

# **Benefits and Changes for Family to Family Graduates**

Report to NAMI of Qualitative Outcome Interviews with FtF Graduates

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## Introduction

The Family to Family Education Program (FtF), while very popular with its participants and teachers, has only recently been formally evaluated. The UMD Center for Mental Health Research team's wait-list control study of FtF's effectiveness regarding individual-level outcomes for family members taking the course (Dixon et al, 2004) gave evidence that FtF is associated with reduced subjective burden and worry ( $P < 0.01$ ) and increased empowerment ( $P < 0.01$ ) for participants. Understanding regarding mental illnesses, the mental health system, and self-care also improved.

When talking with people who have taught or completed FtF one is repeatedly struck by the richness of the stories they tell about the curriculum's impact. Therefore, we were very aware that this quantitative evaluation, while rigorous, necessarily reduced these stories to snapshots in time measured by numerical ratings. Knowing that this does not give us the entire picture of FtF's impact, we designed a qualitative study to interview people who had recently completed FtF, to better hear and learn from these stories. Specifically, we wondered *how* the changes reflected in the wait-list control study results come about -- what things change during an FtF course for participants and how does this affect their daily lives? In designing this study, we focused on the following:

1. Identifying and understanding what (if any) meaningful changes (to their life, psychology, health, relationships, attitudes, beliefs, behaviors, etc.) participants experience as a result of taking FtF.
2. Understanding the change *processes* bringing about these identified changes and impacts.
3. Exploring participants' perceptions of why/how FtF participation seems to decrease subjective burden and increase empowerment among participants, as suggested in the quantitative study.

## Methods

Below is a synopsis of this study's methodology. For more detail, see the appendix.

### Recruitment and Interviews

In order to invite FtF graduates to take part in this study, we visited the last class of 6 different FtF classes in 5 different Maryland counties (including Baltimore city) during Fall/Winter 2003. We explained the study's purpose and format, and asked for contact information from anyone who might be interested in participating. A total of 40 people (out of 61 total) signed up on these "interest" sheets, giving us contact information and permission to call them to discuss the project further. Of these, 33 people were eventually interviewed in 30 interviews (3 interviews were parent couples).

We conducted the interviews 1 to 3 months after each participant's class ended, focusing on what from the class had stayed with participants and become integrated into their daily lives. Interviews took place at a mutually agreeable time and place, often in participants' homes or the local NAMI affiliate office in a private room, and ranged from 45-90 minutes. In addition to

contextual information about the interviewee’s family situation and way(s) they came to know about NAMI and Family to Family, the interviews focused on three main areas. First, we asked participants to discuss what about the class stood out for them. We sought to hear what was most salient, what had stuck with them, and what they found most important to their daily lives. Second, we discussed what effects or ripples the class has had in their lives, from their own emotions to extended family and community. Third, within both areas, we also explored the change processes involved – how did elements of the class lead to, influence, cause, etc the “ripples” that participants noticed.

### Data Processing and Analysis

Interviews were audio-taped, labeled only with date and interview number, and then professionally transcribed. Our first step in data analysis was then to summarize the story that each participant told about their family situation and FtF involvement, according to the three foci of the interviews (see above).

We then catalogued all the ideas mentioned in each category (what stood out, ripples, change processes) across all the interviews. “Change processes” refer to ways that one’s experiences during the course lead to the effects (ripples) that one reports. It was immediately clear that these cannot simply be categorized in a list. For example, interviewees described individual fragments of much larger processes when telling specific stories, and described a variety of change processes during any one interview. We therefore created a way to organize and analyze this particular part of the data in ways that preserved the connections among ‘steps’ and would allow us to see and build larger themes and patterns as we reviewed one person’s entire transcript and compared it to other interviews. (See appendix for details). In the end, we were able to relate the many partial examples of change processes to each other across interviews to create an overall diagram that we think captures the “big picture” of how FtF may lead to changes in people’s lives.

### Results

We think that the final diagram (Figure 1) is a useful way of understanding how FtF participation may result in changes in participants’ thinking and lives. It is an overall schematic – each individual participant may experience only one part or section of the overall process we’ve depicted, or a few, -- and everyone experienced it their own unique way. Further, because this diagram and our discussion of it are the result of a single study, which involved a very limited number of people and their experiences, these results should be regarded as tentative.

The results, below, follow along with the diagram. In it, the parts labeled A, B, and C (right to left) depict different types of new information and insight that participants seem to gain from FtF. D represents the skills that are taught within the FtF curriculum, which seem to function as new tools for the participants. The arcing arrow from D to the main horizontal process is meant to indicate that these skills (D) combine with the information and insight (A – C) to lead to E, F, G, and H: E represents “new ways” of feeling that result while F represents new ways of behaving and relating. The parts marked G & H represent the more immediate and specific (G), and more global (H), outcomes of this overall process. I depicts early engagement factors.

Please note the limitations of such diagrams to depict people's experiences. Although we found it useful to use boxes and arrows to help us depict different parts of the overall change arc, in interviewees' stories it is clear that their experiences are much more similar to the flow of water in a stream (continuous, changing, intermingling, with an overall general direction but much individual variation) than to the string of beads the diagram looks like (discrete, one step leading to the next).

### Sample Description

During 28 interviews we spoke with 31 people, most of whom (23, just under  $\frac{3}{4}$ ) were women, as is common in FtF classes and care-giving in general. Over half our participants (19/31) were parents of the ill person about whom they took the class (the "consumer"), mostly (14) mothers. We interviewed 3 parental pairs. Among the other 12 participants, 5 were spouses of the consumer, 4 were sisters, 1 was the consumer's adult daughter, and two had multiple consumers in their family and so were daughter and wife, and sibling, daughter, and wife, respectively. In the course of the interview, most participants said that the ill relative about whom they took FtF has an affective disorder (12 Bipolar, 6 Depression). Five reported that the person has schizophrenia; 3 schizo-affective disorder, 1 borderline personality disorder and one did not know. Seventeen of the 31 participants live with the consumer, 7 live nearby, and 4 live in a different state. They came from Howard, Baltimore, Montgomery, and Anne Arundel counties, and Baltimore city.

#### A. New Information & Support

(Note: the number in parentheses after a quotation refer to the interview that it came from)

Participants all discussed the importance of the new information they got from FtF. For many, the factual information about mental illness, diagnosis, treatment, medications, and side effects was completely or partly new. It replaced or mixed with previously held misinformation. For example, one father said, "*I always knew it was brain chemistry. However, without specific information I assume, before [FtF] that my daughter could now get out and look for a job and find something. The way these drugs were working on [her] brain, that's ludicrous. So, [FtF] really gave me an under-pinning...*" And later in the same interview: *I pretty soon began to realize that Bipolar is treatable, can be managed in... 60% to 80% of the cases. I didn't know that before, and that was very encouraging.* (001)

Facts were not the only type of "new information" that was important. Participants also said that the chance to talk with peers was enlightening – to discover and feel that one is not alone. The mutual support involved in exchanging stories and the support others offered them was important new information –emotionally as well as practically:

*You hear yourself talk and when it comes out of your mouth and you know it's out in the open and the room doesn't come crashing down upon you, then you feel safe because you were able to go public with it. And after you get it out there it's like there's a new fresh air... It is liberating... I was able to tell someone other than my therapist about what is going on at*

*home... And you hear that there are other people in this room. Other people have similar problems and experiences in dealing with their family members. (014)*

*One big huge thing was the support I received from all the other people in the class. Amazing. Their reassurances, suggestions, hearing what other people when through... all very important and helpful. Sometimes I wouldn't want to go to the class, thought it was a downer to go, but...Every time we had class I left feeling up, because I could say something to help someone, which was good, or someone could say something to help me. (007)*

This concern, advice, and positive regard was very important to most participants, and often new. Even just finding commonality was a shock for some:

*I don't know what I had expected to see when I came to that class. My thought was, "all these people out here look normal." I'm not sure what I expected because they are family members. I'm not sure why I would have expected them to look any different. I looked around and said Um, that lady looks really nice. And I think the reality of it all, that all of us had the same type of problem...that was an eye-opener. (006)*

Many participants mentioned that they stay in touch with classmates long after their class is finished, through individual friendships that developed and/or continuing to meet together as an informal support group. A few even go on to become formal registered NAMI support groups.

Another type of new information that people gained through FtF was first person perspectives of living with a mental illness. Some participants said they had never had in-depth conversations with their ill relative (or other consumers) about their lived experience, and many said that what they heard was different than what they had expected, eliciting their empathy:

*It makes you have a different understanding of what the consumer is going through. I see it much differently than I used to. Much differently. I feel that I am a lot more tolerant and understanding and I tend not to get as angry. (024)*

Finally, one man illustrated the power of new information when he noted that it might change his actions the next time his wife attempts suicide, and has helped reassure his conscience as he tries to help her:

*...When you realize that someone is in such mental anguish you don't know at some point whether you are doing them a favor of interrupting the suicide attempt [versus] letting them out of their pain. ... do you call 911 because you would believe that maybe if we got her treatment then this wouldn't happen? But when it is all over and then you go into the next cycle... and you see her again in such mental anguish. It's like you kick yourself in the butt because you didn't let her die when she was ready to. And you don't know what takes more courage – helping her to live or helping her to die... but the course was able to point out that in the overwhelming majority of cases that people who go through these episodes of suffering trauma with their mental anguish.. can be helped. So, that now suggests to me that I should ... heavily lean towards calling 911 rather than just let her complete the sequence. (014)*

## B. Insights / Acceptance

The interviews revealed that new information often changed people's thinking, creating insights about the nature of mental illnesses and what is / has been happening in their family. Participants attributed these insights to a combination of "corrective" information plus seeing themselves (their ill relative, and their family) reflected in the stories and experiences of others. For some, these insights were fairly subtle, especially among those who were well informed before coming to FtF -- validation of things they already thought or guessed were true, filling in details. But for many others, these insights were quite profound. Many used the term "acceptance" – accepting that it is a mental illness they are dealing with, accepting the consumer as a person who is struggling, seeing and accepting the impact of mental illness on them and their family:

*Somehow reading about and talking about all the negative symptoms of a disease turned my attitude around in dealing with [my son] because, you know, I'm a type-A personality... And I would just get frustrated,...and I would just be real hard on him ...Somehow I just got more of a sympathetic view towards him and his difficulties... I lost a lot of my negativity...and I just feel more sympathetic, and I think it was taking the NAMI class that sort of changed my attitude...[Interviewer: What do you think happened?] Well, I think that it was the information about how common these symptoms are...I mean, that thought had never entered my mind. (030)*

*[When she first shared her family story with class members] I remember feeling surreal, like "I'm telling my story." I'm listening to myself tell this, and "WOW". That's tough. You're just accepting that, you know what? that's a really tough situation to be in. No wonder I'm...[upset, stressed]. (029)*

## C. Shaken Up

These insights and jumps in acceptance were not always comfortable. Often, they shook up the participant's beliefs and assumptions -- the framework through which they experienced and made sense of their relative's illness and its impacts. This unsettled their expectations and assumptions about the present and the future, about what is possible, and about what is helpful – regarding their ill relative, themselves, their roles and coping, other family members, and what they can and cannot control. For example, one person (024) realized the necessity of pacing one's self for a long struggle, and another (031) realized that her younger sister will not ever match her expectations. Many commented on the difficult but useful realization that many things are outside their control and that their expectations need to be adjusted or let go.

## D. Tools / Skills

Losing a long-held framework of understanding without gaining new frameworks and coping tools would distress most people. In contrast, participants' seemed to experience the FtF curriculum as including both new ways of looking at their situation *and* new tools, in the form of the various skills it teaches. This helps to sustain and further their insights. Many interviewees

spoke of how these skills allowed them to do things in new ways, especially regarding communication, problem-solving and handling crises. Repeatedly, participants said they felt “better equipped” for handling situations in their lives.

For example, regarding their ill relatives:

*The communications skills really helped us not to fight as much. [Before] It was a constant fight with her [ill sister]...Everything would turn into an argument and we couldn't really figure out why. And then when we started looking at the communication skills and learning all of the other stuff in the Family-to-Family course we really shifted gears and changed our perspective and I would say changed our expectations even. ... Instead of isolating her and her always feeling like we were blaming her and that everybody was against her, she truly, she even said she started to feel like we were really supporting her and that we were on her side as opposed to you know sitting on opposite sides of the table. (031)*

*Literally the next two days after I had that communications class [my daughter] called me up and bawled me out. And I tried everything and it didn't work (laughter) but I felt better for having tried it. Because sometimes nothing's going to work no matter what you do -- [but] I had something to try. (003)*

*The class helped me to deal with her, with the signs. The signs of the beginning... when she started not taking the medication. What to do immediately if she stopped taking the medication, to confront her in a good manner. I didn't know how to do that [before]. She stopped taking the medication; I would probably have said “Get the hell out of my house. I'm sick of you.” (010)*

Other family members:

*Now I can say things to my parents like, so did you make an appointment with the new psychiatrist [for their daughter, speaker's sister]? ...And those are things I would have never really asked before because there would have been no point in asking because I just wasn't expecting any -- any answer really about it. So now I can say that... so those lines of communication are open. It's okay to go there now because of the NAMI Family to Family. It just made it okay. And my parents met all these other people who have kids who are, you know, in the same and worse situations. And I'm like -- so now it's not a taboo topic. It's not like a topic where everybody goes, ‘ooh’, and leaves the room because that's like what used to happen. It was like it was too uncomfortable to talk about. (015)*

And mental health professionals and bureaucracies:

*Now I can direct my Mr. Fix-it approach with real tools. This book, the binder, 2-1/2 inches thick of paper. I can dig into that with gusto and you know it's a manual on coping skills and resources in the community and how to deal with bureaucrats, insurance companies, medical health professionals and so on. Learning to navigate the system and finding ways to get her*

*treatment and help in a crisis or even in a non-crisis mode. It's like, Yea, we can do this now. It's not as frightening as it was. (014)*

#### E. Emotional Changes

The benefits of gaining new frameworks and skills seems to be twofold for FtF participants – having the skills to use, and an emotional benefit to having them. This, we came to perceive, is true of all the components of the FtF change process that we have described so far: Alongside each type of change, interviewees describe the utility of new information, skills, understanding, and also feeling better because of it: feeling less despair and hopelessness, less fear about the next crisis or challenge, less anxiety, anger, guilt and blaming, and more hope, confidence and feelings of strength and competence:

*I was flat out disappointed and thought, you know what, they're not doing anything and that's making me mad. But now I realize... it's just real scary for them and they didn't know what to do or how to go about doing it. So now I'm, um, I'm less frustrated with my parents and I can be more willing to listen to their reasonings [re her sister's care] (015)*

Additionally, several participants said or implied that aspects of FtF raised negative emotions in certain ways – that they now wondered if their relative was diagnosed properly, were daunted by the complexity of mental illness, or felt more frustrated (but also empowered) as they learned what treatments were most useful because their relative was not getting them. One person said that s/he might have left her/his spouse early in their marriage had he known as much about mental illness.

#### F. New Ways of Acting, “Control”

From the data in this study, it seems that the processes depicted in steps A-E led to, for most if not all study participants, their changing the ways they treat themselves (e.g. self care, self blaming), their ill relative, and others in their family and surroundings. These steps also seem to impact how they grapple with problems that arise, and how they interact with the mental health system and mental health providers (both their relative's and their own if applicable). For example, participant 004 credited FtF with leading her to ask better questions of her husband's psychiatrist, and to acting on her own to continue learning about mental illness. Participant 005 told us the story of his celebrating Christmas very differently than in previous years because he had learned more about things that were destabilizing to his ill son. Participant 025 said that due to less shame and more information she was now speaking up more about mental illness and stigma.

These various specific changes are linked by participants' shifting what they perceived to be within their control to change. For many, this involved letting go of (futilely) trying to control “everything” (a word used by many), or letting go of specific things they now realized were “not theirs to change.” Examples include accepting they cannot change that their relative has a serious mental illness, or behaves a certain way, or how other family members cope with the relative's illness. Paradoxically, accepting certain things as beyond one's control often

helped participants see and act in other areas where they could have substantial and positive impact. Participant 007 said, “*It helped me to see there is nothing I can do to solve the problems she has, but there are ways I can help.*” For example,

*He stands on the steps in the rain and it’s bothering me. [I ask] Are you okay? ‘Sure.’ Why are you standing out there in the rain? It’s cold. He said ‘I just want to be by myself for a while.’ I said okay. But that wasn’t enough and I [started to go] back and then I thought about what they said [in class] about once your family members go down the street or whatever [to not fret when they are away from you since you can’t control what happens anyway] and then I said[to myself]... ‘If he stands out there long enough, he’ll get wet. He’ll get cold. He’ll come back in the house or he will turn into an icicle. That’s not very likely.’ So, I didn’t, you know...I stopped worrying. And also the next day we had a good day and went somewhere. I went to see my grandson play basketball and I haven’t seen him for a month. Anyway, my son went with me and another friend. It turned out that it was a good day. (006)*

Some also said it that by accepting that certain things were likely to happen, were outside their control, they felt less fear and guilt, and so did not have to defend against them so much:

*Basically it’s just [I learned] that I can control me and not try to control anybody else or change anybody else but myself. And that, um, his illness is something that’s long-term and that it won’t change or get better unless he changes. (012)*

Communication. Thus the new information, understanding, and skills made available to participants through FtF combined to give them a clearer vision of ways to improve their situations. One of the most prominent and repeated example was improvement in communication between participants and their ill relatives. Many participants said that before taking FtF they argued frequently and did not communicate well, but that the class gave them *information* (such as that showing ones’ emotions honestly and maturely to the ill person will not destabilize them, or that the symptoms of mental illness make certain kinds of communication hard to process), and *tools / skills* (such as ways to communicate calmly and effectively with someone in crisis or who has cognitive difficulties, and ways to better take care of one’s own emotional health) that improved this. This combination showed participants that previously “hopeless” situations might actually be improved to the benefit of all involved. Many interviewees gave examples, such as:

*Like instead of like yelling at him and everything, -- I learned this in one of the sessions, to start it with ‘I’. You know, like, I need you to do this for me, I need you. And when I tell him that way, he’s doing it more. You know, like first I would say, you need to do this, you need to do this. It’s not -- he doesn’t hear that, you know. (025)*

As with previous communication examples, these improvements extended to other family relationships as well. Participants spoke of being more understanding about others’ needs and beliefs, using the same techniques to disagree effectively with other relatives, and being more open in discussing issues related to mental illness. Similarly, they described changing their

interactions with mental health and other professionals as a result of the combination of their new information, skills, and confidence.

Self Care. Taking care of one's self was another prominent example of new ways of acting. Participants said that through FtF they learned and “got” why it is important to take care of themselves, and that one's self is really the only person one can control and take care of entirely. They therefore were able to let go of some of their desires to control / take care of *everything*—and their guilt that they somehow “should” do so – which previously stood in their way of self care. In the course they also learned various specific ways to take care of one's own needs as a primary caretaker of a person with a serious mental illness, such as setting limits, knowing that it is OK to have one's preferences and comfort count for something, carving out personal time, or relinquishing certain responsibilities. For example, learning to set limits:

*[Before,] I didn't have the knowledge to do it. Like, I could say 'no' if I knew something was wrong but then I would let him talk me into it because he's very good at conning, you know. ... And [now] the light bulb has gone off in me as far as, I could see, that he's manipulative and I see how he tries to use me ...the class helped because I do have this information about dealing with the bipolar and addiction and, the dual diagnosis and all of that. So I understand all of that now, but still I know that I don't have to take that... I guess it helped me see that I can't help anybody else except myself. [later in the interview:] The class helped me know that I need to go to sleep, I need to get my rest -- in order to... deal with this and not be stressed... (012)*

*I said [to a friend, she [speaker's wife] is not directing it at you specifically but just as a group and society in general; she has reverted/retreated into her own shell... I said, but I'm here. So, because in the past [wife] and I never went anywhere without each other. [Now] it's like hey, I got to get out and go do things... I'm sorry but I can't hold her hand 24 hours a day. That's one of things that my priest finally gave me the okay to not feel guilty [about] ...This [class] reconfirmed it in a more cognitive level... took it to a cognitive level where you know why you don't have to feel guilty because you have clinical information that you can rely upon. (014)*

## G. Concrete Benefits

No participant mentioned feeling harmed or set back by their experiences in FtF – all spoke of benefiting in various ways. Many described relief and sometimes happiness as they saw the new ideas and techniques offered in the class pay off, both practically and emotionally. The direct benefits most prominently discussed were:

- Better coping and problem solving by participant, and so more confidence.
- Feeling less tension, stress, exhaustion, anger, frustration
- Better relating to ill relative and others
- Noticing their ill relative seemed to experience less tension and better relating.
- Acceptance

*I think a lot had to do with the Family-to-Family course...I think all of that combined really helped us. When crises have occurred since then we have been able to handle them a lot more efficiently and deal with them as opposed to -- It was almost like a crisis would occur and we would escalate it by our reaction. But now I think that we are a lot calmer and a lot more accepting of, you know. And maybe there was a little bit of denial on our part too, earlier on, like this can't be happening. And now, okay, this is happening and we're accepting it and let's...what's a proactive way we can handle this? What can we do? (031)*

*Well, on a personal note it sort of made me realize what kind of person that I am... it gave me motivation to do more and to want to volunteer, which is something that I wouldn't have considered before this class. I wouldn't have felt capable of something like that. So... it was good for my self-esteem in a way. It made me feel more comfortable and confident that, you know, this is a really unfortunate situation that we're in but I can handle it and there's things I can do to make it better and more livable. And that's what I want to do. (015)*

Participants described ongoing developments in acceptance over time. They seemed to find that accepting the realities of one's loved one having mental illness (such as its likely long-term course, one's inability to control large portions of the experience, the likelihood of future hard times) can be freeing in that it allows one to fight reality less, not waste energy on futile efforts, lessen frustration, and concentrate on more useful efforts.

#### H. Global Benefits

Participants' stories also show that these direct benefits (above) combine and ripple more broadly into their lives. Many emphasized that they still experience tragedy, despair, anger, and frustration, but that their overall lives are better as a result of the changes in information, perspective, skills, and behaviors they gleaned through FtF. Among study participants, these global benefits can be summarized in four themes:

- Increased quality of life for one's self, and sometimes for their ill relative and others,
- Increased feelings of empowerment, of having the abilities and confidence to speak up and change things that are possible to change.
- Increased activity level, using more active coping styles, mobilization, advocacy
- Decreased depression, despair, and stress related symptoms

A few examples are below:

*The NAMI program actually saved our marriage. As a matter of fact, may even have saved my wife's life. Gaining insight into the illness has given me the strength to keep working on the relationship. Learning what I know about depression has helped me make better decisions when my wife is getting symptomatic. (009)*

*But emotionally I feel a lot stronger, a lot better. That's the word I want to use. (010)*

*I just don't think my parents knew how to handle it really well and they didn't know what steps to take, and so bringing them to NAMI was huge for me and for them because it just showed them there's a million things we can be doing that we've never even thought about doing before. (015)*

These global benefits, as well as the more concrete preceding ones, and the emotional and skill changes discussed earlier, do not seem to necessarily end when the FtF course ends. Quite contrary, many people described them as still developing when we interviewed them 1-3 months after the class had ended.

### I. Early Sustenance / Engagement

Although the various change processes sketched above do not necessarily happen linearly, there is an element of time order overall. Interviewees told stories of gaining more benefit from the class as the weeks went by and various parts solidified and mixed with the rest of their lives in unique ways for each person. Many spoke of initial ambivalence about the class, uncertainty as to its value in the first week or two, and concerns that the 12 weeks was a burdensome investment of their time and disruption in their (often already harried) routines. Therefore, we were interested in understanding what brought people back during the initial weeks of a course – what did they “get out of it” in the early sessions, so that they came back?

Participants came into FtF through numerous routes, most often word-of-mouth from people who had previously taken FtF, from FtF teachers, or from others at NAMI (eg., calling the office). Some credit the encouragement (and even sometimes a little pressure) they received from these people as getting them “in the door.”

Regarding why they then came back, first, many people spoke of the tremendous relief they felt in gaining a sense that they are not alone -- to have the chance to talk with others who “get it.” This itself was enough to bring some people back. Second, many said they felt less crushed by their own family situation as soon as they heard others’ stories, often finding them much worse:

*The first thing I remember about the first meeting is that I met people whose stories were much more tragic than my daughter's story... I guess that is one of the effects of taking the class, you realize that things could be a lot worse in some cases. That in itself is therapeutic in a way. I mean it's, “there but for the grace of God go I.” (001)*

*It's an inspirational program... You know if you have one arm you can't feel too sorry for yourself when you see people that don't have any arms. And some of those people [in class], their situations are so tragic in comparison [to ours]. I was just in awe of their courage, their fortitude, and their sacrifice. Just amazing. What people will do for people they love. (017)*

Participants said that such experiences made them feel thankful for what they do have, resolved or inspired that “if others can cope with that, I can cope with this” – overall, less self pity, despair and hopelessness by meeting people who understood and some who were coping with much worse situations.

Finally, some participants said that the information offered in the first couple classes – from the teacher and the notebook – led them to see that the course would be a useful source of resources and therefore was worth their investment. For example, participant 017 said, “*I think that [attending] was an effort to do, but once you see the other people---the class instructor, how it is handled, you are more reassured with every class that you go to and I think two/three classes into it you look forward to going and look forward to that support and just feeling better about yourself and your ability to go.*”

#### J. Time regret

It was very clear to us that not everyone benefited the same from FtF. One important factor in this difference seemed to be the amount of time between when a family initially began experiencing their relative’s mental illness and when they entered FtF, which ranged from 1 to 30 years in our sample. Participants who had been dealing with their relative’s illness for a short amount of time usually did not know much about the topics covered in the FtF curriculum. Therefore, much more of the class was new and revelatory. They were the participants most likely to enthuse about FtF being “amazing”

Family members who had been coping and caretaking for decades were, on the other hand, much more likely to tell us that they had had to figure out things on their own -- by trial and error, by asking doctors, by reading, etc. Participant 007 said, “*You have no choice. You have two choices. Either develop some skills or go crazy yourself.*” Therefore, the benefits they described from FtF were more often of a milder form -- adding in details, correcting small misconceptions, validating things they had not been sure about. These people also seemed to vary considerably in how much access to information and skills they had in the years prior to FtF, and in how able they were to craft healthy and effective coping strategies. Therefore, a number of them expressed what we came to call “time regret,” wishing they had had earlier access to the FtF curriculum. For example,

*I think I cried when I saw the FtF class description. We’d been going without this information so long, and it seemed like something that could really help. (007)*

*Well, you know, this is my great regret that I didn't find it long ago...I guess I heard about NAMI through my church, and in a sense I felt, well, I'd been through so much by that time that I didn't need this, you know. And in a sense that's true. I'd learned an awful lot by that time. ... but having just finished the course, I realize there were a lot of holes in my knowledge, which NAMI offers -- the course is so thorough. And I only wish I'd had that from the beginning. (011)*

*If somewhere in the early stages of a caregiver having to deal with this particular situation they could be aware this kind of class existed, it would probably be worth a lot. They’d probably almost pay to go because a lot of what this particular class taught ... [There] are things that could be so valuable if you got them early in the realization that you might have to deal with this particular kind of situation for a long period of time... Nobody gave us anything like that. So, here I am taking this class six years into the experience versus six months or six weeks into the experience (005)*

## Discussion

This study's results shed useful light on FtF's fit among "self help" interventions in general, help us better interpret the results of past quantitative evaluations of FtF, suggest direction for future research, and highlight several points that FtF teachers, organizers, and supporters may want to consider. Each of these is discussed below.

Overall, the results from this study fit very well with what is known about self-help and mutual aid interventions in general: the beneficial sharing of common challenges and sorrows in a supportive peer group as a way of lessening isolation; the resulting "normalization" of problems when one sees others "like me" who have them; the exchange of coping strategies and practical information that helps problem-solving. At the same time, each such effort is also unique in itself – Family to Family is a highly structured intervention in contrast to open support groups, for example. It also addresses a highly stigmatized condition. Therefore, while it certainly can be understood through the framework of "self-help," it is also important to pay attention to its unique aspects.

This study echoes the results of the previous wait-list control study and helps make clear how those results may come about for participants. First, participants' discussions herein of feeling "better equipped," more confident, and having "more options" to solve problems as a result of FtF all can be seen quite logically as part of the increase in empowerment measured in the quantitative study. The steps leading to these changes – being exposed to new information, changing perspectives and understanding, acquiring new skills, etc are all very much in keeping with current knowledge about how empowerment develops. Second, participants also discussed how receiving and giving support, seeing results from their new "tools," and changing their expectations of control and self-care lifted their spirits and made their caretaking role and family's situation seem more manageable and less depressing. This process certainly may be what led to the quantitative study results of decreased subjective burden among those taking FtF. It also suggests that the reductions in depressive symptoms that we observed somewhat unclearly in the quantitative study might warrant further consideration in future research.

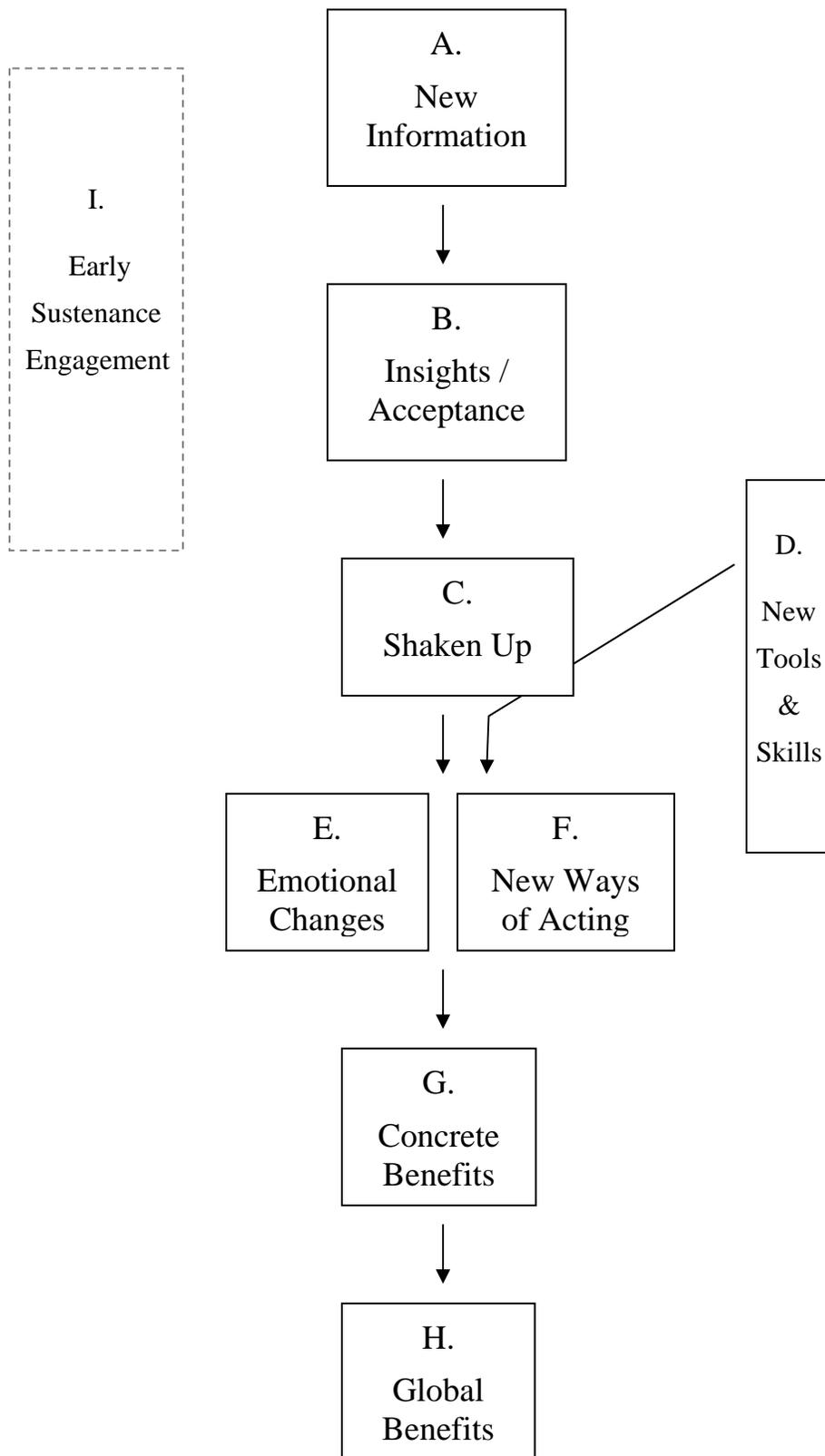
Many participants observed that changes in their own thinking and behavior improved their interactions with their ill relative and other family members, sometimes profoundly. A few spontaneously remarked that their ill relative benefited from this – seeming less anxious or upset, or feeling that the family was more caring or supportive, etc. This chance finding (asking was not part of the interview) supports the thinking (enacted in several UMd-NAMI studies currently in development) that while FtF and similar programs are designed to benefit family members primarily, their benefits for the related consumers is worth examining as well.

Regarding implications for NAMI's administration of the FtF program, it is worth highlighting that the "time regret" phenomena was quite poignant in these interviews and underlines the importance of making FtF available to family members early in their relative's illness. NAMI may want to consider prioritizing ways to reach such families, such as through EAP's, inpatient psychiatric units, and/or primary care physicians (among others).

Publicizing the growing body of evidence supporting FtF's effectiveness can be useful in this endeavor, both for direct-to-family publicity about FtF and for gaining the confidence of health care professionals who can recommend FtF to families.

Nonetheless, experienced FtF leaders know that it is often difficult to persuade relatives/caregivers of newly diagnosed people to take FtF even when they know about it – because such people are often uncomfortable thinking of themselves as having a relative with a “serious mental illness” and in flux regarding their own caregiving identity and role. The stigma associated with mental illness is certainly part of this. Therefore, addressing these barriers to early family participation is also worth consideration.

**Figure 1: Flow of Change in FtF**



## Appendix: Methodology in Detail

### Methods

#### Recruitment

In order to invite FtF graduates to take part in this study, we visited the last class of 6 different FTF classes in 5 different Maryland counties (including Baltimore city) during Fall/Winter 2003. We explained the study's purpose and format, and asked for contact information from anyone who might be interested. A total of 40 people (out of 61 total attendees) signed up on these "interest" sheets, giving us contact information and permission to call them discuss the project further. Of these, 33 people were eventually interviewed in 30 interviews (3 interviews were parent couples).

Of those who expressed interest but were not interviewed, two declined when contacted, one was too ill to participate, and seven did not respond to our initial contacts or to later communications after first expressing interest. Two of these scheduled interviews but then cancelled them and did not respond to our efforts to reschedule.

#### The Interviews

We conducted the interviews 1 to 3 months after the participant's class ended, focusing on what from the class had stayed with participants and become integrated into their daily lives. Approximately half the interviews were conducted by both Stewart and Lucksted, with Lucksted usually leading; the other half were conducted by only one of us due to scheduling challenges. Interviews took place at a mutually agreeable time and place, often in participants' homes or the local NAMI affiliate office in a private room, and ranged from 45-90 minutes.

In addition to contextual information about the interviewee's family situation and way(s) they came to know about NAMI and Family to Family, the interviews focused on three main areas. First, we asked participants to discuss what about the class stood out for them. We sought to hear what was most salient, what had stuck with them, and what they found most important to their daily lives. Second, we discussed what effects or ripples the class has had in their lives, from their own emotions to extended family and community. Third, within both areas, we also explored the change processes involved – how did elements of the class lead to, influence, cause, etc the "ripples" that participants noticed. We sometimes overtly asked about these processes, but much more often they were inherently part of the participants' stories and we only had to seek occasional elaboration.

#### Data Processing and Analysis

Data Preparation. Interviews were audiotaped, labeled only with date and interview number, and then professionally transcribed. During transcription, names and other identifying details were replaced by anonymous placeholders that preserved the context of the information while protecting privacy (e.g, "younger sister," "nearby small town," or "Dr. A."). Transcripts were then spot checked against the audio-recording for accuracy, or when the transcriptionist

highlighted a passage as unclear or confusing. The transcripts, and our field notes regarding specific interviews and developing ideas across interviews, constituted the data for this project.

#### A. Individual Interview Summaries

Our first step in data analysis was to summarize the story that each participant told about their family situation and FtF involvement, in 6 areas:

1. Demographics and family context
2. How they came to contact NAMI
3. How they came to contact FtF
4. What things stood out in the class for them
5. Did they relate any change processes they noticed during the class
6. What effects on daily life have they noticed from the class (ripples)

#### B. Demographic Sample Summary

Second, we excerpted factual characteristics from each individual summary, such as relationship between interviewee and ill relative, interviewee gender, living situation, how long ill person has been ill, diagnosis, and how they found NAMI and FtF in order to be able to factually describe our sample. (See Table 1)

#### C. Cataloging What Stood Out

In preparation for more in-depth coding and theory building, we first listed the facets of the FtF course that each interviewee told us stood out as important and meaningful to them (part 4 of our initial summaries). We each separately tried to categorize similar responses together, and then discussed our respective results until we could agree on the most meaningful categories and which responses fit into which (consensus coding). We ended up with 5 categories that we think capture the most important facets of the course for participants reflecting back 103 months after FtF ended:

- Information
- Skills and Strategies
- Empathy and Insight
- Resources
- Social Support

The meaning of each category and illustrative examples are discussed in the Results section. Note that this list does *not* mean that each participant experienced all of them. Quite contrary, there was wide diversity, and the list should be understood as an accumulation across all interviews.

#### D. Cataloging “Ripples”

We then used the same procedures to develop a list across interviews of what interviewees reported as the important effects that taking FtF had in their daily lives thus far (part 6 of our initial summaries). From their descriptions we came to see these as “ripples” extending out from the course experience into their daily lives. Using the consensus coding procedures, we eventually settled on eight categories of “ripples.” We were acutely aware that this was a preliminary cataloging rather than in-depth analysis and, among other things, inadequately addressed the interrelationships among categories. In no particular order:

- Self care actions

- Sharing class information with others
- Well-being benefits to the person who took the class
- Improved communication and relationship between the interviewee and the ill person, and/or between the interviewee and others (other family members, etc).
- Advocacy, involvement in NAMI to help others
- Individual advocacy on behalf of ill relative
- Using the strategies learned in class consciously

Again, these categories are a cumulative list across interviews; each interviewee reported a unique combination of a few or many of them. In a more developed form, they are detailed in the Results section.

#### E. Change Processes

We were also very interested in what changes FtF creates in a person's life, but also *how* these changes come about (the change "processes"). We viewed these "change processes" as linking course experience to the effects or ripples they reported.. That is, we posited that important facets of FTF interacted with what participants bring to the class to create the change processes which then lead to the outcomes or lasting effects.

In planning data analysis, we saw that these change processes could not be simply listed and categorized as had parts 4 & 6 of the interview summaries. First, in reading the transcripts we could discern many more changes processes at work, woven within interviewee's words, than they stated explicitly. Therefore, if we simply categorized only the change processes we had extracted for Part 5 of the interview summaries, we would have a very incomplete data set for this construct. (unclear??)

Second, most change processes are described by interviewees as a chain of steps (A leads to B leads to C), not as unitary ideas. Third, interviewees described fragments of much larger processes when telling specific stories, and described a variety of change processes during any one interview. We therefore wanted to analyze this particular data in ways that preserved the connections among 'steps' and would allow us to see and build larger themes and patterns as we reviewed one person's entire transcript and compared it to other interviews.

Therefore, we approached the "change processes" data in a new fashion: One of us (Lucksted) again closely read each transcript, and diagrammed the steps depicted in each instance where an interviewee seemed to be describing a change related to FtF, emphasizing with arrows what the person said led to what. We ended up with more than 250 separate statements, most containing multiple steps. One example (→ meaning "led to"): Class information on family impact → better understanding of sibling issues → not blame sister as much for resentment towards ill brother.

The other of us (Stewart) then inspected these diagrams and compared them to the existing summaries of each interview for accuracy, and to the transcripts when needed for clarification. We then discussed them and made a few changes based on her second reading.

Some interviews included frequent and rich descriptions of change, while others few and/or sparse ones – variation due to what interviewees thought of or chose to share, speaking styles, our interview questions and styles, etc. Invariably, most diagrams present fragments of larger arcs of change – whatever fragment was relevant to the specific experience the interviewee

was describing at that point in the interview. Across interviews we noticed many similarities, overlapping ideas, and ways that individual fragments fit together.

To help structure our analysis of how these specific fragments “fit together” into larger change processes, we tentatively abstracted the fragments into types. From the data (emergent coding), we initially developed 14 categories. For example “the skills / problem-solving parts of the FtF curriculum → the interviewee feeling better prepared for crisis, with better options than before → the interviewee feeling less anxious” was a common category across numerous interviews. We could then sort all the diagrammed fragments into one or more categories, and think about their meanings and roles more in-depth by considering many examples of that category (the fragments) at once. This also helped us see relationships between categories and to discern higher order groupings. At first, we thought that three main themes captured the meaning of all 14 categories: Support, Insight, and Mobilization. However, this became a stepping stone rather than our conclusion, because it did not depict how the 14 categories or 3 main themes interact with each other, nor what causes what. Our primary interest remained understanding of overall arc of change that FtF involved for the participants we interviewed.

Therefore, we sought to create a structure that would relate all the various change processes, themes, and fragments to each other and depict a holistic schematic of what the FtF participants said they experienced. Through discussing the individual change fragments, the larger arcs of meaning, and testing various ideas on each other and with the data, we began to layer separate specific expressions of change on top of each other and fit them together to accumulate larger patterns of bigger change processes. After immersing ourselves in these ideas and the data, we drafted a tentative overall diagram of what we thought captured the “big picture”. We then went back through the all the change moments and fragments that we had previously mapped out and tested this initial diagram against their specific instances. This led to a number of refinements until we were much more confident that the diagram was depicting a “big picture” that was true to the individual interviews as well as being conceptually useful.