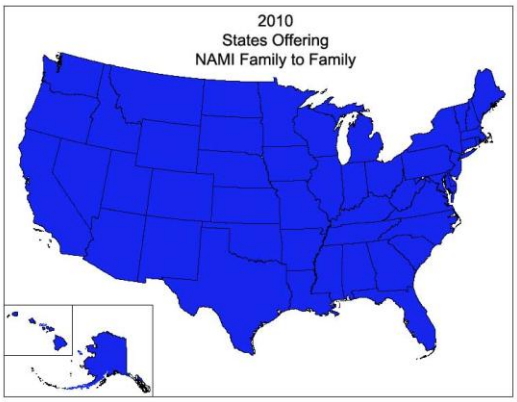
NAMI

The Nation's Voice on Mental Illness

Family to Family



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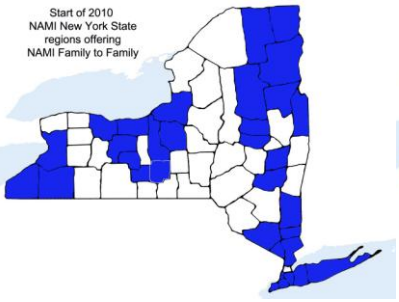
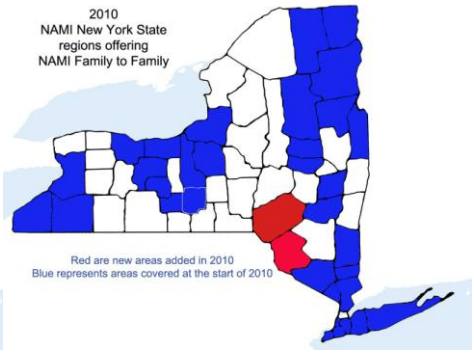




Cumulative Program Data as of June 2010

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: 200,000+
- Family-to-Family Teachers trained: 7,000+
- State Trainers trained: 300+
- Spanish state trainers: 23
- Family members now graduating per year: 12,000-14,000

NAMI NYS also offers this course in Spanish called De Familia a Familia and it follows the same format as the English version. A new 2011 manual is available bringing the text up to date with the English version. NAMI NYS has several state trainers for the Spanish version and is looking for interest in expanding this offering.

NAMI NYS Family to Family has increased the number of affiliates offering the course by two in 2010. NAMI Delaware and NAMI Sullivan now have trained teachers.
There were 35 course offerings assisting over 400 attendees in 2010, held throughout the state. Reviews from the participants and the teachers have very high ratings. 2010 saw multiple revisions to the course with over 200 updated pages. 2010 showed a 12% increase in presentations over 2009.

NAMI Education, Training, and Peer Support Center Team

Lynne Saunders, Director of Field Services (with an emphasis on family and Veterans programs)
Cynthia Evans. Director of Field Services (with an emphasis on consumer programs)

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, Director of Training (with an emphasis on family, child and adolescent programs)
Sarah O'Brien, Director of Training (with an emphasis on consumer programs)

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

Candita Sabavala, Departmental Project Director

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.

Maura Bulger and Carmen Argueta will continue as our indispensable departmental Coordinators, responsible for support functions across programs, with Carmen taking on the additional role of Spanish Language Specialist. In their support role as departmental assistants, *Blakelee Sharpe* will be in charge of document management, and *Marshall Epstein* will manage the demanding task of order fulfillment for all programs.

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

- 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 transcultural.

NAMI Family-to-Family
National Alliance on Mental Illness

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 18 years the program has been operating, over 3,500 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 200,000 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, 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 and co-occurring addictive and brain disorders).

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 to-date 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.

In 2007, a supplemental PTSD take-home module for the Family-to-Family was prepared by the Veterans Healthcare Administration, National Center for PTSD. 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

Class 1: Introduction: 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."

Class 2: Schizophrenia, Major Depression, Mania, Schizoaffective Disorder: Diagnostic criteria; characteristic features of psychotic illnesses; questions and answers about getting through the critical periods in mental illness; keeping a Crisis File.

Class 3: Mood Disorders, Borderline Personality Disorder, Anxiety Disorders, Dual Diagnosis: Types and sub-types of Depression and Bipolar Disorder; diagnostic criteria for Borderline Personality, Panic Disorder and Obsessive-Compulsive 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; chemical imbalances in the brain; pathophysiology of brain cells and neurogenesis; genetic research; infectious and developmental "second hits" in utero which may cause mental illness; the biology of early recovery; family and consumer stages "at odds"; NAMI Science and Treatment video.

Class 5: Problem Solving Skills Workshop: The four steps in defining a problem; evaluating our past efforts; devising new options; solving the problem; setting limits.

Class 6: Medication Review: 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.

Class 7: Inside Mental Illness: 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 overcome demoralization and protect one's integrity in mental illness.

Class 8: Communication Skills Workshop: How illness interferes with the capacity to communicate; learning to be clear; how to respond when the topic is loaded and when to back off; talking to the person behind the symptoms of mental illness.

Class 9: Self-care: Learning about family burden; sharing in relative groups; handling negative feelings of anger, entrapment, guilt and grief; how to balance our lives.

Class 10: The Vision and Potential of Recovery: Learning about key principles of rehabilitation and model programs of community support; a first-person account of recovery from a consumer guest speaker.

Class 11: Advocacy: 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!

Investigating the Evidence-Base for NAMI's Family-to-Family and Peer-to-Peer Programs

By Alicia Lucksted, Ph.D., Rebecca Hawes, Ph.D., and Lisa Dixon, M.D., M.P.H.,
University of Maryland Division of Services Research
(NAMI Advocate article, winter 2007)

Over the last decade, NAMI-national, Maryland NAMI affiliates, and our research team at the University of Maryland, Division of Services Research, have collaborated on a series of studies to examine the benefits that people receive when they complete the Family-to-Family Education Program (FtF).

We are also beginning the same research process for the Peer-to-Peer program. In both cases, our collaboration focuses on improving the programs and investigating the research evidence for their effectiveness.

In this article, we first describe the FtF research, results, and the exciting current study. We then summarize the recently completed Peer-to-Peer pilot study and its future directions.

Research on the Family-to-Family education program for serious mental illnesses

To date, our research team has conducted two quantitative studies and one qualitative study, which demonstrate this: FtF is effective for reducing the subjective burden and depression that participants initially have reported, while increasing the empowerment they perceive they have gained. These studies, summarized below, provide the foundation for our current randomized trial of FtF: Our study is funded by the National Institute of Mental Health (NIMH).

"Subjective burden" is a research term summarizing how much emotional stress family members rates themselves as feeling, as a result of objective stresses and other worries.

"Objective burden," in contrast, is a research term for the sum total of the concrete problems that serious mental illness can bring to a family, such as changes to schedules, relationships, routines, and financial expenses.

"Empowerment" refers to one's sense of having both the rights and the information or skills needed to understand a given situation and to meet one's goals within. In our studies, we asked family members about their sense of empowerment regarding their overall family group, their community, and their dealing with the mental health system.

First Study: Pilot study of the effectiveness of the Family-to-Family education program

The initial FtF pilot study involved 37 family members who completed the FtF program. They were interviewed by our university research team of trained family-member assessors at "baseline" (just before taking the course), immediately after completing FtF; and six months after completing it.

Our results indicate that FtF participants demonstrate significantly greater family, community, and service system empowerment, while they also feel less displeasure and worry less about their family member who has a mental illness. We found that these benefits were sustained: six months later, they still held.

(Advocate Article, winter, 2007)

Second Study: Outcomes of the peer-taught 12 week Family-to-Family education program

Building on the pilot study, we next used more scientifically rigorous methods to further explore the effectiveness of FtF: In this second study, 95 family members who were planning to enroll in FtF; but who had to wait three months for the class to begin, consented to be interviewed four times: three months before the class, immediately before it, immediately after, and six months after. The interview conducted three months in advance of the course served as a control measure. That is, did simply signing up and waiting for FtF confer any benefit, or was it first necessary to attend the class?

We found this: people completing FtF indicated less subjective burden and more empowerment. They also indicated an increase in knowledge and understanding of serious mental illness, the mental health system, and self-care. These benefits were sustained after six months. Importantly, simply signing up for FtF and waiting for three months provided no improvement. This second study provided additional evidence for FtF's effectiveness.

Third Study: Qualitative study of Family-to-Family

These statistical results are in keeping with the stories FtF graduates tell about how the course helped them. To better understand the process of change for FtF participants, we taped interviews with 31 FtF graduates, one to three months after they completed FtF; and focused on changes sparked by the course that had become integrated into their lives.

Using recognized qualitative analysis methods, we discerned categories of change. Data suggest that new factual and emotional information provided by FtF shifted participants' understanding. The new information, skills, and perspectives allowed participants to adapt more to their relative's illness and their own care-giving and family roles.

These shifts led to both "proximal" positive changes (such as better family communication and less anger) and more "distal" benefits (less stress, less conflict in the family). Further, participants described these important early benefits of coming to FtF: feeling immediately welcome, hearing that others face the same problems they do, and the valuable information offered from the very first meeting. These benefits led them to come back for the ensuring meetings. We call this "early sustenance." Although people differ, we were able to sketch out steps of change that fit well with participants' stories.

Current study: A randomized trial of Family-to-Family

In the fall 2005, our research team at the University of Maryland in Baltimore (UM-B) was awarded a four-year grant to continue research with NAMI on FtF: This grant award became possible because of tremendous work that had been done on previous studies by Maryland NAMI affiliates, staff, and FtF teachers, Dr. Joyce Burland, and staff at NAMI-national.

The current UMB research team consist of co-principal investigators Lisa Dixon, M.D. M.P.H., and Alicia Lucksted, Ph.D.; co-investigators Anthony Lehman, M.D., Alan Bellack, Ph.D., and Bette Steward (Maryland FtF state coordinator, national FtF trainer, and a member of the UMB center's staff), Rebecca Hawes, Ph.D. (UMB FtF project coordinator), and Deborah Medoff, Ph.D. (UMB statistician).

(Advocate Article, winter, 2007)

The current grant allows the team to conduct a larger, more scientifically rigorous, and more comprehensive study. It includes the use of "random assignment," a cornerstone of evidence-based

practice in the medical and clinical fields. In this case, that means each family member who volunteers to take part in the study does so knowing that he has an even chance of being assigned to either of two groups: one participating in the "intervention" (FtF) now, and one not doing so until after their study participation is complete (the "comparison group," who wait one round).

The rigor of this current study will provide a solid evaluation of the effectiveness of FtF and knowledge about the efficacy of self-help family programs in general. Thus, its results could put FtF more prominently "on the map" as an emerging evidence-based practice.

Overall data collection began in spring 2006. The study will span four years. To date, we have enrolled 56 family members. Starting with four NAMI affiliates, it is possible that future years of the study will involve other affiliates in Maryland or elsewhere in the United States. One of our team members, Bette Stewart, who is also the Maryland FtF coordinator for NAMI, serves as a centralized FtF referral person for interested family members. She frees up affiliate staff time by informing interested people about FtF; explaining the study, helping those who want to take part to take the FtF course of their choice, and helping those who want to be in the study to do so.

Benefits to consumers also studied

The grant also allows us to look at how FtF may benefit consumers who have a family member taking FtF: This has never been done before, and is an exciting addition. With careful attention to issues of confidentiality and consent, some consumer relatives of FtF participants are being interviewed to explore whether having a family member who takes FtF also benefits them.

Peer-to-Peer research following the FtF footsteps

Over the past 18 months, Alicia Lucksted, from the University of Maryland team, has been collaborating with Kathryn McNulty, NAMI director of consumer education programs and Peer-to-Peer's creator, and Lorener Brayboy, consumer education programs coordinator, to conduct the first evaluation study of NAMI's Peer-to-Peer program.

This work look promising. Currently available in 24 states, Peer-to-Peer, while highly valued by its graduates, has not yet been systematically evaluated. As discussed above, the FtF research, in this era of "evidence-based practice" research, is the best way to bring attention to the program while learning more about its effects.

Building upon the collaborative relationship forged through the FtF projects, Dr. Lucksted and NAMI national have designed a pilot study that was completed in June 2006.

Pilot study design

Supported by an Astra-Zeneca educational grant for Peer-to-Peer, this first pilot study was designed to measure whether Peer-to-Peer participants report benefits from the program. First, the team (McNulty, Brayboy, and Lucksted) designed a 23-item survey tapping the main points of the Peer-to-Peer curriculum, demographic questions, and participant comments.

(Advocate Article, winter, 2007)

Next, between July 2005 and April 2006, we enlisted the help of Peer-to-Peer in various states to administer the survey to volunteer participants at the beginning and end of each course in their areas. The anonymously completed surveys were mailed to the University of Maryland Center for Mental Health Services, where the data was analyzed. Our final pilot study sample included surveys from 138 individuals in 13 states.

Results

The pilot survey results show that participants benefited, especially in the areas most closely tied to the core Peer-to-Peer curriculum. Specifically, they showed significant gains as reflected by a statistically significant, high level of agreement with these statements: "I am confident about my current level of knowledge about my mental illness"; "I am satisfied with my ability to manage my mental illness"; "I feel I have a great deal in common with people around me"; and "I am usually confident about the decisions I make." Those gains also were reflected by a statistically significant, high level of disagreement with this statement: "I feel powerless a good deal of the time."

All these gains were indicated as contrasted to participants' responses surveyed before they took the course. The statistical results of this pilot were greatly enhanced by comments which participants wrote in response to this final, open-ended question asked on the post-course survey: "Please describe any personal changes or insights you have experienced as a result of Peer-to-Peer." One hundred twenty-seven people wrote something. Overall, these comments clustered into:

(a) Gained information, tools, and skills from the Peer-to-Peer curriculum;
(b) Appreciate the human connection in the course; feel less alone;
(c) More positive feelings about myself as a result of taking the class;
(d) Feel more motivated to take responsibility for my own well-being;
(e) Want to get more involved in advocacy as a result of taking the class.

Conclusions

This Peer-to-Peer pilot study was modest in scope, but corroborates anecdotes from graduates which suggest that taking Peer-to-Peer yields real benefits. IT also showed that evaluating Peer-to-Peer is feasible – an important pilot outcome for future research funding.

Following the path of the Family-to-Family collaboration and research described above, the University of Maryland Center for Mental Health Services Research and NAMI plan to build on this pilot to conduct additional studies, working toward establishing the evidence base for Peer-to-Peer.

Currently, the Peer-to-Peer research team (Lucksted, McNulty, and Brayboy, plus Unviersity of Maryland doctoral student Courtney Forbes) is designating a second study. In it, Peer-to-Peer participants will be interviewed in depth before and after they take the course with a more rigorous research design that will allow us to reach more detailed and scientifically stronger conclusions.

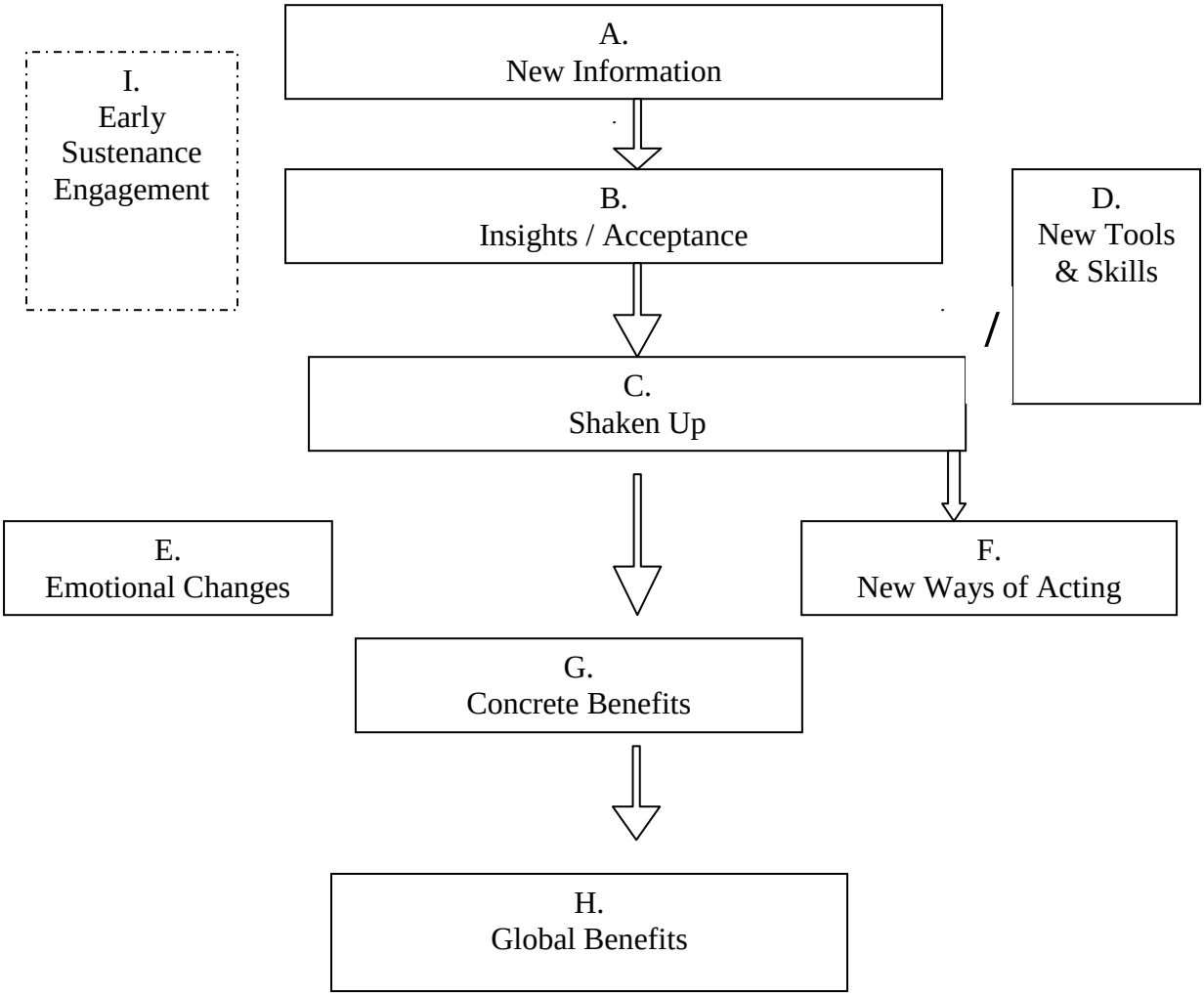
We also intend to design yet a further study, one that will explore the impact that being a Peer-to-Peer mentor has on people who take that role.

In the future, we look forward to reporting the results from our Family-to-Family randomized trial and from the next Peer-to-Peer studies.

(Advocate Article, winter, 2007)

Family-to-Family Qualitative Interviews Results: Processes of Change for FTF Graduates

A. Lucksted & B. Stewart, 2005



(Advocate Article, winter, 2007)

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 both enough.

Sincerely,

Margaret (Peg) Miller, M.D.

Videos:

Family to Family
http://www.youtube.com/watch?v=osN2YiNbRrw