in relative groups; handling negative feelings of anger, entrapment, guilt and grief; how to balance our lives.
- <u>Class 10</u>: <u>The Vision and Potential of Recovery</u>: Learning about key principles of rehabilitation and model programs of community support; a first-person account of recovery from a consumer guest speaker.
- <u>Class 11</u>: <u>Advocacy</u>: Challenging the power of stigma in our lives; learning how to change the system; meet and hear from people advocating for change.
- Class 12: Review, Sharing and Evaluation: Certification ceremony; Party!

ABSTRACT

Family-to-Family as an Evidence-based Practice: Preliminary Results

2nd Version, November 2010: includes 6 mo follow up results
 Lisa Dixon, MD MH Alicia Lucksted, PhD
 University of Maryland Department of Psychiatry

Please note: this abstract reflects partial and preliminary results of the UM Family to Family study which could change as the project goes through the peer review process for publication. Additional results will be available at a later date. Please contact aluckste@psych.umaryland.edu or 410-706-3244 to check for updated versions.

<u>Aims:</u> The purpose of the study was to evaluate the effectiveness of the National Alliance on Mental Illness Family to Family Education Program (FTF). This program is delivered by trained family-member teachers and is available free of charge throughout the country. We hypothesized that individuals randomized to take FtF immediately would show greater coping, less distress and subjective family burden, and better family functioning after FTF compared to (control condition) individuals asked to delay taking the class but having access to all other NAMI or community supports over the same time period.

Methods: Each family member expressing interest in FtF within the geographic area of five participating Maryland NAMI affiliates was directed to the state FtF coordinator. She evaluated each person's appropriateness for FtF, and then ascertained their interest in the study. If interested, they were referred to research staff. A total of 1532 individuals were screened, of whom 1168 were eligible. Of these, 27% (N=318) consented to be in the study. were randomized, and completed the baseline assessment. A total of 160 family members were randomized to FtF and 158 to Control. Participants were contacted for a follow up interview three months later, corresponding to the end of the FtF course. All interviews were conducted by raters who were blind to the participant's study condition. Follow up rates exceeded 80% and did not vary by condition. To assess differences in coping, distress, burden and family functioning (measured with continuous variables) we used a General Linear Mixed Model (SAS Proc MIXED) to compare scores at the three month assessment controlling for baseline and FtF class. Participants had an average age of 51.9 (SD=10.9); A total of 61% were parents, 13% wee siblings, 10% were 77% were women. spouse/partners, 8% were other, and 7% were adult children of the consumer. A total of 66% were Caucasian, 27% were African American, and 7% were of other races/ethnicities. Six months after the end of their FtF course, FtF-condition participants were interviewed a third time using the same measures; control condition participants were not.

Results: In the intent to participate analysis, individuals having received FtF showed significantly greater overall empowerment and empowerment within their family, the service system and their community. Individuals who received FtF also had greater knowledge of mental illness, higher ratings of constructive emotion focused coping, and lower ratings of anxiety than individuals in the control condition. In addition, individuals who received FtF reported higher problem solving skills, related to family functioning. When the 17 individuals who did not attend any FtF classes even though they were assigned to the FtF

condition were excluded from analyses, FtF was also significantly associated with reduced depression symptoms and reduced overall distress. At 6 mo follow up, all effects were sustained. Additionally, individuals in the FtF condition experienced significantly reduced subjective burden (worry and displeasure) between the ending of FtF and the assessment six months later. This suggests accruing benefit of FtF, though the absence of a control does not allow us to confidently attribute that benefit to FtF rather than the passage of time.

Conclusions: This rigorous community-based randomized trial provides strong evidence of the effectiveness of the NAMI Family to Family Education Program, the most widely disseminated family support service in the country, and the longevity of its effects. This suggests that FtF merits consideration as evidence based practice.

DRAFT: Preliminary Results 2nd Version

Testimonial from a Family Member Psychiatrist Who Took the Family-to-Family Course in North Carolina

Dear Marcia and Paul: (Marcia and Paul Garrett are trained NAMI family-member teachers and state trainers now living in Kentucky. They are both members of the Family-to-Family Hall of Fame, honoring their commitment of having taught more than 10 classes)

I want to thank you both for presenting the NAMI Family-to-Family course to us in Salisbury. Having taught some classes myself, I had an inkling of how much physical and emotional energy it takes to teach a course like that. I can only say that your efforts are well worth it. The course was wonderful. As the daughter of a mentally ill parent, and as a psychiatrist, the Family-to-Family course is much more valuable than I could have ever imagined.

Your course turned out to be a treasure that I fervently wish had been presented to me during my training instead of ten years into my practice. But perhaps it has taken ten years of practice to realize how important this course is. You see, during my psychiatric training, I learned about diagnoses, medicines, side effects, blood tests, how to interpret research, and what other forms of therapy to prescribe to help the patient. In order to do well during medical school and psychiatric training, you have to be logical, read the literature, and, in general, demonstrate that you know a lot.

In the ten years that I worked with the severely and persistently mentally ill, it became clear that I could be a walking psychiatry textbook, up-to-date on the latest in every type of psychiatric treatment, respected by my fellow psychiatrists. The patients and their families do expect me to be well trained in the science of psychiatry. However, they are much more interested in how well I understand, empathize, and communicate with them, their particular problems, how the illness and the medications are affecting them. Very, very little about that was taught during my training.

The Family-to-Family course was the first course that spelled out for me what it was like to be a patient with a severe mental illness, and what it was like to be a family member. It was the first course that literally demonstrated for me that it was like to try to listen to someone while having auditory hallucinations. It was the first course that taught me concise, empathetic communication with a patient. It was very useful in helping me deal with my mentally ill mother. In fact when I used some of the empathetic listening skills taught in the class with my mother, her joy and relief that someone actually understood how she felt was so overwhelming that it almost reduced me to tears.

Finally, I gained incredible respect for the family members of severely mentally ill people. I listened to their problems, their fears, and concerns. I learned how I could be more helpful to them and their family member who has a mental illness in my role as a psychiatrist. I don't know how the patients and their family members do it. The media, which regularly holds up sports heroes and other celebrities as courageous, needs to spend some time in a Family-to-Family course to get a real picture of courage.

I cant'	' thank	you	botl	h enou	gh.

Margaret (Peg) Miller, M.D.

Sincerely,

NAMI FAMILY-TO-FAMILY OPERATING POLICIES (4/2009)

It is understood that NAMI State and Affiliate organizations, and their Education Committees, may not set policies at variance with the F2F policies stated below. These guideline are also to be followed by Family-to-Family trainers and teachers:

- 1. All NAMI material is copyrighted. Permission to use the material in a setting other than the NAMI F2F must be sought from and given by NAMI.
- 2. Permission to reproduce Class Handouts or Homework Handouts must be secured through NAMI. In every case where permission is granted, NAMI must be referenced as the course of the material.
- 3. No portions of the NAMI F2F curriculum can be used in offering another family education course or any other kind of course.
- 4. No group or individual can rewrite any of the NAMI F2F material, or add any new material to the curriculum.
- 5. The format or presentation of F2F cannot be changed or revised in anyway when offering it in the community.
- 6. The F2F is conducted over a period of 12 consecutive weeks. This time frame must not be altered, or shortened, in any way.
- 7. No more than a one-week hiatus is taken for holidays which may occur during the course term (Thanksgiving, Easter, etc.). When the course begins in the fall, it should always end by the 1st week in December, as the Christmas New Year's holiday weeks create too long a break in continuity.
- 8. Prospective teachers must be family members or partners of first degree relatives (parents, siblings, children, spouses) who have a serious mental illness. People who do not have this close relationship are not permitted to teach, as much of the teaching task is based on the family caregiver's lived experience.
- 9. All teachers and trainers in the Family-to-Family program must be NAMI members.
- 10. Consumers who are first-degree family members may also be enlisted to teach the course. It is understood that all family-member teachers of Family-to-Family will have reached a comfortable place in their recovery from the trauma of serious mental illness, and are able to sustain themselves through the emotional turbulence that may arise in their classes.
- 11. Prospective teachers for F2F may include individuals who have not taken the course as well as course graduates who elect to do so.

- 12. Due to the investment of time and money to train volunteers, prospective teachers must agree to teach a minimum of two course cycles. It is understood, of course, that unexpected life situations may occur that will necessitate compassion and flexibility in this policy.
- 13. Untrained family members are not permitted to serve as Family Educators. In cases where a teacher must drop out during the course, an untrained substitute may be appointed to help with lecturing, but may not continue as a teacher without the requisite training.
- 14. The weekend Teacher Training Workshop may not be altered, or condensed, in any way.
- 15. Family member participants will not be charged a fee of any kind for enrolling in and participating in the 12-week NAMI F2F.

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Family-to-Family State Teacher Training

Cost Sheet at a Glance

Materials for 9 co-teacher teams to be trained (18 people)

Teacher Manual (printed by state or local affiliate hosting the teacher training)

\$ cost TBD at state/local

level

16 / 61	
Blue Card Sets (1 per team @ \$4)	\$ 36.00
Emotional Stages Chart (1 Per team @ \$2)	\$ 18.00
Tribute Video (1 per team @ \$4)	\$ 36.00

Total Materials Cost \$ 90.00

Outreach Materials: For English, Spanish, or African American Outreach

F2F Poster 8 ½ x 11 @ \$2.00 (Qty. 25) F2F brochure @ \$3.75 (Qty. 50)

Note: Classroom/Homework Handouts Master Copy Set – Printed by state or local affiliate. Cost TBD at state/local level.

Free Materials available from NAMI for your teachers:

New pages for Curriculum (sent annually)

F2F teacher kit (national resource material to display in classroom)

Access to the F2F Intranet site filled with downloadable resource material

Teacher Training Cost (we recommend a retreat site as it is substantially less expensive than a hotel for rooms and meals)

At a hotel:

2 nights lodging for 18 participants + 2 trainers \$ TBD based on hotel rate Meals for 18 participants + 2 trainers \$ TBD based on hotel rate

3 lunches

2 breakfasts

2 dinners

If you must recruit one or two trainers for the teacher training session from another state, you must cover the travel (airfare @\$400 or mileage @ .51 cents per mile), lodging, meals, and a trainer fee (negotiable – ranging from \$500 - \$1,000).



You can obtain a copy of the latest NAMI Peer-to-Peer Coordinator Contacts list when you contact namieducation@nami.org



The NAMI Peer-to-Peer Recovery Education Course is a free ten week, two hours per week experiential education course on the topic of recovery for any person with serious mental illness. The Course is similar to NAMI's Family-to-Family Education Course in that it is based upon the idea that living with serious mental illness is, among many other things, an experience of trauma, and the recovery path occurs in predictable stages. The Course is designed to offer an opportunity for growth regardless of individual stage, and the diversity of experience among course participants allows for a lively dynamic that moves the course along. The classes are taught by teams of trained mentors- or peer-teachers- who themselves have learned to live well.

The Course uses a combination of lecture, interactive exercises and structured group processes to promote awareness, provide information, and offer opportunities to reflect on the impact of mental illness as it expresses itself uniquely through each participant's life. Each week builds upon last, bringing participants through a progression of self-awareness that has its roots in universal experiences associated with recovery.

What is the mission of Peer-to-Peer?

The mission of Peer-to-Peer is to help people with serious mental illness achieve and maintain wellness.

What methods are used to accomplish the goals of Peer-to-Peer?

Training:

Peer Mentors are certified through a three day, peer-led training session offered by their NAMI State or Local office. Trainers of Mentors are certified by attending a 2 ½ day, peer led training session offered yearly by NAMI National.

Technical Assistance Calls:

NAMI National offers ongoing, bimonthly technical assistance to Peer Mentors through free teleconference calls in order to ensure continued program quality.

Curriculum Updates:

The course is reviewed and updated yearly by the Director of Training

What is the unique value offered by Peer-to-Peer?

There are many do-it-yourself, workbook-style education and support programs available from other organizations, institutions and individuals. This course differs from all of them with regard to both substance and performance. Peer-to-Peer offers comprehensive

information on: the biological bases of mental illness; personal and interpersonal awareness, effectiveness, and coping skills; and information on addictions, spirituality and basic self-care. Additionally, NAMI's Peer-to-Peer Recovery Education Course provides participants with two tangible products related to preventing and accommodating relapse: a Relapse Prevention Plan and a generic Advance Directive for Mental Healthcare Decision Making.

Testimonials

"This course has literally been a life saver. It has opened my eyes to better understanding my illness and methods of recovery I did not know about before taking the course."

"This course has given me a sense of who I am. I understand what is going on with me and I am able to cope. I have gained employment and committed to my recovery. I've come a long way since I started."

"I came here wanting to know more about my mental illness and I came away with something more: to help people around me to know more about my illness. So it exceeded my expectations."

"I believe the course was extremely educational and I have learned tools and techniques to manage the day to day and long term stresses of having a mental illness. In addition, I have gained greater insight into my disorder."

"I have made friends that will remain in contact after the course."

"This course has given me insight, information, and an understanding of my illness."

"It has helped encourage me to pursue finding a full time position."

"It gave me a better understanding of the mental illness I have and how to manage it."

"I feel I am more willing to examine to examine how my actions, behaviors, and thoughts come out of my illness and to be more forgiving of myself."

"It made me feel I was not alone in coping with a mental illness, it gave me hope that I could recover and that my life would not always be filled with chaos, it gave me positive role models to inspire me to strive for recuperation and success in life."

Process for Joining the NAMI Peer-to-Peer Program

- 1. Organizations wishing to join the program must first demonstrate their readiness and capacity to sustain the program in the field. Do they have adequate funding to support the program; do they have a pool of peer mentors (teachers) who will commit to teaching at least two course cycles; is the organization's infrastructure ready to handle the tasks of program direction and coordination; can they support a paid Program Director, or find a dependable volunteer to do this key job?
- 2. Upon signing a contract with NAMI to inaugurate the program, the organization schedules the initial teacher training, a weekend event held from Friday morning until Sunday afternoon. Two NAMI national Peer-to-Peer trainers travel to this training site to conduct this session for the first 12-20 mentors coming into the program.
- 3. Once the trained mentors have taught at least one cycle of classes, two mentors may be selected to be program trainers. The selected mentors attend the training of trainers session when it is next scheduled. From this point on, these trainers conduct all training of mentors for the program in their home state or country. As the teacher pool grows, organizations may send other teachers to be trained as trainers. This is how the program becomes self-sustaining and grows.
- 4. Sites can obtain a free electronic download of the Peer-to-Peer curriculum and are responsible for copying the material for classes, as well as for obtaining needed supplies. Sites bear the cost of travel for two NAMI national Peer-to-Peer trainers as well as their lodging and meals. Sites are responsible for the costs associated with holding a centralized training for the initial and subsequent groups of Peer-to-Peer mentors. Sites must pay for the cost of copying class handouts for each cycle of classes, the cost of teacher manuals, and the costs connected with effective outreach for the course (advertisements, brochures, posters). After the program trainers are in place, the organization pays variable costs for all future mentor trainings, and the cost of copying mentor and trainer manuals.
- 5. The NAMI Department of Education, Training, and Peer Support stays in close contact with each organization running the program, offering technical assistance and consultation.

Sample Yearly Budget - NOTE: Training costs vary according to where the training is held, what time of year (if booking a hotel), how many trainers are flying in, how many trainees there are, and negotiation with the training site. Ongoing cost varies according to number of classes held.

Training Budget

STANDARD BUDGET

Item	Cost	
Trainer Stipend	\$1,000.00	(\$500 per trainer)
Trainer Airfare	\$700.00	(\$350 per trainer)
		(\$100 per night, 2 nights, 16 trainees + 2 single
Lodging	\$3,800.00	rooms for trainers for 3 nights)
Meals	\$6,750.00	(Catered by hotel)
AV equipment / presenters	\$200.00	(Easel pad/paper for both days)
Meeting Room	\$0.00	(Typically free at hotel)
Training Material	\$500.00	(General supplies)

SHOESTRING BUDGET

Item	Cost	
Trainer Stipend	\$500.00	(\$250 per trainer)
Trainer Airfare	\$700.00	(\$350 per trainer)
		(\$100 per night, 3 nights, 2 trainers, single rooms.
Lodging	\$600.00	Trainees local)
		(Tightly budgeted, discounted meals. Eg:
Meals	\$1,600.00	bagels/pizza/chips/bottled water)
AV equipment / presenters	\$0.00	(Offered free at hotel)
Meeting Room	\$100.00	(Nominal fee)
Training Material	\$500.00	(General Supplies)

Peer-to-Peer Class Budget

Item	Cost	
	\$250 -	
Mentor Stipend	\$500	(Per Mentor)
		(Variable depending on class size and amount of
Supplies	\$50 - \$200	donations/discounts)
Location for Class	Variable	(Many locations are free, some require nominal fee)

Other Costs

Item	Cost	
	Up to \$500	(Brochures, posters, pass along cards, relapse
Ongoing Materials	per year	prevention grids, DVDs, shipping costs)
Coordinator Salary	Variable	
Traveling		
Reimbursements	Variable	





What is NAMI Connection?

The NAMI Connection Recovery Support Group Program is a peer-based, mutual support group program for any adult living with a mental illness. Connection groups provide a place for individuals who have in common the experience of living with mental illness, to share experiences and use them as learning opportunities. Groups are a safe space to confront the challenges that all consumers face, regardless of diagnosis

Each group:

- Meets weekly for 90 minutes
- Is offered free of charge to NAMI members and non-members alike
- Follows a flexible structure without an educational format
- Does not recommend or endorse any medications or other medical therapies

All groups are **confidential** - participants can share as much or as little personal information as they wish.

Connection groups maintain a positive atmosphere through **sincere**, **uncritical acceptance** modeled by the facilitators, the guideline to "keep it in the here and now," and the invitation for group members to share "what has worked" for them. These groups provide a place that offers respect, understanding, encouragement, and hope.

Connection groups should add to, and not replace, the treatment plans determined by individuals and their mental health care provider.

The vision of the NAMI Connection program is that every person in this country who lives with a mental illness will have, within reasonable traveling distance, a Connection group to attend.

Who Are NAMI Connection Facilitators?

Connection groups are led by **two trained facilitators** who are in recovery themselves and are at a point where they want to "give back" to others. They understand the daily challenges of living with a mental illness and can offer encouragement and support. Using structures and processes, the facilitators' responsibility is to keep the group talking. Facilitators are trained to lead, but not to instruct or do therapy.

Connection facilitators attend an intense two or three day training designed to help them develop the skills they need to facilitate a Connection Group.

Individuals wishing to become volunteer facilitators apply to be selected to attend trainings. All applicants are interviewed using a screening tool specially developed for Connection applicants. Those selected to attend receive skill training in the Connection model. Certified facilitators commit to a minimum of one year of service facilitating, in pairs as leaders, weekly 90 minute groups and to uphold the fidelity of the Connection model. Groups can have more than two facilitators who can share responsibilities. Facilitators need to be, or become, NAMI members.

Sample Training Budget – THREE DAY TRAINING of 18 Attendees

Training team = one coordinator + 3 trainers; total expense (without travel): \$5,786.25*

*Please note: If you can find a retreat center or facility other than a hotel, your training costs will decrease considerably – this budget is just an estimate, many states spend less than this.

	AMOUNT	COCT	TOTAL
ITEM	NEEDED	COST	EXPENSE
Manuals	18	\$20.00/binder	\$360.00
Facilitator Charts	18 sets	\$12.00/set	\$216.00
Facilitator Sand Timers (one and two minute)	18 sets	\$3.50/set	\$63.00
Marketing Materials - Brochures	1 pack	\$5.00	\$5.00
Marketing Materials – Pass-Along Cards	1 pack	\$2.50	\$2.50
Marketing Materials - Posters	1 pack	\$3.75	\$3.75
Lodging for Trainers and Coordinator for three nights (single rooms)	4 x 3 nights	\$89/night	\$1,068.00
Lodging for Trainees for two nights (shared room)	9 x 2 nights	\$89/night	\$1,602.00
Breakfast for all attendees for three days Lunch for all attendees for three days	22 x 3 days 22 x 3 days	\$7.00 \$9.00	\$462.00 \$594.00
Dinner for all attendees for two days	22 x 2 days	\$15.00	\$660.00
Meeting rooms (one main and two breakouts	3	WAIVED	\$0
Laptop	1	LOANED	\$0
Screen	1	LOANED	\$0
Projector	1	LOANED	\$0
Trainer Stipend (Optional, but encouraged \$250-\$500) Mileage or Travel Reimbursement (Optional,	3	\$250	\$750.00
Encouraged)	3	TBD	TBD
GRAND TOTAL			\$5,786.25

CONNECTION TESTIMONIALS

I don't know where I'd be without NAMI Connection; it literally saved my life. I'm so grateful for my group and now I just want to share this program with everyone living with a mental illness.

It is such a blessed relief to meet so many wonderful people who are intelligent and Capable, while dealing with a mental illness. All the facilitators have been so fabulous! Thank you so much for this program and giving me hope and the vision of a

NAMI Connection has enabled me to take a good look at my illness and see that I am not alone. The program has given me additional tools to not only accept my illness, but to help others along the way.

NAMI Connection has helped not only me, but also my family, to accept my mental illness.

If just one word were to be used to describe NAMI Connection, that word would be lifesaver; but otherwise NAMI Connection is a word and meaning of its own, complete with a heart that beats by the many people that it has helped.

The Connection group is the best one because people can solve problems there. It isn't just a bunch of sad stories; people are coming up with solutions and stuff to do for the next week. One of our group attendees is taking her meds and getting herself to her counselor and is just about able to go back to her career in great part due to Connection.

Getting involved with NAMI Connection has helped me to get involved with other people who share the same issues as I do, which means I've made some really good friends. It has also helped me to become more of an advocate for myself in dealing with illness and has helped me to start taking better care of myself.

I am grateful every day for the opportunity to facilitate this group because it has given me a new positivity that I hadn't had for a very long time.

I am not alone! There is a place where people understand me, are there to help me, and I feel better about myself when I help someone else. I can get involved in NAMI Connection and make a difference!

NAMI Connection has broadened my view of the entire support group process. I enjoy referring to the posters because this provides a structure which we all know we have in common. I also gain confidence in myself with each group I co-facilitate. Thank you NAMI Connection for providing a supportive sanctuary for our communities!

NAMI Connection has made me realize that I can truly feel comfortable around my peers, and I really needed that feeling!

When I first separated from my wife I thought I was going to be alone. I was suffering from mental illness and I had no friends or relatives who could truly support me. Then I found the NAMI Connection support group. During the worst time of my life I had people to talk to who completely understood my illness and my problems. I made new friends and had something to look forward to all week. I believe that surrounding myself with people who cared and understood is what got me through my divorce. Now I am in full recovery rebuilding my life and relationships. I was so thankful for NAMI Connection for being there for me I decided to become a facilitator. Now I am finding even more growth, recovery, and healing through helping others.



You can obtain the latest In Our Own Voice state contact list when you contact nami.org



The In Our Own Voice: Living with Mental Illness Program is NAMI's national effort to educate the general public and, more importantly, change the attitudes, preconceived notions and stereotypes of who and what persons living with mental illness look and act like.

This is accomplished through community presentations, giving NAMI organizations at both state and local levels the opportunity to have a precious advocacy resource – a group of trained speakers. The trained presenters give first-hand experience on what it is like to live with a mental illness, as well as convey the NAMI treatment, acceptance and recovery message. Research by Dr. Patrick W. Corrigan, Professor of Psychiatry at Northwestern University, and Executive Director of the Center for Psychiatric Rehabilitation at Evanston Northwestern Healthcare, indicates that the "best practice" for reducing stigma is through this kind of direct and personal contact.

There are two phases to the "IOOV" program. Phase one is the training, which lasts two full eight-hour days. The training consists of teaching attendees to share their story utilizing the "IOOV" format and philosophy. The training emphasizes the two roles of the "presenter" – how to share his or her story, and how to master the best techniques for leading group discussions.

The video and presentation format used in the field is divided into four sections, starting with an Introduction and moving on to the sequential topics of Dark Days, Acceptance, Treatment, Coping Skills and finally Successes, Hopes and Dreams. The attendees are taught how to use the 15-minute video at each interval to share part of their story and then engage the audience in a discussion on the topic. The training also imparts audience facilitation skills, and identifies specific audience discussion points for a variety of audiences such as others with mental health challenges, family members, providers, general lay audiences, politicians and law enforcement personnel. As a result of attending the training, consumers become effective advocates in their community carrying messages that are powerful and heartfelt. Presenters with the IOOV program put a face on mental illness that will resonate with the public and help them better understand the realities of persons living with mental illness.

The second phase of the program occurs after presenters have attended the IOOV training and have been certified by the trainers leading the training. They are then qualified to give the IOOV presentation in their community and are paid a stipend of 305 for each presentation.

At each event, audience members are asked to complete an evaluation form which has a comment section allowing them to give feedback on the presentation. Audience members are also given a special take-home pamphlet, which includes a general fact sheet and overview of the presentation they have just witnessed. NAMI Affiliate representatives are strongly

encouraged to attend each presentation to hand out their local information and ask audience members to join their local NAMI.

The people attending these sessions are as diverse as the people we train. The IOOV program goes to audiences in outpatient/inpatient facilities, to those in drop-in centers, business groups, local county jails and faith-based organizations. Many presenters also teach in the Peer-to-Peer and Provider Education Programs, and are often called upon to do the presentation in Class 10 of Family-to-Family. IOOV presenters are consistently being asked to enter different learning institutions ranging from elementary schools to university medical school classes. In some areas, IOOV has become a formal part of police academy and crisis intervention trainings. We are proud and gratified that the IOOV program and presenters have been featured in newspaper articles all over the United States.

With the President's Freedom Commission Report focusing on the need to eliminate stigma, it is exciting to report that NAMI's In Our Own Voice program has positioned itself to become the largest anti-stigma program in the country.

Staff at NAMI's national office offer technical assistance to each state organization sponsoring the program, to its regional IOOV Coordinators and to presenters requesting guidance and support. Staff also assist with business and marketing planning on all levels, and are ready to go to work with any NAMI Affiliate interested in getting the IOOV program implemented in their community.

Testimonials for In Our Own Voice

"I have been working on the problem of stigma for the past seven years and have discovered that people with mental illness suffer the same sort of prejudice and discrimination as members of some ethnic groups. Through my research, I have discovered that the best way to change public stigma is through direct contact; help a member of the naïve public meet and interact with a person with mental illness. NAMI's In Our Own Voice has organized the wisdom of this research into a readily useable package for tearing down stigma. IOOV provides the structure for people with mental illness to tell their stories to the public. The bravery and eloquence of IOOV speakers rank among the many freedom fighting activities that have advanced civil liberties during the course of American history."

Patrick W. Corrigan, Psy.D., Professor of Psychiatry Northwestern University Executive Director Center for Psyciatric Rehabilitation Evanston Northwestern Healthcare

According to the feedback that I have received, I have given renewed hope to family members of those given a mental illness diagnosis: doing a presentation has allowed me to overcome fears and has brought me out of a depression that I had been experiencing while preparing for a presentation, enlightens others that are on the outside as to what mental illness can look like and feel like on the inside, reinforces the importance of my coping strategies when I find myself going south, restores my joy when I go over my successes, hopes and dreams.

Anonymous IOOV Presenter

Teaching others how to become an IOOV presenter is very rewarding because I know I am helping people see that they are capable of really making a huge impact in the lives of others. The tools that are taught in the course help people not only be good presenters but better advocates for themselves. I felt like I empowered the presenters for the rest of their journey and this was such an incredible feeling.

An IOOV Trainer, Presenter & Coordinator

I know that I have developed healthy new purposes for my life and that I am doing the work I am meant to do. I know that I am changing the face of mental illness, and that I have transformed my pain into the power to make a difference. I love doing presentations and will do as many as I am offered!"

Kate McGinnity, Presenter

Sample Yearly Budget for IOOV– Example Only

Training costs vary according to where the training is held, what time of year (if booking a hotel), how many trainers are flying in, how many trainees there

are, and negotiation with the training site)

COST CENTERS	SAMPLE BUDGET 1 YEAR	SHOESTRING BUDGET 1 YEAR	PUT YOUR NUMBERS HERE
Coordinator Salary	\$15,600 (20 hrs/wk @ \$15/hr)	Volunteer (10hr/week)	
Training Cost- 2 days: -Breakdown of training cost:	\$9,400	\$1,899 *assumes only local trainees	
✓ Trainer Stipend	\$1000 (\$500 per trainer)	\$1000 (\$500 per trainer)	
✓ Trainer Airfare (for two trainers from out of state)	\$650	\$60 (gas and mileage for two in-state trainers)	
✓ Lodging for 16 participants, 2 trainers	\$1800 (hotel)	\$340 (Lodging required for trainers= 2nights per trainer@ 85 per night) All local participants, no hotel arrangements	
✓ Meals	\$4,500 (hotel-total cost of meals for both days of training, includes meals and snacks)	\$514 (Includes discounted 2 breakfasts, 2 lunches, 1 dinner, snacks, plenty of water for 20 people- includes trainees, trainers, coordinator plus one extra)	

COST CENTERS	SAMPLE BUDGET 1 YEAR	SHOESTRING BUDGET 1 YEAR	PUT YOUR NUMBERS HERE
		Breakdown of discounted meals: o 48 bagels with cream cheese (2 breakfasts): \$54 o 48 subs, cookies, chips (2 lunches): \$248 o 5 pizzas (1 dinner- 2.5 slices per person): \$63 o 20 cookies, bags of chips (1 snack): \$29 o 120 bottles of water (3 per person per day): \$120	
✓ AV equipments presenters	\$300 (hotel)	No AV cost- donated by venue	
✓ Meeting room	\$500 (hotel)	\$25 (nominal fee)	
✓ Training Materials	\$300	\$300	

COST CENTERS	SAMPLE BUDGET 1 YEAR	SHOESTRING BUDGET 1 YEAR	PUT YOUR NUMBERS HERE
Stipends	\$5,760 8 Presentations per month for a year@60 per presentation	\$1,440 2 Presentations per month for a year@60 per presentation	
Ongoing Materials Cost Pamphlets - \$17.50 per 50 Brochures - \$12.75 per 50 State/local brochures-	\$800 per year	\$200 per year	
TOTAL COST:	\$31,650	\$3,539	



NAMI PROVIDER EDUCATION PROGRAM: COURSE DESCRIPTION

Background

The NAMI Provider Education Program is based on The NAMI Family-to-Family Education Program. It has been extensively rewritten to apply specifically to the learning needs of line personnel at public agencies who work directly with individuals suffering from severe and persistent brain disorders.

The course is held for 5 consecutive weeks, for 2 1/2 hours per session, and for staff convenience, it is offered at an agency site. A maximum of 25-30 participants can attend the course, and class members are expected to come to all 5 classes. As in the NAMI Family-to-Family Education Course, the curriculum format is composed of short lectures, followed by time for elaboration of the teaching points in group discussion and group exercises. Arrangements to give the course at a CMHC are made through the agency's Executive Director and the director of the agency's Community Treatment division.

Course Perspective

The NAMI Provider Education Program presents a penetrating subjective view of family and consumer experience in serious mental illness. We consider the devastating event of brain disorder to have a profoundly traumatic impact upon our lives. We believe that our adaptation over time involves learning how to manage a traumatic syndrome process, and to become strong in our demands for services which provide the best support for recovery. Even though we move through stages of emotional resolution from disbelief to acceptance, we can never put the trauma completely behind us. Given the episodic or chronic course of brain disorders, the possibility of relapse threatens always to bring a "reenactment" of the initial trauma. It is our dedicated purpose in this course to help providers realize the hardships that families and consumers endure, and to appreciate their heroism in finding a way to reconstruct lives which must be lived, through no fault of their own, "on the verge."

The Teaching Team

The teaching team of the Professional Provider Program is one of its most unique features. The team consists of 5 people: 2 family members who are trained NAMI Family-to-Family Education teachers; 2 consumers who are knowledgeable about their own mental illness, have a supportive relationship with their families and are dedicated to the project of recovery; the fifth team member is a mental health professional, who is also a family member or consumer, functioning as the team coordinator. The teaching team attends an intensive Training Workshop to prepare them for teaching the course, and then meet together on their own to rehearse the class lectures.

NAMI PROVIDER EDUCATION PROGRAM: GOALS

- 1. To validate the subjective, lived experience of consumers and family member caregivers as a **Primary Knowledge Base** for developing staff skills and competencies in public agencies serving individuals with serious and persistent mental illness.
- 2. To emphasize the <u>Bio-Psycho-Social Perspective</u> necessary for a global understanding of neurobiological brain disorders and a full appreciation of the consequences of these serious illnesses on those who suffer them: However, the primary focus of the course is:
 - <u>Psychological</u>: The subjective dimensions of coping with these brain disorders and comprehending their traumatic impact on consumers' and families' personal lives.
 - Social: Rebuilding capacities to reconnect, to live with dignity and hope, which includes advocacy for improved community services and expanded opportunities.
- 3. To introduce <u>Clinical Principles and Strategies of Secondary Intervention</u>* as a durable working concept for effective provider/consumer/family collaboration, based on knowledge of family and consumer stages of adaptation to the traumas and life dislocation caused by serious brain disorders. <u>Course Motto</u>: Once you know where someone *is* in the adaptation process, you can "provide" what they *need* to support and strengthen them to come through it.
 - (* Pragmatic, concrete, practical steps taken to keep things from "getting worse.")
- 4. To demonstrate <u>Principles of Empowerment and Strength-Based Collaboration</u> by presenting a collective, cooperative "model" Teaching Team -- an actual "in vivo" colleagueship of 2 family members, 2 consumers, and a family member or consumer mental health professional, specifically trained and legitimized to direct a comprehensive 30 hour educational program for line staff.
- 5. To create a <u>Safe, Compassionate Learning Environment</u> for family members and consumers to disclose to providers the painful, emotional, human aspects of their experience; to affirm a shared_sense of family with providers as an alternative to the traditional division of "them and us"; to_foster mutual appreciation for the hard work and dedication required by everyone who lives with, cares for, or works with these serious brain illnesses.

NAMI PROVIDER EDUCATION PROGRAM: CURRICULUM

- CLASS 1: <u>ORIENTATION:</u> Introductions; Key principles guiding the course; Group exercise in building mutual respect and protection; The personal and family experience in critical periods of mental illness (Our trauma stories)
- CLASS 2: <u>CLINICAL BASES:</u> Basic principles of secondary prevention/intervention in Community Psychiatry: Clinical strategies for responding to psychological trauma; Secondary prevention stage models of family/consumer emotional adaptation to mental illness; Group exercise to determine consumer and family needs in critical periods of mental illness (Stage I)
- CLASS 3: RESPONDING EFFECTIVELY TO CONSUMERS AND FAMILIES IN STAGE II: The cascade of secondary traumas when families cope alone; Understanding symptoms as stressors (group exercise); Other significant stressors complicating passage through Stage II (Adverse effects of psychotropic drugs; Stages of adherence to medication; Co-occurring brain and addictive disorders; The trauma of incarceration and attempted suicide.
- CLASS 4: <u>INSIDE MENTAL ILLNESS</u>: Gaining empathy and understanding of what it is like to contend with the psychological impact of brain disorders; Understanding defensive coping strategies to protect against loss of identity and demoralization; Reiterating our appeal for trauma informed care; Up from obscurity: The whole family experience.
- CLASS 5: WORKING TOWARD RECOVERY: Suggested confidentiality guidelines: Case Study: How to frame collaborative work with consumers and their family; Recovery as conscious choice and action; Certification/Celebration

RESOURCE LIST

GLOSSARY OF TERMS

BASIC REFEENCES

PREFACE TO THE NAMI PROVIDER EDUCATION PROGRAM FIELD GUIDELINE

The NAMI Provider Education Program is designed to be taught by 5-person Teaching Teams, each comprised of 2 family member Family-to-Family Education course teachers, 2 consumers and a family member or a consumer mental health professional. It is to be presented to line staff at public mental health agencies in your state. It is optimal to train 3 teams to inaugurate the program in a state; the information in this Guideline is based on 3 teams participating.

The impact of the program rests in large measure on choosing teaching team members who can speak frankly about their lived experience with the pain and trauma of coming through serious and persistent mental illness, and who endorse the practice of consumer/family/provider collaboration.

The choice of target mental health centers is vitally important as well. As a start-up strategy in your state, it is wise to select progressive mental health agencies whose administrative leadership is supportive of the concept of family/consumer/provider collaboration.

It is essential to involve your State President and Executive Director in these negotiations "at the top," and to make every effort to enlist the support of the State Division of Mental Health. Your initial Provider Course training will, we hope, be the launching of a NAMI program that will become a permanent staple in staff training in your state.

It is understood that agencies signing up for the program will require participants to make a commitment to attend all 5 classes, and that clinical supervisors and division directors will attend as well.

States inaugurating the NAMI Provider Education Program should have their funding in place, and target agencies for the course should be selected and contacted prior to the Training Workshop.

The training component of this program enables team members with different perspectives to model the collaborative team approach and to maintain composure in any kind of agency culture.

Be sure you have reviewed the information on the Coordinator's Guide NAMI has already sent. After you have read the material in this Guideline, please contact namieducation@nami.org to schedule a planning call. At this time, we will go over all details and focus on the specific questions and concerns you might have.

THE ANNAPOLIS COALITION

ON BEHAVIORAL HEALTH WORKFORCE EDUCATION

May 24, 2004

Dear Dr. Burland

The Annapolis Coalition on Behavioral Workforce Education has completed its review of the nominations for Educational Innovations. We are pleased to inform you that your program entitled "NAMI Provider Education Program" has been selected as one of the 20 Innovative Educational Practices to be highlighted in an article to appear in a special issue of Administration and Policy in Mental Health, a peer-reviewed journal that aims to improve the effectiveness of behavioral health programs. As an Innovative Educational Practice, a description of your program will also be included on the Annapolis Coalition Web site, www.annapoliscoalition.com.

The NAMI Provider Education Program will be included in the above article entitled "Innovative Approaches to Education: Promising Directions for Behavioral Healthcare Reform. This article details the process by which innovations were selected as well as a brief description of the selected Innovative Educational Practices. I have included description of each of the innovative programs along with this letter.

At some point in the future, we will be mailing a certificate to you recognizing this award. We congratulate you on this award and applaud your efforts to improve the quality and relevance of education and training in behavioral health.

John A. Morris, Co-Chair The Annapolis Coalition on Behavioral Health Workforce Education

25 Park Street, 6th Floor New Haven, CT 06519 Phone (203) 785-5629 Fax (203) 785-2028 EXECUTIVE COMMITTEE

Coalition-Co-Chairs Michael A. Hoge, PhD Yale University School of Medicine John A. Morris, MSW University of South Carolina School of Medicine Members Neal Adms, MD, MPH California Department of Mental Health

Allen S. Daniels, EdD University of Cincinnati

Leighton Y. Huey, MD University of Connecticut Health Center

E-mail info@annapoliscoalition.org

Gail W. Stuart, RN, CS, PhD, FAAN Medical University of South Carolina

Web www.annapoliscoalition.org

veo www.aimaponscoantion.org

Susan Hardesty, M,D., Medical Director Institute of Psychiatry Medical University of South Carolina

April, 2007

It is my privilege to speak to the quality and benefit of NAMI Provider Training. Our hospital currently has its 5th class in this training. In this time when each training effort has to be cost-effective, it is clear that our leadership has a strong appreciation of the benefit of this experience.

We have shared with the consumer and family instructors some of the most personal experiences of their lives of consumers and their families. The sessions are personal and powerful. They teach us and move us to tears. We become humble as they challenge to reexamine our constructs of psychiatric illness and treatment. We walk in their shoes. We are moved, embarrassed, challenged, and we come away changed. The format is at first different, but it is the format that later facilitates the intimate sharing that has to occur.

I envy you the opportunity to embark on this journey with new eyes, an open heart and mind. You will be changed.

Santa Clara Valley Health & Hospital System Mental Health Department 828 South Bascom Ave., Suite 200 San Jose, California 95128 Tel (408) 885-5770 Fax (408) 885-5792

April 30, 2007

To Whom It may Concern:

The Santa Clara County Mental Health Department is pleased to support NAMI Santa Clara in their pursuit of a grant to further develop their Provider Education Course. NAMI Santa Clara County is a wonderful organization that serves our consumers, family members, staff, and the community at large. Their work continues to shine the way toward helping individuals and family members deal with mental health issues.

NAMI Santa Clara County has offered the Provider Education Course or our staff during the past two years. This course is one of the highest rated trainings that we offer. We view this course as one of the key learning experiences for our staff as we transition to an organization that values wellness and recovery for our consumers. The attendees learn so much about the consumer and family member's experiences and point of view, which helps to bridge the gap between providers and consumers. Most of the attendees have expressed that the course has profoundly affected their work. Many have stated that this was the best training they have every taken.

The Mental Health Department has successfully collaborated with NAMI Santa Clara County on many projects through the years. Their leadership is strong, and their trainers and volunteers have made a significant difference in our county. We fully support their effort to expand their services for our staff.

If you would like more information, please feel free to contact us at 408/885-5770.

Sincerely,

Nancy Peña, Ph.D. Mental Health Director Michael Ichinaga, Ph.D. Quality Improvement Manager

The Department of Mental Health is a division of the Santa Clara Valley Health & Hospital system. Owned and operated by the County of Santa Clara.

True North: The NAMI Provider Education Program Comes of Age

by Joyce Burland, Ph.D

The final report of the President's New Freedom Commission on Mental Health concluded that the nation's mental health system was "in shambles", and proposed a set of guidelines designed to fundamentally re-invent mental health care. The urgent tone of the report has inspired an outpouring of commentary calling for innovation and "seismic" change. In part, this shift in direction reflects the influence of leaders within the system whose progressive views on mental health reform have gained ground once the ailing system was officially declared beyond resuscitation. But the real credit for advocating radical transformation in the way people with mental illness are served in America belongs to the foot soldiers in the family and consumer movement.

This is another way of saying that our unwavering insistence on inclusion, validation, and respect over the last generation has not been in vain. A review of the recent system-change literature reveals that our ideas, and our ideals, inform many of the papers and proposals currently in circulation. Chief among these is a concept, staggering in its potential to revolutionize mental health care service delivery, called "True North."

In navigation, true north defines an ordinal point determined with reference to the earth's axis, rather than its magnetic poles. Synonymous with "accurate", "legitimate", "trustworthy", this term signifies an absolute reality rather than something which is manifest or assumed. A craft navigating by true north will unfailingly find its intended destination. In health reform, True North stands for an unerring guidance point in system transformation. Donald Berwick, the originator of this metaphor, proposes that in planning for reform, "the experience of consumers and families and communities" must serve as True North. This means the ordinal point for system quality derives from the recipients' reality-- our lived experience, our needs, our beliefs and strengths, as well as our reactions to services extended in our behalf. In their Quality Vision for Behavioral Health, authors Allen Daniels and Neal Adams advance this concept, stating—that in reinventing mental health care, "nothing is more important in the end than maintaining focus on the experience of recipients of care and their families. This commitment must set the compass and serve as 'True North' on the roadmap for change."

Rarely do we get a more telling correction, or subliminal analysis, suggesting why the mental health system veered so far off course. If the truth be told about our perceptions right now, the most significant feature of our reality is that so few people know anything about it. How many times have we heard families and consumers say that no one can possibly fathom the excruciating dislocation of mental illness, until it has actually happened to them or to someone they love? The late Senator Paul Wellstone observed

that most Americans learn about mental illness only through "intense involuntary immersion in it." Most others are oblivious to the enormous pain and trauma of this passage, and remain totally unaware of the tragic insufficiencies of our nation's response to it.

Many observers have attributed this cluelessness to the social distance (actually social isolation) imposed on those stigmatized by brain disorders. However, relatively few cite the drastic impact of professional and academic misdirection affirmed throughout most of the 20th century. The claim that mental illnesses derive from poor parenting and/or weak character suggests that the source of our trouble is more a private failing than a legitimate national concern; such a view from authorities in the mental health field deeply anesthetized the moral awareness of civic responsibility in the public mind. Furthermore, this same mistaken certainty supported the clinical premise that since the experts already "knew" the causative personal details of our reality, there was little left of any importance to

learn from us. Inevitably this assumptive error jarred the compass off True North; a mental health system evolved to assist people stricken with serious mental illness without an accurate or sufficient understanding of the true nature of this human experience.

In 1995, NAMI-Vermont developed and piloted the Provider Education Program in each of the state's ten public mental health agencies. This training model specifically targeted agency line staff – the yeoman workers who provide most of the day-to-day services to consumers and their families. Many of these direct care providers have no prior education or training in clinical interventions of any kind; they comprise a segment of the mental health workforce estimated at 40% of public agency clinic staff, and 60% of patient care staff in county and state psychiatric hospitals. We invited this group to undergo intense *voluntary* immersion into the private universe of families and consumers, promising that this experience would help them to offer what we needed most-- an understanding, empathetic, well-informed partner to work with us toward recovery.

Setting our compass squarely on True North; we trained NAMI family members, consumers and providers to teach the course in teams of five. They vowed to come to class prepared to reveal every raw emotion, personal truth and unedited response to mental illness, relating to the course content, as a core part of the curriculum. Operating from our no-fault educational mantra that "You Can't Know What No One Has Told You", we opened the door to our subjective, often chaotic world. We trusted that in ten weeks of working through the course together, the cumulative accounts of our lived experience with mental illness would tap into a common humanity and compassion more powerful than any socially or professionally conditioned belief system. And it worked: By the end of each course in the pilot project, the participants had witnessed the immense challenges involved in coping with mental illnesses, and acknowledged the elemental value of learning how to collaborate with supportive family caregivers.

Since 1997, NAMI organizations in 20 states and the Province of Ontario, Canada, have joined in to offer the program. Over 750 consumers have been trained as teachers, and over 9,000 staff members have taken the course. From every quarter we hear from providers that our commitment to "True North" has opened their eyes to suffering and heroism they hadn't seen, warmed their hearts to consumers and family members they hadn't understood, and made the Commission's call for a "consumer-and- family centered system" a tangible reality. Recounting our lived experience has demonstrated that recovery and resiliency can be achieved; it has reinforced the principle that our shared humanity must govern every domain of mental health care. Most radically, the program has called into question the claim that authority accrues only to an "all-knowing" professional elite. This model of training is a potent catalyst of transformative *empowerment*—of advocacy-througheducation -- enabling consumers and family members to take their rightful place as frontline experts and legitimate instructors on the subject of living with mental illness.

In 2004, the NAMI Provider Education Program was selected as an outstanding innovative training program by the Annapolis Coalition on Behavioral Workforce Education. This coalition of progressive mental health administrators and clinicians argues that "without conscious, concerted and urgent attention to improve workforce education", meeting the goals of the President's Commission may elude us altogether. To speak of system transformation, without insisting on cutting-edge training programs for the workforce at all levels, defeats the purpose and spirit of reform. If we ignore this "elephant in the room," the workforce will retain the old attitudes and habits which blind them to the competencies required for compassionate and collaborative practice. We must join together, as system reformers and advocates, to train and re-train the workforce, and to make True North the ordinal point for change in mental health care in America.

Building a Consumer and Family Centered Workforce in Mental Health:

The concept of patient centered care emerges in every discussion of healthcare reform. The field of substance use disorders treatment has made major strides in this area though its long tradition of engaging those in recovery as both employed and voluntary members of the workforce. In the case of mental health care reform, consumer and family empowerment will hold one of the keys to meaningful and lasting system transformation. There are multiple opportunities to build consumer and family driven systems of care by validating the historically invisible consumer and family care-giving workforce as an integral part of the delivery of mental health services.

Recommendation 5: Because consumer and family driven services are important to the delivery of patient centered care, a comprehensive consumer and family workforce development strategy should be implemented in mental health. The five core elements of this plan should include: (1) increased federal, state, and private support of consumer and family services; (2) the identification of consumer and family core competencies through a partnership of the Center for Mental Health Services with consumer, family, and professional organizations; (3) accountability among education and training programs to engage consumers and families in the redesign of training programs and as educators of all segments of the workforce, including other consumers and families; and (4) accountability among oversight organizations to ensure that all providers receive formal education and training in communication skills and collaborative decision-making with consumers and families. The *National Coalition on Workforce Development* could oversee implementation of this workforce plan.

The amount of mental health care provided by the employed workforce pales in comparison to the self-care and peer support offered by consumers and families. There are enormous, but overlooked opportunities in the mental health field, to educate consumers and family members in an effort to improve their capacity to understand their illnesses, navigate and maximally benefit from available services, and help others in distress. A competency set for consumers and families should be developed with federal support, followed by a dramatic increase in the education and training of these individuals. Consumers and families should not only serve as educators within these programs, but should also be included as educators of the pre-service and existing workforce, teaching about the lived experience of illness, treatment, and recovery. These educational initiatives require increased federal, state, county, and private support, as do organized peer support programs, which remain grossly under-funded in comparison to traditional treatment interventions. Finally, consumers and families will be better able to use their skills and obtain patient center care if providers have received formal training regarding communication and collaborative decision-making with consumers and families.

From: Expert Panel Recommendations to the *Institute of Medicine* Committee on <u>Crossing the Quality Chasm: Adaptation to Mental Health and Addictive Disorders</u>, August 19, 2004.

$\frac{\text{BUDGET FOR THE 5-WEEK NAMI PROVIDER EDUCATION}}{\text{COURSE}}$

NAMI COSTS	2 TEAMS (10)	<u>3 TEAMS 15)</u>
<u>Course Materials Cost</u>		
All manuals and Handout Copy Sets are Available electronically		
Trainer Costs 1 Trainer: Travel	\$ 400.00	\$ 400.00
TOTAL PAID TO NAMI	\$ 400.00	\$ 400.00
STATE COSTS Training Site Costs 1 ½ days, @ \$200 per trainee, lodging/meals (estimated)	\$ 2,000.00	\$ 3,000.00
Program Field Costs 25 Participants' Class Notebooks @ \$2.00 Honorariums for Teaching Teams @ \$250 per teaching Teams are the statement of the	\$ 50.00 her 2,500.00 250.00	\$ 50.00 \$ 3,750.00 250.00
	\$ 2,800.00	\$ 4,050.00
TOTAL STATE COSTS	\$ 4,800.00	\$ 7,050.00
TOTAL PROGRAM COST	\$ 5,250.00	\$ 7,450.00

NOTES

The NAMI trainer will arrive a day early to set up the Workshop. Training site costs vary depending on choice and expense of accommodations. <u>Class handouts are copied by the host agency, or by your office, or paid for by your funding source.</u>

In writing grants, many states have added a figure of \$1,200 - \$1,500 to cover their overhead expenses.



NAMI FAMILY SUPPORT GROUP FACILITATOR SKILLS TRAINING PROGRAM

"As much as I already knew about running a support group, this training gave me many valuable guidelines and new techniques. I know I will run a much better group with these skills under my belt, with more participation and more group interaction. I want to thank the NAMI state facilitator trainers for an altogether delightful, if strenuous, series of training exercises." Local Support Group Facilitator

The NAMI Family Support Group Facilitator Skills Training model differs from the more traditional "share-and-care" model in that it offers an innovative set of group structures and processes specifically designed to help facilitators in their support work with caregivers dealing with mental illness. These various procedures come with clear guidelines to follow; used together, they encourage full group participation and result in upbeat, constructive support group meetings. Both seasoned and less experienced facilitators have found these new methods easy to learn, and a joy to utilize, because they steer the group process through many problematic situations which commonly undermine support group effectiveness.

As a facilitator, how do you guarantee that the meeting will start and stop on time? What do you do when someone monopolizes the group's time? How do you respond to disrespectful group members? How do you shift a group away from "catastrophizing", or handle the intense sadness a group expresses? What's the best way to deal with "hot potato" subjects such as relapse, involuntary commitment or suicide? How do you encourage quiet people in the group to talk? What about participants who insist they have a problem that's just not solvable? How do you help a group do its own work and not look for a leader direction at every turn?

NAMI family support group facilitators face these issues in their groups every day. Participants in the training testify that the skill-building offered in the 2-day training makes them feel much more confident and secure as support group leaders. Recognizing that NAMI support groups provide the entry point for thousands of family members new to NAMI, the state and affiliate organizations involved in this program report that the resulting improvement in their support groups correlates highly with increased membership and identification of new leadership.

The NAMI Family Support Group Facilitator Skills Training model has been adapted for consumer facilitator training and used in the NAMI Connection Recovery Support Group Program.

NAMI state organizations are encouraged to send facilitators to the annual NAMI National Family Support Group Facilitator Skills Workshop Training to become state trainers and will then conduct Facilitator Skills Training Workshops for local facilitators in their state.

Forty-four states, British Columbia, and Mexico promote the NAMI Family Support Group Facilitator Skills Training model. If you are a local support group facilitator and would like to attend a facilitator skills training, contact your state NAMI to find out when the next facilitator training session will be held.





National Alliance on Mental Illness

The fundamentals of caring for you, your family and your child with mental illness

NAMI Basics is the new signature education program for parents and other caregivers of children and adolescents living with mental illnesses. Development of this program was based on the success of other NAMI signature education programs for consumers and families available across the country. NAMI drew on course elements which have been extensively tested and found to be highly effective in the field. These elements include:

- recognition of mental illness as a continuing traumatic event for the child and the family;
- sensitivity to the subjective emotional issues faced by family caregivers and well children in the family;
- recognition of the need to help ameliorate the day-to-day objective burdens of care and management;
- gaining confidence and stamina for what can be a life-long role of family understanding and support; and
- empowerment of family caregivers as effective advocates for their children.

The process of emotional learning and practical insight for families occurs most readily, and dependably, on the guided group process which takes place when individual family members are in a class together. This program will also take advantage of advancing technology which allows programs to virtually connect families and provides broader access to vitally important information.

The NAMI Basics Education Program includes the following components:

- 6-2.5 hour classes of instructional material, discussions and interactive exercises which may be delivered as a series of consecutive weekly classes, or on consecutive Saturdays to accommodate the time constraints faced by families of children and adolescents.
- A section of the NAMI web site will be dedicated to disseminating information, including informational videos that can be viewed online, and resources for this program and to connecting family program participants.

• In addition to the core course of 6 classes, additional topic modules will be developed for independent presentations for families interested in specific topics, such as transition issues, and advocacy.

The program includes a rigorous evaluation process to both build an evidence base on the effectiveness of the program and also to help ensure that the program continually delivers best practices to meet the unique needs of families.

NAMI Basics Education Program Curriculum

Class 1: Introduction: It's not your fault; Mental illnesses are brain disorders

Special features of the course; learning about the normative stages of our emotional reactions to the trauma of mental illness; our belief system and principles; recognizing that mental illnesses are biological brain disorders.

Class 2: The biology of Mental Illness; getting an accurate diagnosis

An overview of human development; specifics of brain development; current research on brain mechanisms involved in mental illness in children and adolescents; overview of the diagnostic process; and overview of the types and subtypes of major mental illnesses that can develop in childhood and adolescence (ADHD, ODD, CD, Major Depression, Bipolar Disorder, Anxiety Disorders, Schizophrenia, OCD and Substance Use Disorders).

Class 3: Treatment Works

Telling your stories; overview of treatment options available; explanation of evidence base practice designations; review of various types of mental health professionals in the field; overview of medication as a treatment option for children and adolescents, including the current debate within the field on the subject of treating children and adolescents with medications, including black box warnings.

Class 4: Objective and subjective family burden

Acknowledge the strains of family burden and the impact of mental illness on each family member; learning various skills that can be used to improve day to day communications within the family as well as during episodes of crisis; communication skills, problem solving skills, tips for handling challenging behavior, crisis preparation and response, developing a relapse plan.

Class 5: The systems involved with your child and the importance of record keeping

Learning how to keep records on your child; reviewing a sample record keeping system; overview of the systems your child may be involved with including the mental health system, the school system and the juvenile justice system; introduction to issues that will arise as your child reaches adulthood.

Class 6: Advocacy, Review, Sharing and Evaluation

Building an advocacy team for your child; meet people who are resources fro you in advocating for your child; invitation to join NAMI in the fight to end discrimination and ensure access to appropriate treatment services; reminders about self-care; evaluations and certificates.

Comments from Parents/Caregivers who have been Trained to Teach The NAMI Basics Education Program

- "I really, really, liked the emphasis on the practical aspects of parenting a child with special needs."
- "I wish this course was available when my child was first experiencing difficulty."
- "This class was unexpected wonderful! I did not expect to learn so very, very much! This program is well written with excellent segues between topics. It covers so much more than BASICS that the title doesn't do it justice."
- "This program rescues parents and children and may improve the school system, mental health (public and private) system and the juvenile justice system as parents are empowered with information and confidence."
- "Not only have I learned a lot of mental health and issues related to understanding my child, I have also learned much about NAMI and the concern they have and benefits of being a part of this organization."
- "This is such a great step by step program that walks parents every step of the way. It is as if you are holding their hand through it all."
- "I am so excited that this level of help is available it's exactly the kind of thing that I personally have been looking for over the past 3 years. Knowing it's now available to other parents is really exciting for me."
- "This will become my go to book for everything and I am so ready to get started and spread the knowledge to other family members."
- "I, as a parent, have gotten a lot from the text and realize many more parents need this information. The resources section is beyond words."
- "This program does cover the *basics* for any person who has to deal with a family member with a mental illness as well as pointing them in the next direction they need to go."
- "The course is inclusive of almost all aspects of family and child and resources. I could have spent a lifetime getting all this information on my own. I feel supported, strong and ready to go forward."
- "Extremely informative and rewarding experience. It was much more thorough than I had anticipated and I particularly like the way the information is worded. It is sensitive to parents and at the same time honest and "real". It was presented with humor and in a down to earth manner, which are very important to learners."
- "I find it truly remarkable and unbelievable that this training is free to those who are interested."

NAMI Basics Education Program Operating Policies 2009

It is understood that NAMI State and Affiliate organizations, and their Education Committees, may not set policies at variance with the NAMI Basics program policies stated below. These guidelines are also to be followed by Basics teachers and trainers.

- 1. All NAMI material is copyrighted. Permission to use the material in a setting other than the NAMI Basics Education Program must be sought from and given by NAMI.
- 2 Permission to reproduce Class Handouts or Additional Resource Handouts must be secured through NAMI. In every case where permission is granted, NAMI must be referenced as the source of the material.
- 3. No portions of the NAMI Basics Education Program can be used in offering another family education course or any other kind of course.
- 4. No group or individual can rewrite any of the NAMI Basics material, nor can the format or presentation of the NAMI Basics Program be changed or revised in anyway when offering it in the community.
- 5. The NAMI Basics Course may be conducted in the following formats:
 - over a period of 6 consecutive weeks, 1 class per week
 - over a period of 3 consecutive weeks, 2 classes per week
 - across consecutive Saturdays, with no more than 2 classes taught on any one Saturday

These time frames must not be altered, or shortened, in any way. Under no circumstances should the entire course be taught in a single weekend.

- 6. No more than a one-week hiatus is taken for holidays which may occur during the course term (Thanksgiving, Easter, etc.). When the course begins in the fall, it should always end by the 1st week in December, as the Christmas New Year's holiday weeks create too long a break in continuity.
- 7. Prospective teachers must be parents or other primary caregivers of an individual who developed a mental illness as a child or adolescent. People who have not had a parental type relationship with a child or adolescent with a mental illness are not permitted to teach, as much of the teaching task is based on the parent/ caregiver's lived experience from those early years. Examples of people who would not be eligible to teach the course include; teachers, mental health professionals, day care workers, or adults living with mental illness who do not also have the primary responsibility of caring for a child in their home.

- 8. Prospective teachers for NAMI Basics may include individuals who have not taken the course, as well as course graduates who elect to do so.
- 9. All teachers and trainers in the Basics program must be NAMI members.
- 10. Due to the investment of time and money to train volunteers, prospective teachers must agree to teach a minimum of two course cycles. It is understood, of course, that unexpected life situations may occur that will necessitate compassion and flexibility in this policy.
- 11. Untrained family members are not permitted to serve as NAMI Basics Teachers. In cases where a teacher is unable to continue teaching the course, an untrained substitute may be appointed to help with lecturing. The substitute will not be allowed to teach the course again until they participate in a regular weekend Teacher Training Workshop.
- 12. The weekend Teacher Training Workshop format may not be altered, or condensed, in any way.
- 13. Participants will not be charged a fee of any kind for enrolling in and participating in the NAMI Basics Education Program.



NAMI Basics Education Program Pilot Evaluation Final Report Summary June 2008

The NAMI Basics Education Program was developed in 2007. It is a six-class psychoeducational program designed specifically for parents and other caregivers of children and adolescents who have either been diagnosed with a mental illness/serious emotional disturbance or who are experiencing symptoms but have not yet been given a formal diagnosis. The program is taught by two trained parent teachers using a detailed curriculum. The goals of the NAMI Basics Education Program are:

- To give parents/caregivers the fundamental information they need to be effective as a caregiver
- To help parents/caregivers cope with the traumatic impact that mental illness has on the child living with the illness and the entire family.
- To provide tools for parents/caregivers to use even after completing the program that will assist them in making the best decisions possible for the care of their child.
- To help the parent/caregiver take the best care possible of the entire family especially themself.

A pilot evaluation was conducted by Missouri State University on the NAMI Basics classes provided in three states, Illinois, Utah and South Carolina between January and May, 2008. A Pre-Post Test design was used to measure each participants' changes in knowledge about mental illness in children and adolescents, as well as changes in their own perceptions of (1) the impact of the illness on their family and (2) their personal ability to influence treatment interventions and advocacy related to their child's illness.

The following describes the participants in the pilot classes:

- Average age of participants was 45 (range of ages 23 to 82 years)
- 81% of participants were female
- 66% were married
- 83% were Caucasian
- 78% reported some college level education
- 63% reported that the child they were concerned about had two or more diagnoses. The most commonly endorsed diagnoses were:

ADHD - 52% Mood Disorder - 54% Anxiety Disorder - 26% Oppositional Defiant Disorder - 15%

- Average age for the child first being diagnosed was 8 years
- 72% indicated the child was 10 years or younger at the time of the first diagnosis
- Average length of time in treatment was 5 years, with a range of 2 months to 10 years.

RESULTS & CONCLUSIONS

The study found that parents/caregivers who participated in the NAMI Basics Education Program demonstrated an increase in their own knowledge about mental illness in children and adolescents, as well as the assessment, treatment and advocacy regarding the illnesses. The study also found that the perception that parents/caregivers had of themselves and their own reactions to the illnesses of their children were improved after taking the course.

The researcher concluded that participation in NAMI Basics appears to be associated with increases in knowledge about childhood and adolescent mental illness, assessment and treatment, and advocacy. NAMI will pursue further evaluation of the program to provide more empirical support for the utility of this program and contribute toward eventual designation as an Evidence Based Practice.

NAMI Basics Education Program Research Project 2008-2009

NAMI Basics is a peer-led educational program for parents and other caregivers of children and adolescents with a mental illness. Development of this program was based on the success of other NAMI signature education programs for consumers and families available across the country. NAMI drew on course elements which have been extensively tested and found to be highly effective in the field. These elements include:

- Recognition of mental illness as a continuing traumatic event for the child and the family;
- Sensitivity to the subjective emotional issues faced by family caregivers and well children in the family;
- Recognition of the need to help ameliorate the day-to-day objective burdens of care and management;
- Gaining confidence and stamina for what can be a life-long role of family understanding and support; and
- Empowerment of family caregivers as effective advocates for their children.

The NAMI Basics Program is a six week course (15 total hours) taught by trained teachers who are also the parents or other caregivers of individuals who developed symptoms of mental illness prior to the age of 13. A research study is currently underway to evaluate the impact of the NAMI Basics course focusing on the following outcomes:

- Parental stress in dealing with their child's illness, insurance, and providers
- Parental empowerment in getting information to better help their child, advocating for services, and dealing with their child's difficulties
- Parental self-care, meaning taking care of their emotional, physical, and psychological needs
- Family problem solving and communication skills

The study is being led by Dr. Barbara Burns, Duke University and Dr. Kimberly Hoagwood, Columbia University. All caregivers who participated in the NAMI Basics Education Program in Tennessee and Mississippi between October 2008 and December 2009 were asked to participate in the study, which consists of a pre-test, a post test, and a three month follow-up.

The final report of the findings of the study, including conclusions and recommendations from Dr. Burns and Dr. Hoagwood, is expected in the fall 2010.

For more information about the study or the NAMI Basics Education Program, contact:

Dr. Teri Brister, Director of Training 601-829-0591 tbrister@nami.org

Sample One Year Budget for NAMI Basics Education Program

Amount to Budget

1 State Teacher Training per Year (16 trainees & 2 trainers) \$9,6				
Lodging: \$109/night x 2 nights x 18 =	\$3,924			
Meals: \$50/day x 3 days x 18 =	\$2,700			
Teacher Manuals: \$50/manual x 16 =	\$ 800			
Travel for trainees: \$.48/mile x 100 mi roundtrip x 16 =	\$ 768			
Travel for National Trainer =	\$ 500			
Actual Total:	\$8,692			
Class Costs (4 classes)		\$2,000		
Participant Manuals:				
\$25/manual x 20 participants/class x 4 classes/year =	\$2,000			
2 State Teachers to NAMI National Train the Trainer Train	ing/year	\$2,500		
Registration: \$450 x 2 =	\$900			
Airfare to St. Louis, MO: \$350 x 2 =	\$700			
Meals: \$50/day x 3 days x 2 =	\$300			
Lodging: \$109 x 3 nights x 2 =	\$654			
Actual Total:	\$2,554			

Other items that might be included in a Program Budget:

Program Director Salary + fringe + travel

Administrative costs (% of total program budget)





In-Service Mental Health Education for School Professionals

NAMI is delighted to announce the expansion of our *Parents and Teachers as Allies* inservice mental health education program for school professionals. This two-hour in-service program focuses on helping school professionals and families within the school community better understand the early warning signs of mental illnesses in children and adolescents and how best to intervene so that youth with mental health treatment needs are linked with services. It also covers the lived experience of mental illnesses and how schools can best communicate with families about mental health related concerns.

This program responds to the recommendations included in Goal 4 of President Bush's New Freedom Commission report on mental health that calls for schools to play a larger role in the early identification of mental health treatment needs in children and in linking them to appropriate services. Our program is based on NAMI's highly successful *Parents and Teachers as Allies* (P&TA) publication.

The components of the in-service education program for school professionals include the following:

- 1. <u>Welcome and Introductions</u> an education professional, who is also a family member, welcomes the school professionals and introduces the topics to be covered, often with a personal story.
- 2. <u>Early Warning Signs of Mental Illnesses</u> a facilitator walks the school professionals through the early warning signs of mental illnesses, closely following the P&TA publication.
- 3. <u>Family Response</u> a parent or caregiver of a child with mental illness covers the predictable stages of emotional reactions among family members dealing with the challenges of mental illness and the lived experience of raising a child with a mental illness.
- 4. <u>Living with Mental Illness</u> a mental health consumer that experienced the early onset of mental illness shares a view from the inside, including a discussion about the positive and negative impact that their school experience had on their life.
- 5. **Group Discussion**
- 6. Closing Remarks and Evaluation

This program is designed for teachers, administrators, school health professionals and others in the school community. NAMI is also developing a program module for parents and caregivers in the school community on the early warning signs of mental illnesses.

The program is designed to target schools in urban, suburban, rural, and culturally diverse communities. The Parents & Teachers as Allies publication has also been translated into Spanish and is available at http://www.nami.org/CAAC.

NAMI is working with the University of Maryland on the evaluation component to measure the program's success and to help ensure continuous quality and program improvement.