NAMI Spotlight: Joyce Burland –

Founder of NAMI’s Family-to-Family Education Program

and Mental Health Leader

This is the full interview with Joyce Burland, Ph.D the National Director of the Education, Training and Peer Support Centers for NAMI. Dr. Burland, who authored the NAMI Family-to-Family education curriculum and the Provider-Education program, will be leaving NAMI in July, 2011, after more than 20 years of dedicated service and expert contribution to the organization. Dr. Burland’s sister and daughter both live with schizophrenia, and her experience in coping with the illness in her own family deeply influenced her understanding of family trauma associated with mental illness.

Dr. Burland earned her B.A. at Vassar in 1955 and her Ph.D. in clinical psychology at Fielding University in 1988. For a number of years, Burland worked at a public mental health agency and had a private practice serving individuals affected by mental illness and their families.

NAMI: Lets start at the beginning: where are you from?

Joyce Burland: I'm from Missouri. I've always loved the straightforwardness, friendliness and community that I first experienced as a youngster in St. Louis, where I lived until I was 10. My mothers family is generations of New England, and that's where we went each summer. We loved stories in our family, and singing and food and companions. Because of dads political career, we were always surrounded with interesting people, talking about things happening in Washington, D.C.

NAMI: Dad was Clark Clifford.

JB: Yes. Initially he was a naval aide to Harry Truman, then became Counsel to the President. Later, he went into private practice. He also served as Secretary of Defense under Lyndon Johnson, My parents were wonderful; they gave us a very interesting life.

NAMI: After graduation from college in 1955, what did you do from there?

JB: I married and went to back to Washington, D.C. I lived a life of raising my three children. We moved to New York; I was divorced in 1969 and remarried in 1971.

NAMI: Tell me about your family's experience with mental illness.

JB: In 1960, my sister was 30, living in Washington. She had a psychotic break with schizophrenia, and has never had any insight into her disorder. She's never been hospitalized.

NAMI: How did you understand what was going on with her?

JB: After she had her fifth child, she had postpartum depression, and she became psychotic very suddenly. Her husband called me up in an absolute panic. We didn't know what to do. We got
her to a psychiatrist, who immediately blamed her family. She had a wonderful housekeeper, and I would go over, and mother would go over and help out—but neither of us had a clue about what to do or how to do it in relation to her illness.

She was crying all the time. And then she would take a candle into a closet and lock herself in, and she became intensely religious, having delusions that she was chosen to lead the world in some holy way. She became mute, which can be an aspect of psychosis. I remember sitting outside the closet door for hours—talking to her through the door. We reacted like most families when something like this strikes by searching for any excuse other than mental illness for what was going on. We went through a period of denial, although when you see someone break down with schizophrenia, there is no question that you are looking at a physical event. But at the time, there was nothing to tell us that.

If you ask where the genesis of the Family-to-Family course came from, it was ultimately in that very trying time of searching for some reasonable explanation for the chaos we were experiencing and finding no help. This is what was so emotionally traumatic for us, this sense that the person you love and know has departed and you're all just lost.

NAMI: And the psychiatrists at the time did what?

JB: The accepted course of treatment for her was to talk about her delusions with a psychiatrist, who would then connect them to family dysfunction. It didn't take long before she became very angry with all of us and with her husband, accusing us of causing her difficulties. They separated, and that really left her adrift. She refused to see my parents for the last 15 years of their lives, which was a tragedy for them. She's now 78, still living alone. She has never accepted treatment, has never had one shred of insight, but some of the positive symptoms have kind of burned out now that she's older; She had a lot of life skills in place before this happened to her and she has managed to put her life together with much of the grace and talent we remember so well.

NAMI: Would you talk briefly about the costs of her illness?

JB: The cost to children is that the person that you depend on for your sense of rootedness, your view of reality in the world, is giving you all kinds of really weird messages. Its very hard for kids living with a person with mental illness who is psychotic not to get pulled into it. I think the fact that there were five of them was a great help, because they could band together to bring each other up. As I talk to children of a parent who lives with mental illness today, I hear two things: That its really shocking to outgrow your parent, which you do very quickly, and that your relationship with your parent improves a lot when you get old enough not to need them any more. But there is an enormous price. Of all the people that I work with and teach, my heart is always softest for the children.

NAMI: Your daughter became ill in 1980.

JB: Yes, she was 19 at the time, and studying to be a dancer in New York, while I was working on my graduate degree. Within a period of six weeks she went from a robust, athletic dancer to a painfully thin anorexic person diagnosed with schizophrenia. And, again, she had no insight into her condition. I took her out on her 19th birthday—she had just come back from dancing in a recital, and she was all steamed up, very excited and very high and a little out of touch. At one point, as I looked across the table at her, I thought, “she looks exactly like my sister did in the early days of her breakdown” and my heart sank. We went to see a doctor. And even then, in 1980, he went right for the family stuff. He asked to see her dad and me together, telling me in
no uncertain terms that our divorce a dozen years earlier had precipitated her illness. Another doctor said it was an “infant psychosis” breaking through again due to maternal emotional abandonment. I thought, “this is happening twice in my family, and its happening the same way” and “I'm still not getting any answers that make sense.” She became catatonic; in the hospital we discovered that the medications had no effect. Still very psychotic, she tried so hard to manage her life, but the continuous episodes were just heartbreaking. Eventually she learned how to escape the hospitals: she would hitchhike all over the country; she spent years in a state mental hospital. It took many more years to find the right medication so that she could finally be helped into recovery. She is an absolute treasure and she is our family heroine.

NAMI: So there were times when you didn't know where she was?

JB: Absolutely. Were it not for the kindness of strangers, as the saying goes—people would find her on the side of the road, pick her up, take her to a coffee shop, ask her if she had a home number. I would get on a plane, go and find her. She ended up in Seattle. She was hospitalized for four years there. I was going out once a month, on a plane to Seattle. And then she was out again. Looking at families today, knowing my own story and hearing so many others, I don't know how we all got through it.

What hit me so strongly, with both my sisters illness and then my daughters, was: “How can we be going through something like this with no help?” When family members came down with cancer and heart disease and other things, we were immediately contacted, we were given information, brought in, told how we could help. We were given a prognosis. But with this, in over 20 years, I got no information.

One of the most bizarre experiences, one that I remember so vividly, was that first night when we finally got my daughter into the hospital in New York. I was asked to stay behind because someone had to do a psycho-social history—at two o'clock in the morning. And I said to them, “I am absolutely exhausted, and I know this is important to you, but can I come back?” “No, no, we have to do this now.” And I said, “At two o'clock in the morning? I can barely stand up.” This was after three or four days of trauma trying to get her help. And I suddenly thought, they want information from me, but they have no interest in giving me anything at all. So I dutifully sat there until four in the morning and gave a psycho-social history. There was no comforting, no sense of my travail, no sense of my need for respite or even for information. They just needed to get a psycho-social. This was on a Friday, and I learned later that nobody did a damn thing with the information until Monday.

I just suddenly saw the harshness and the idiocy of what I was dealing with. This is the way people are treated when their family member comes down with a psychosis, and this is unacceptable. It was a formative experience—I thought, “People going through this have to be rescued from this kind of treatment.”

And I think the second formative thing that happened in those years was that I came to deeply understand the trauma of mental illness for her. To be wandering the earth without any assistance, in ways that you are victimized as someone with mental illness can be—I thought, she may recover from the illness; I don't know if she'll ever recover from the trauma.

NAMI: How did you find NAMI?

JB: By 1986, I had moved to Vermont from Long Island where I had attended my first NAMI support group. I saw something in the Brattleboro newspaper about a family support group for
mental illness, and there it was, AMI of Brattleboro. So I went to the group, and that is how I got connected. I was on the state board within a month.

As for finding NAMI national, in 1990 Dr. Agnes Hatfield from the University of Maryland, who was then the family education leader in NAMI ran a weekend conference where she asked a representative from each state to consider starting family education themselves or advocate with mental health professions in the state to offer family education. I thought, “This is exactly what I've been thinking for years: We've got to do: something for families.” The message really was go home and get something going.

NAMI: So that was perhaps the first NAMI conference devoted specifically to the topic of family education.

JB: Yes. She divided the country in half, and I paid my own way because I was so eager to find out what was out there. By then (1998) I had earned a Ph.D. in Clinical Psychology, and I was becoming more focused on the question, what do I think we need to do for families?

I did take a look at Agnes course, and its a very sturdy course, but by then I had completely different ideas about what I thought families needed, and they centered around two main ideas: One occurred to me very early on, and being in the profession and doing all my clinical work at a large public agency, it was very clear to me that professionals were never going to have the time to educate families. By then the caseloads were already very high. And educating families meant opening a church at six o'clock at night or working with them on Saturdays. That was not the way to go. And the reason I was so clear on that was that I had, number two, an abiding faith that NAMI family members could be the teachers. We lived through these things. We had come out the other side. We had picked up a lot of information on our own, and—we needed to turn to each other. We have the problem, and the answer is us. And so that began to structure all my thinking.

NAMI: They are not going to do it, and we can do it.

JB: Its not even that they are not going to, its that they really cant. I had seen how it is for providers, in seven years in a busy mental health clinic, you devote most of your Saturdays to paperwork. So my first thought was, family member-teachers are the answer to the labor problem in family education. I also thought, knowing the trauma that I had survived, that emotional intelligence about what's happened to families and to their lives is fully as important as medical information, and family education needs to be designed with an understanding that families need a process that takes account of that fact. A process that understands that medical information out of context is informative: its helpful, but its also limited.

NAMI: What did you think a process like that would look like?

JB: As I thought about the course I thought about all the things that had been clear to me as I came through it. I came into this experience with the same set of biases and expectations about mental illness that had been taught to me in my culture, and I had to learn to let go of those in order to be realistic and fair about what was happening to my daughter. And I had to learn to see her as a heroine rather than someone marked by illness. These are things you live through and you learn. And I thought that if families could have time to sit down together and go through the emotional process of coming to terms with mental illness in the family, and if we could engender a love for lifelong learning about mental illness, we could build something and do a lot of good for a lot of families. There's so much you need to know and so much you need to change to make the kind of shift in understanding I'm talking about.
NAMI: What would someone need to learn in this course, as opposed to all that they are learning from other aspects of their experience coping with all of this?

JB: Most people focus on only one thing: the only person they are interested in learning about is one person. And we know how tremendously situations vary and how complex they are. So the course was written to give a great deal of information. My theory was that every person coming to that class would be looking for something different. They have a mosaic forming in their mind about what they need to know about their family member.

NAMI: How do you balance your awareness of that fact with the concern not to overwhelm those entering family members?

JB: What I learned in going through it is, if you want to be effective with families you need to be utterly transparent and extremely straightforward. In class one, we tell them straight out that we are going to give them a feast of facts, that we know everyone in the room is probably looking for something different, and its quite all right to let a lot go by if it doesn't pertain to your particular interest or the person that you love. But we hope that by the end of the 12 weeks, the mosaic that they finish will give them a very clear picture of the person that they are trying to help. Were not so much educating as we are asking them to join us in a process of emotional recognition of how this has impacted their lives.

NAMI: And so you invite them to share of themselves?

JB: That's the strength of the group. My other conviction was that if you put a group of family members in a room with two family member teachers, you are going to get to a lot of deep stuff. Tears come often. In the first class, we give them what we call the “family stages of adaptation,” the coming through mental illness, and as they see that, they begin to recognize the normalcy of their own responses to it, and they begin to see that there is a way through and that you can come from chaos to acceptance. That's not easy, but its possible. Were always asking people to share what's going on for them and to share what they are learning in the class about their family member. Attitudes are also very important, because so often we come into this thinking “we can fix it,” as I think one comes into any serious illness. That's our protective cover for coming to terms with some of the dire aspects of illness. We dispel that notion right away. We have a series of things we tell them about the courses principles and one is, there is no magic here. Class one covers the core of what families need: what would happen if we went to a hospital and someone sat us down and said, there are ten things you need to know about what's going to be happening to you, and we just want to give them to you and make it very clear to you. And one of the things that you need to know is that there is no magic; if we had a cure for mental illness, we wouldn't be here in the first place. We don't have that yet. What we have is a very troubled system. We have a field of inquiry which really only got started in the 1980s, so were way behind other realms of medicine. But what we do have is a collective love and a collective will to examine our attitudes about mental illness and rid ourselves of any attitudes that are going to obstruct and inhibit our ability to help our family member.

NAMI: What are some of those attitudes?

JB: Here's one: if you face mental illness with an attitude that if they just worked harder and pulled up their socks, they would be fine, then I'm going to tell you that is the straight, wide road to failure. But so many of us do, and I did; I just thought my daughter wasn't trying hard enough and that if she just put a little more effort into it, she could come out of it. These are things that we are taught in our culture because our culture doesn't understand the reality of mental illness. They think this is characterological, and that its a simple matter of duty: its our duty to fix it.
These are not characterological illnesses; people do not ask to get mental illness; and they are being asked, really, to go on a hero's journey.

**NAMI:** And I suppose partly that's because we all know examples of people who have exhibited multiple signs of recovery, and people infer that it is characterological because you can say: that person climbed out, right?

**JB:** Its even worse than that; they say that if they are doing well in recovery they couldn't have been very ill.

**NAMI:** But meanwhile the person close to me is not climbing out, and my strategies aren't working. So the person coming into the education program has inevitably experienced a fair amount of failure, right?

**JB:** You are going to experience a fair amount of failure, absolutely, because the system is failing all around you. And nobody is giving you information that might let you do something that is going to be effective. Failure and frustration is the name of the game.

**NAMI:** Failure, in fact, is what brings you in.

**JB:** And that's why I think the other thing that is very important that we tell families is, we know you are doing the best you can. We trust you to be doing the best you can. Its like being thrown in a pool. And you are struggling to stay afloat. But now, here's what we've learned: there is a huge amount of literature in the family movement that is generally unknown to the outside, of things that we have learned to help us in this struggle. One of the things that we have to learn is to see these illnesses for what they are. Often in class someone says, “how should I respond?” And we say, how would you respond if this were leukemia? We see that happening in class all the time. What were telling them is quite diametrically opposed to the way they've been reacting. One of the mottos of the course is: you cant know what nobody ever told you. So much of this really is new. Even so, I think this country has become more sympathetic and more empathetic with regard to other illnesses. I think we understand the heroism of cancer survivors, and we understand the discipline of people who live beyond heart attacks. And we reach out to those people and those families. Mental illness, as class members will often say, is the illness where you never get a covered dish. You are immediately isolated by stigma when this happens.

**NAMI:** But you can understand where it comes from.

**JB:** Sure. But we have to help families not to buy into it. We understand that everyone coming through that door is a product of the society and culture in which we live. A society and culture which tends to make quick, harsh judgments and expects people to “get over it” on their own. And we also know that is a protective position. Because if you think your family member can fix it, and is going to get over it, you can move on at some point, and put it all behind you. Now, that idea impedes any kind of communication and effective collaboration with somebody with mental illness. They are caught in this traumatic event in their lives where they are literally wiped out for a period of time. I think what's happened is the characterological blame has attached to getting mental illness, whereas actually if you take a characterological approach, character is what pulls people into recovery. Its that human wish, once you understand what you're dealing with and what you have to do to be well –recovery becomes an independent, personal decision to move forward in spite of ones disability, you see. A great deal of personal courage and personal will exists on the recovery side, but that always got off-loaded on the other side as, “that's why they are sick, because they just cant pull themselves together.”
NAMI: And this is why insight is so crucial to the whole thing?

JB: It is a great gift, and the 50 percent of people with mental illness who don't have it face a very difficult struggle. We can learn by ways other than insight, but most of them involve getting dropped on your head. You keep hoping you can keep them alive long enough to come in from the cold, and that insight will come, because its such a long traumatic road without it. And the anguish of families watching their family members refuse medications, remain ill, wander off . . . we had two people in a recent class who didn't know where their family members were. This happens a great deal of the time. And so its just anguish to help them get through. How do you get through this kind of existential pain? Will you do it by joining, knowing that you are not alone, learning where some of the remedies and solutions are, hoping that they will work for you, and then being able to find a way to withstand the hard times? That's what you face.

NAMI: Can you talk a little bit about the role of mental health professionals in this process?

JB: I think were trying to help professionals learn that the only way you are going to be effective helping people with mental illness is to make a bond with that person, an effective bond, and become a partner with that person, to let them run the show in their illness because the individual is the most expert about what's going on with him or herself. So this will take a sea change in the professional approach to mental illness. And when you read the recovery literature, its not so much a matter of going back to who you were before this happened to you as finding out who you are in the wake of the event, the strengths you possess now, the person you are now, not who you were before. You cant go through this without being changed.

NAMI: So its the struggle to go from being told, “you are a schizophrenic,” to saying, “I am a person with schizophrenia.”

JB: “A person with schizophrenia in recovery taking forward with me the strengths that I have forged in my own overcoming.”

NAMI: “By virtue of my own wrestling with this part of myself.”

JB: Well, wrestling with this hard luck in my life. The hardship is terrible, and I would not ever have wanted it to happen to anyone I love, but the only upside of hardship is wisdom. And this takes time. Another absolute fundamental of the family education course is our assumption that everybody needs to be someplace; wherever you are is just fine with us, we know you are doing the best that you can. Here is information, collaboration, bonding, and a sense of togetherness for 12 weeks—you use it in the best way for you. We trust you to know what to take from this; we don't give advice. Its all here for you take what you need.

NAMI: And what do people in the course come out with? Where do they go with all this?

JB: Here are a few examples of comments from a recent class 12: “I cant tell you how my attitude has changed about the person that I love.” “I cannot tell you how I have found voice now to ask for things that I never thought I could ask for in order to help them before.” “Where else can I go in NAMI to learn how to be an advocate?” “When is your next teacher training? I want to participate.” “My family member is moving into services because I've been able to guide them more realistically.” Everyone who takes this course comes out in a different place, but tremendous things happen for each one. Then, too, some people may continue to think, “Golly, I wish he would get well all by himself.” I know at least that we've started for them a process of inquiry and self-examination and learning how to learn.
NAMI: What keeps them coming back to all 12 classes?

JB: That's a wonderful question. Of course, the easy answer is, the course; it's a very good course. It sounds immodest, but that's the answer. The course really provides the architecture for this powerful experience we see so often, and this came into being over three or four years of watching it in the field and making corrections.

NAMI: And you're getting something from the course that you need that you are not getting anywhere else in this country.

JB: That's right. You can't get it anywhere else, because of the value of lived experience. It's only when you have gone down that road that you know what others need. It's why we were so eager for our provider course to go out across the world, so we can sit down with people working in the field and say, let's just hang out for 15 hours together; by the end of it we will, as closely as we can, give you the lived experience: of coming through mental illness, of trying to help someone coming through mental illness. This is a human event, and we must look at it first and foremost as a human event. Get all that clutter out of your mind, forget what you were ever told about it, were people struggling with some very grave difficulties here. Let us give you a real sense of what that's about. And of course it changes them forever. This is what we have not been able to get established in our culture-- this understanding of the human dimension of mental illness, because if everyone understood it and realized what it takes, then we would have a social contract about providing really good care for the people coming through it.

NAMI: Would you tell me the story of going with your father to the Canadian Embassy?

JB: Oh, the Canadian Embassy. Well, my father was very dear. When my daughter became ill, he and I sat down, and that is when I found out that my first cousin had a child with schizophrenia. My mother had known the whole time and never told me. That's how silent everybody was about mental illness when I was growing up. My father said, “I want to know more about this.” Dad was always a great pragmatist. He had no illusions at all. And even though stigma was a problem in those days, he was very interested. So he said, let's see if we can get any family history on this. And then Mom found in her side of the family one of her uncles eldest sons was, again, quite a brilliant boy, had become an engineer, had gone to South America, and broken down and wrote hateful letters home and accused his family of high crimes and misdemeanors, and was definitely a person with psychotic episodes. So we got a clear idea that this was a biological illness, and then one day I told him, I'm working with NAMI, and its this public organization and we need more prominent people to be involved in it. And he said, “OK, I will; I'm ready now.” And so he attended a NAMI tenth anniversary gathering at the Canadian Embassy with me. As we walked into the reception, the first people we saw were three people he worked with at the White House on a daily basis. In talking to them in this setting, it turned out each one had a child with schizophrenia.

NAMI: Are you kidding?

JB: I'm not. Mrs. Carter was there, and a lot of official Washington was there. And we walked in the door of the Canadian Embassy, and there were a large number of people gathered in clusters. And he looked around the room, and then he started moving around the room meeting everybody. We stayed two and a half hours. While driving home he told me that none of these coworkers had never shared that their children had a mental illness.

NAMI: And how did that strike him?
JB: Well, he was incredulous. Daddy was very Edwardian. He was just the most wonderfully urbane and charming and polite person in the world. But given his generation and position in the world at that time, this was really a kind of coming out. Of course, I was radicalized by my education; he always called me the revolutionary in the family. I wish back then in the 1980s or early 1990s that we had a number of famous people who came forward and said, were tired of this silence—lets break it and get something done for the people we love with mental illness.

NAMI: In your own succinct way, would you briefly describe these education programs?

JB: Well, the Family-to-Family course is for any family member. That's the ticket to get in the course, that you are a family member with a first-degree relative who has a mental illness. And you may be somebody with mental illness as well; many people who are family members are also consumers. The course is restricted to families so that they will have the space and the safety to talk deeply and honestly about what they are going through. Our measure of success in this course is how well we are supporting the caregiver. We are lifelong caregivers; we will be depended on to one degree or another throughout the life of our family member, so the course is built for caregivers’ support.

And then, there are certain things that consumers will say to each other if there are no family members present. They get to a much deeper level of interaction when they are together, and so Peer-to-Peer was the second course, where people with mental illness could focus on issues of recovery. In Our Own Voice is a program that grew out of a wonderful idea of having people with mental illness talk about how they came through the experience and moved into recovery. Its a public education program that is now reaching thousands of people every year.

NAMI: What's our feedback mechanism? How do we know that, for example, the support to families is accomplished?

JB: All of our courses have extensive evaluations that we ask people to fill out at the end. Numbers don't tell me much. I want to know what someone is thinking. We've now taught over 300,000 people, and they are each telling us the same thing: that this is eye-opening, life-changing, a real turnaround for them. They can see a way forward and through this.

Were beginning to see all the programs working together. Many people start out with In Our Own Voice and then become Peer-to-Peer teachers. The provider education program I wrote really at the request of many family members and professionals who had gone through the course saying, we've got to have a common language; people in the field have got to have the advantage that I've had going through this course as a professional. And we have Parents and Teachers as Allies, which is our school program, helping teachers with early recognition of mental illness. Because if we can catch the symptoms early on, and get children into treatment, we can spare a child a lifetime of pain.