

**Daughters and Sons of Parents with Psychiatric Disabilities  
Panel Presentation**

Transcripts

**THE THIRD GENERATION:  
DAUGHTERS AND SONS OF PARENTS WITH  
PSYCHIATRIC DISABILITIES**

**&**

**SEPARATING FACT FROM MYTH:  
CHILD WELFARE AND PARENTAL MENTAL ILLNESS**

Presented at the

**2004 National Conference  
National Alliance for the Mentally Ill  
Washington D.C.**

**September 10, 2004**

**These transcripts were made possible through the generous support of the  
New Jersey Self-Help Group Clearinghouse-[www.selfhelpgroups.org](http://www.selfhelpgroups.org)**

# TABLE OF CONTENTS

<b>Letter to the Reader</b>	<b>Page 2</b>
<b>I. Panel One: The Third Generation: Daughters and Sons of Parents with Psychiatric Disabilities</b>	
<b>JOE DONOVAN Introduction</b>	<b>Pages 3-4</b>
<b>CHRISTINE KOTULSKI</b>	<b>Page 4-5</b>
<b>CHAI YING WEI</b>	<b>Pages 5-7</b>
<b>MARY ANN WIDENHOUSE</b>	<b>Pages 7-9</b>
<b>HEATHER BURACK, MSW</b>	<b>Pages 10-12</b>
<b>Q &amp; A</b>	<b>Pages 13-18</b>
<b>II. Panel Two: Separating Fact from Myth: Child Welfare and Parental Mental Illness</b>	
<b>MAGGIE JARRY</b>	<b>Page 19</b>
<b>KATE BIEBEL, Ph. D</b>	<b>Pages 20-23</b>
<b>JIM MCNULTY</b>	<b>Pages 24-26</b>
<b>LUCINDA SLOAN-MALLEN</b>	<b>Pages 27-30</b>
<b>DR. ANAND PANDYA</b>	<b>Pages 31-32</b>
<b>MAGGIE JARRY Closing Remarks/Recalling the Child's Perspective</b>	<b>Pages 32-34</b>
<b>Q &amp; A</b>	<b>Pages 34-36</b>
<b>III. APPENDIX A: Panel Participant Biographies</b>	<b>Pages 37-42</b>
<b>IV. APPENDIX B: Handout Discussed by Panel Participants</b>	<b>Pages 43-44</b>

August 13, 2005

Dear Reader,

The following statistics may surprise you: according to Joanne Nicholson and Kate Beibel at the University of Massachusetts Medical School, 68% of women and 57% of men with diagnosed psychiatric disorders are parents. The figures are even higher for people (especially fathers) with serious and persistent psychiatric disabilities.<sup>1</sup> To quote Kate Beibel, “women and men with a lifetime prevalence of psychiatric disorder are at least as likely to be parents as are adults without a psychiatric disorder.” Yet persons with psychiatric disabilities play the important societal role of parent in the lives of millions of people (young and old), often called “invisible children.”

The 25<sup>th</sup> anniversary of NAMI was an exiting benchmark for National Alliance for the Mentally Ill as an organization. This anniversary was a time of celebration and reflection and it also provided a special opportunity for NAMI to consider the growing number of daughters and sons of people with mental illness who are envisioning their role in the future of NAMI. The 2003 NAMI National Conference in Minneapolis featured an early version Susan Smiley’s documentary *Out of the Shadow* and readings by Lynette Brasfield and Virginia Holman. The panel discussions transcribed here were envisioned as an opportunity build on the 2003 convention in order to continue representing the complexity of issues facing daughters and sons of parents with psychiatric disabilities, their parents and extended family in this public forum. The 2004 NAMI National Conference in Washington D.C. featured these two panel discussions and the completed documentary, *Out of the Shadow*, by Susan Smiley. Approximately 150 people benefited from listening to the *Daughters and Sons of Parents with Psychiatric Disabilities* panel presentations in 2004. With support from the New Jersey Self-Help Clearing House, these transcripts from those presentations are now available for hundreds of people that were not able to attend the 2004 Washington D.C. conference, but for whom the content of these panels is vitally important.

Thank you to the National Alliance for the Mentally Ill National Office and National Board of Directors for supporting and approving the presentation of these panel discussions. Thank you to all of the panel participants. Thank you to all who lent support to the creation of these panel presentations including: Barry Ackerson of the University of Illinois at Urbana-Champaign; Ed Madera of the New Jersey Self-Help Clearing House; Richard Kagen at the Parsons Trauma Center; Pauline Anderson at the International Center for Clubhouse Development; Nerrelle, Paola and Elizabeth Fudge and Vicki Cowling of the Australia-based organizations COMIC and COPMI; authors Virginia Holman, Lynette Brasfield and Victoria Secunda and documentary maker Susan Smiley. Thank you to Alex Baker for his work transcribing these presentations. We hope that these transcripts inspire more people to lend support to this effort.

Sincerely,

Maggie Jarry & Joe Donovan

---

<sup>1</sup> See the Parenting Well website (<http://www.parentingwell.info/>) for more information and access to both research and tools to support parents with diagnoses psychiatric disability and their daughters and sons.

**PANEL ONE:  
THE THIRD GENERATION:  
DAUGHTERS AND SONS OF PARENTS WITH MENTAL ILLNESS**

**JOE DONOVAN:** Welcome. We're beginning our session entitled, "The Third Generation: Daughters and Sons of Persons with Mental Illnesses." First of all, I want to remind everyone that this session is being recorded and that you can purchase copies of this at the NAMI recording sales booth.

First of all, my name is Joe Donovan and I've been active with NAMI for several years now. So I'm really quite proud to bring this to everyone here. I want to start and talk about the fact that this is NAMI's 25<sup>th</sup> anniversary, which I thought was really interesting, because I was not a member of NAMI 25 years ago, but I have a story from 25 years ago which makes this relevant. Because 25 years ago I was in the ninth grade. And that was the year my mother was hospitalized for the third time. That was also the year of her second divorce and that was the year I decided I needed to get away, and I basically ran away from home for about three or four months before I finally decided to come back.

Which kind of leads to the issue of why this is happening. One of my biggest problems as a child—you know, I was fourteen years old—and no one could answer my questions as to: what's going on with my mom? And I went about fifteen years before I discovered NAMI. And that was a major period of my time that I really did not know anything about what my mother was going through. I just knew she took medication from time to time, she'd be in the hospital from time to time, she would have problems with a lot of challenges. So since I've been a member of NAMI, I've dreamt of putting together a panel like this. So I'm glad to do that.

We've got several things here. You will have found folders of materials, which we will have, and we will discuss a little bit about later and sort of a survey card which we'll be collecting at the end, and Maggie at the corner will keep track of those. Because we know that some people are going to want to ask questions possibly but we may not be able to hear them, so we would like to be able to at least take them with us so that we can get back to you and answer your questions later by email or something like that.

And then, the next step is, there are actually two workshops. We're the first workshop of a series—this one we'll get to in a moment, the second one we'll actually talk about some of the knowledge that has been developed about what it means to be a consumer who has children and raising children and what it means. And also some of the services that have been kind of developed about how we keep track of providing services to parents who have mental illnesses and their children, and that we'll have at 5:00. And then later this evening—you've already seen some handouts for Susan Smiley's film "Out Of the Shadow" which will be playing at the NAMI movie night at 7:15 tonight and we welcome you to attend that.

I'm going to start off with now beginning to introduce our speakers. First off, I'm going to introduce Christine Kotulski, who is currently working on a memoir about growing up in a family torn apart by schizophrenia. Her mother, Mildred Smiley, whose life is seen in the documentary "Out Of the Shadow," suffers from schizophrenia. Millie went undiagnosed for

many years before the pieces of her life were put back together when the illness that started in her young adult years was given a name. Tina's story follows her years growing up with her sister Susan in a single parent household and tracks the course of Millie's illness through a first person narrative about how one family nearly slipped through the cracks. Like many living with schizophrenia, the survivors, the families and the sufferers, Tina and her family have had to navigate the often frustrating and complicated maze of today's mental health system. Through her experiences, Tina deconstructs the shame and stigma the disillusionment and fear and reveals an underlying story of survival which at the very least provides a sense of hope, a way to heal, and the long difficult road to forgiveness. Tina and her husband have been married for seventeen years and have three children. They now live in Minnesota. That's it.

[Applause]

**CHRISTINE KOTULSKI:** I want to first thank Maggie and Joe for getting this panel together and recognizing the need for a way to heal as a son or daughter of a parent with a mental illness.

I gladly accepted Maggie's invitation for a couple reasons. One is, the disillusionment of my mother's illness created such havoc within our own family that it was very difficult for my sister to get along when my mother had regressed in her behaviors. And through the film, and the filming of the documentary, my sister and I were able to actually heal our relationship. And that was a huge road that we're still traveling, but we at least have come together and become friends. And as a daughter of someone with a severe mental illness and not having the resources to understand that mental illness and even know that my mother had a mental illness, made me feel unwanted and unloved, not only by my mother, but by my family, because it wasn't talked about. And when I was thirteen, I tried to commit suicide. And the two greatest things that came out of that was one, I survived. The other one was that there was a physician who recognized that I did not have a mental illness. What I had was a learned behavior that I had learned from my mother. And I was adopted into—well, I was placed in a juvenile mental health facility for six months.

And the doctor could have taken two different courses. One, he could have maybe labeled me as someone with a mental illness and given me anti-psychotic medications. He didn't. His treatment was that he recognized that I did not trust anyone. He recognized that I was extremely fearful. And he recognized that my only hope was to adopt me into the family of the other adolescents that were in the facility. And so, through the recovery of six months of psychotherapy, of every day having to talk, and embrace, and learn to trust other people—because I didn't trust anybody—I was able to embrace my mother's illness and to embrace my mother. And I was able to forgive my mother, because I was finally able to understand my mother. The feelings of that, growing up as a child in a single parent household—I could have decided to suppress those feelings, and which I did at some point. Because some of those feelings didn't come to the surface until I had children of my own.

And one of the things that's remarkable, if I say remarkable, is that as a parent, I wanted to show my children the beauty of my mother. Because I knew she was very beautiful. So I sheltered my children from my mother's illness. I didn't allow my children to see my mother when she didn't take her medications, because I wanted them to see how beautiful Millie is. And when she was noncompliant, we simply didn't bring the children to see her, because I was afraid that my

children would have the impression that their grandma Millie is crazy. Because they go to a school—peer pressure is phenomenal for children, and at some point my children weren't necessarily going to listen to me. There's a point in child development where a mother and father can say all they want. They're not going to listen to us as much as they are going to listen to their peers.

I think my sister was meant to start this film because I finally actually got to the point where we showed the film to my two oldest sons, fifteen and almost thirteen, a month and a half ago. And my fifteen year old boy started to cry and he said I'm sorry as he was crying. Not that he was sorry because he didn't listen to the rules, and sometimes broke the rules that we have in our house. He was sorry because he finally understood why I react to sudden noises all of a sudden, or why I'm not always as liberal with letting them go ahead and go out with their friends on a school night. I'm very protective of that. And he said he finally understands.

And my mother, as you know if you've seen the film, has come a long way, and I'm extremely proud of her courage to face the illness. And one of the beautiful things about the timing was that Millie became noncompliant with her medications approximately three weeks ago, and right now she's back well on her way to recovery. And I brought my son with me and he was such a calming effect for Millie, and the timing was just perfect. And as a family to be able to come together by being able to share and acknowledge that a family has a mental illness is really the road to recovery. And through my memoir I really want to bring light to people who may not experience mental illness in their family, but judge people with mental illness. Because I believe that we all are created in the image of God. And my mother is no less than god himself, or Jesus. I'm not a religious fanatic, but my mother is beautiful, and she has schizophrenia. And I'm beautiful because of my mother, and my sister is beautiful because of my mother. And I embrace the illness, and because of that I'm able to embrace my mother, and that's why I'm here today.

[Applause]

**JOE DONOVAN:** Next I want to introduce Chai Ying Wei, who received her MA degree in clinical psychology at Columbia University, and works at the New York State Psychiatric Institute. She has been working closely with the NAMI national office and is eager to assist in local affairs. She currently serves on NAMI New York City Metro's board of directors, and is the daughter of a mother who suffers from major depression. Chai Ying has been very active in NAMI, and has recently translated two books: *When Someone You Love Is Depressed*, by Laura Rosen and Xavier Amador, and *I'm Not Sick, I Don't Need Help*, by Xavier Amador and Anna-Lisa Johanson, from English to Chinese and helped them to be published in Taiwan where Chai Ying is originally from.

**CHAI YING WEI:** I think it's kind of hard to talk in front of so many people. I guess I'll just start out by telling you what I think, what the theme of my story is. I think it will be well put if I say it's a kind of a subtlety. Growing up, my mom was depressed. And although we've never been aware of the situation and from our perspective, my mom is just depressed. She was not abusive, you know, she didn't do anything outrageous. And so, you know, depression is not like schizophrenia, where you have a lot of symptoms you can see, you could recognize that something is wrong and there is something, some problem we have to deal with. To us, my mom

is just sick a lot. She has always had physical complaints, so to us kids it's just, you know, mom's sick a lot, she's not healthy, that's it. And also, her change has been slow, because you know, with depression you don't see the drastic change. So it's like growing up, you know, its sad how she has become is how she has always been—that's just the way she is and that's an accepted fact. And also because you know the symptoms of mood disorders, it's hard to identify if her personality is like that or if the illness made her become like that. And so I remember growing up we never thought—I have two older sisters and one younger brother—we never thought that there's any difference between our family and other peoples' families. And I guess it wasn't until the year before I came here—this is my third year to be in the States for my school—and the year before I came here I finally talked to her doctor and finally got confirmation that, you know, my mom has an official diagnosis of depression.

And I think that's the time that I started to take that factor into account about how I've become, how I am. And so, even—I remember whenever I came to NAMI, it was very overwhelming, I heard a lot of people's stories, a lot of them are so tragic and traumatic. And so I would listen to their stories and feel extremely overwhelmed and moved, because they have the strength to deal with all those things that happened to them. And on the other hand, I would feel, I think I'm lucky—compared to them there's nothing bad, there's no significant event that happened in my life that I could say was traumatic. And so I should feel lucky, or luckier, shouldn't I? But you know, somehow, I wondered, but why is there this urge or this feeling inside of me that I just want to curl up somewhere and cry? And you know, why is that? If I'm fine and everything in my family is normal?

And so, I guess a friend's words hit me. She said that, “Oh, the suffering is subjective. If you feel you are suffering, if you feel you are sad, then you are.” So I guess the point is not—oh and I also remembered I was talking to my therapist, or course, you know, therapist. [laughter] Yes. And I remembered I was talking to my therapist, and I was trying to tell him that I'm not trying to find out what's wrong with my family, I was trying to figure out what's going on, what happened. And he thought that was well put. And I think now, I believe it doesn't even matter what happened. What is important is that no matter what happened it does have some impact on you, and you have to recognize and admit it, and try to see what's the impact on you and the way you are and how you are right now, how you are or what you are right now—your past, how should I put this, those impacts that are in you.

It's interesting because I guess I am at this life stage and friends around me are either getting married or having kids right now, and I found myself—and my friends would joke around with me, you are still fooling around. And so I found myself in this situation that—ok, there's this guy I liked, and he told me he liked me too, and so it seems to me that it's up to me to make a decision whether or not we could, just, get the ball rolling. [laughter] If I say yes, then we could just madly fall in love, but I found myself having these fears—I was totally freaked out. I had these fears, this anxiety, and this confusion. Usually you would think this is normal, and that's what people do, but I guess my work with NAMI made me realize that my mother's relationship with me has something to do with it and if I want to be with someone, then I have to deal with that first.

And so I guess my conclusion in short is that no matter what happened before, there might be nothing wrong, no body else has seen anything else wrong in your past or you might not be able to see it, but you have to accept it as something—you are affected by it. I am affected by my mother's mental illness and I really have to identify what's the impact so that I will be able to move on. And to tell the truth, until today, my mom still thinks that I am like *her* therapist, and as you guys all know, if I am her therapist I cannot be her daughter. And the truth is that I can still not tell her my own feelings but I believe one day I will find a way to do it. Because I think my mother's mental illness has given me, has trained me to have this ability to deal with whatever problems happen in my life. Ok, so that's my story. Thank you.

[Applause]

**JOE DONOVAN:** Next we're going to hear from Mary Ann Widenhouse, who currently lives in the beautiful smoky mountains of Western North Carolina—seen a lot of flooding recently—with her husband Caroll, of 39 years...today. Ooooooh. [Applause] And her son Daniel, the youngest of her four children, and her mother Grace, who had her first encounter with some very intense psychiatric symptoms when she was sixteen. Grace is now 92 and is in recovery from her last episode 7 years ago. It is because of the last episode that Mary Ann became acquainted with NAMI and has since served as a Family to Family teacher for the last six years. A past affiliate president, a member of the board of directors of NAMI North Carolina for four years, and currently is an In Our Own Voice: Living With Mental Illness presenter for her affiliate, frequently co-presenting with her mother, also a trained presenter. A mental health consumer herself, she intimately understands both a perspective as a daughter and that as a parent. By profession, Mary Ann is a registered nurse, who graduated from Lenoir-Rhyne College in Hickory, North Carolina in 1965, but is not currently working as such. It says she has spent this past year helping, assisting Smokey Mountain Center, the local public mental health system, serving the far western seven counties of North Carolina—very, very rural—with the implementation of recovery focused programs such as WRAP, Wellness-Recovery Action Plan, and has become a certified peer support specialist, and is one of the first in that area to be trained and she will soon be employed by that Smokey Mountain Center to facilitate WRAP classes in the community. I welcome Mary Ann...

[APPLAUSE]

**MARY ANN WIDENHOUSE:** When Joe asked me to help with this or offered the opportunity for me, I thought, well I like Joe, I respect him and I thought well, I'll help him out with this, I do have some experience—60 years worth of experience—of being the daughter of someone with a mental illness. But I wasn't sure of what I could bring to the program, because I'm like Chai Ying.

I grew up in a very stable environment, I didn't have the trauma that many people have had. My parents were married until my father died seventeen years ago. My father had a very good job, we lived in the same house from my age of 2 up until I left. We sold the house five years ago. So, you know, we had a stable environment. My parents set a marvelous example for me of their faith in God and their commitment and their love to each other and their family, serving others, and their love of nature and all of God's creation.



They left a legacy with me, an example with me of that, and so, I didn't realize how my mother's illness may have impacted me until I read a little piece of paper Maggie sent to me. You have it in your packet, it's called "Daughters and Sons of Persons with Mental Illness: Common Experiences in Adulthood." And I looked through that and I said, ok, I have that one, and I have that one, and I went through and of the 18 that were listed, I had 9 of those. And I'm thinking, wow. That was very insightful to me. I kind of went, hmm. Maybe some of the things I am dealing with may have come from experiences I had growing up. I do know one experience I had growing up was I judged my mother. We did not understand what was going on with her. She would sometimes have very intense symptoms of anxiety and she would take medication or go off to her room and we would have to kind of walk on eggshells and be cautious not to upset mom. But I judged her erroneously, and I have learned since that my mother did have a mental illness and it wasn't psychologically based—she wasn't taking medication as a copout or a crutch. She needed that medication because she had an illness.

My mother is the reason I am here today working with NAMI and for that I will be forever grateful, because it was because of my mother's experiences seven years ago when she had a major relapse and she was living in North Carolina with me, and she still is that I became involved with her treatment. And I found NAMI. The very first meeting I went to we had a lady called Maria, she's an Italian lady, she said "Mary Ann, read. Read everything you can on your mother's illness." And so I did, I went to the hospital library and I read nursing journal books on my mother's illness. And I learned not only about my mothers' illness, but I also learned about myself and my needs as a family member dealing with this.

One of the things that happened was, I found Family to Family. Family to Family came into my life shortly after I found NAMI. We didn't have Family to Family all over North Carolina, and so my first encounter was during a teacher training, when I was being taught to become a teacher—I had never attended the class.

Even during that training, the impact on me was tremendous. I learned that while there are psychological issues involved, this is a biologically based illness and what the medications do. In addition the communication skills exercise was well as the problem solving and the empathy exercises were very enlightening to me. Talking about empathy for my mother—my whole attitude toward her changed because of that exercise. I got a glimpse of what was going on inside of her and it helps me to treat my mother less judgmentally, more as the beautiful person she was and honor her courage and strength that she was hanging in there. Even at 92, she gets up every morning, she gets dressed, and she goes about her day. And it's amazing to me, to see a lady who seven years ago had a series of ECT treatments still hanging in there with her faith and her love for her family and her love for everybody.

So Family to Family had a major impact on me, and that's the issue that Joe kind of wanted me to talk a little bit about today. Family to Family is about the person sitting in that class. It's about that family member who is sitting in that class, whether it be a spouse, a mother, a grandmother, a sibling, a niece, I've had all of those in my classes, or a child of—I've had all those people in my classes, and I've see the impact in their lives of how their ability to cope with their loved one's mental illness changes. We share a lot of information. It's twelve weeks, two and a half

hour classes, and there's a lot of information, there's a lot of discussion, there's a lot skills building in that class. And people take what they need from that and then go home with a notebook about that big so that when their needs change they can look through it.

One of the things I now understand, having come to this presentation and understanding a little bit now about the impact on children of their parents' mental illness, I believe that as we change and grow with Family to Family, and every year I get new information as we change and grow with Family to Family, I believe that it would be very helpful to have this sensitivity of the impact on children of their parents' mental illness. Because in my class I have spouses who may have young children, I have parents who may have young children, I have grandparents who may be taking care of young children and I have siblings who may have younger brothers and sisters. And so there is a lot of information that we can bring, those of us who have been through that, and other information that can be collected that might be helpful to the people in the Family to Family classes.

I will tell you two more things that have helped me to heal. As Joe said, I am a WRAP facilitator, and WRAP stands for Wellness Recovery Action Plan—it's a system developed by a group of consumers to take responsibility for their own illness, for their own wellness, excuse me, their own wellness. Mary Ellen Copland kind of organized it and produced it. As a WRAP facilitator I have finally learned how to, and given myself permission to, take care of me. It's finally OK. It was always: no, the other person is more important, yours is on the back burner. Now it is important for me to take care of me because I cannot give my best unless I am well.

The second was peer support specialist training. That taught me how to relate to someone else. And because of that I decided to employ those skills with my mother. And I now look at myself as no longer a caregiver, I am a support person in my mother's life. I have given back to her, at 92, responsibility for making decisions, because she was relying on me to tell her when to get up, what to wear, when to take a bath, all those things. I've given that back to her. It wasn't a happy time at first, but I've given that back to her and at 92 she's learning to ask for what she needs. She's learning how to understand what she needs. And it is marvelous to watch her grow and learn, because she's never had that before.

So, I'm very grateful for this opportunity and I thank Joe for allowing me to do this, it's been very enlightening, and I'm putting it into my mind and I'm looking at how it's affecting me. So thank you, Joe.

[Applause]

**JOE DONOVAN:** Mary Ann just started off with an interesting comment, which is that there are similarities, which I think very few people growing up with a person with a mental illness have—children do, sometimes they are different. You never know what the differences are between one person's mother may have this diagnosis another person's mother may have this diagnosis, there could be very different types of events that take place in childhood. But we have found that there are some common themes and our next speaker is going to share some of them. Her experience in trying to develop some of that. And her name is Heather Depres Burack. She is a licensed social worker with an eclectic background. She spent six years working with people

with mental illnesses through the clubhouse model of rehabilitation at Fountain House in New York City, and then as assistant director at Club United, a new clubhouse program in Harlem. She has more recently worked with youth in after school and youth development programs in family counseling in Brooklyn, New York. She also conducts empowerment workshops in a variety of contexts with youths and adults. She often integrates creative arts, particularly dance and video for healing and community building. Heather is also interested in exploring the meaning and ramification of growing up with a parent with mental illnesses. She is herself an adult child. She has done research into conceptualizations of mental illness and into the lives of these adult children. Ms. Burack's particular interests lay in the subtler and often ignored redemptive aspects of this challenging and unique experience. She wishes to share with others so that together we can shed light on our experiences and inspire each other.

[Applause]

**HEATHER BURACK:** Hi. I just want to start by saying it's wonderful to hear everybody's stories. We connected before but we didn't all share our stories in this coherent way. And I'm reminded of when I was in college and I would meet somebody, and I would click with a lot of different people for a lot of different reasons, but there would be this special feeling I would get but I wouldn't know what it was. And then somewhere, I'd know the person for a few months, sometimes even two or three years, and we'd be drunk at a party or something [laughter] and there was a coming out. And this is the age when you're starting to sort of understand what mental illness is, because it was never explained accurately, and I realized that there was something about this person that I connected with and I had no idea that we had this common bond and then there's this wonderful feeling when we recognized it. Sorry, I'm a little nervous.

So, I have this long history to get to. After many years of working in the field, I have just finished an MSW program, during which I did research on adult children, qualitative research, and I also wrote a paper based on my own experiences, which were corroborated by other people, about these redemptive aspects which I'll get to at the end of my discussion.

My mother was diagnosed probably formally when I was seven, going in and out of hospitals, the usual type of circumstances for someone with a diagnosis in that she has schizophrenia and all of the upheaval, et cetera, that comes with that. One thing I'm going to do here is just quickly review where we're at generally, in terms of the studies that are out there and what the knowledge base is --and then cover a little bit in terms of what Mary Ann referred to in the list that's in your packet of some of the legacies of growing up with a parent with mental illness.

We're often called the forgotten ones, for good reason. Although there was a 1955 study that said we need to look at the families of people with mental illness --as some of us know, it was largely forgotten, both for the children and for the parents and for everybody else. Nonetheless, the studies that were out there often looked at: the *disease* of mental illness, and which then tended to take attention away from the family. Then, de-institutionalization brought a lot of people out of hospitals --and that may be one of the influences of there being at least more studies that have been done, these studies often placed the focus on how the families impact the treatment of the mentally ill person, him or herself. Also, they looked at treatment methods and practices in terms of caregivers. These studies reflect that interest in the families sometimes tends to focus on

parents, sometimes more than on the offspring. In terms of studies on offspring, there are the two in terms of children and adult children (or adult offspring) –those that look at offspring through looking at the mentally ill consumers *as parents* and then in terms of the effects on the younger children themselves. However, in terms of adult offspring, a lot of the stuff that's out there tends to, in my opinion, be general in terms of growing up with trauma --For example, by acknowledging the PTSD symptoms experienced by adult offspring, some of it similar to adult children of alcoholics, but not always specific to the experience, which is often subtle, as Chai Ying said, and often hard to distinguish. But this shows how important it is and why we need more studies.

There may be a lack of recognition of people with mental illness as being parents and not a valuing of that role which, as those of us who know people who are diagnosed who are parents, they take that role very seriously generally and it is a great source of pride. Also, the tendency not to focus on the children may be due to the usual shame and stigma that we see affecting mental illness generally, and the fact that the symptoms that an adult offspring might show may be subtle, may not be apparent, and may represent a delayed onset. Maybe its in the 20s, the person's in their 20s or 30s before it's apparent.

So the gaps—I won't go into detail about the gaps or the research because basically one can see that just about in any area, there's a need in terms of recognizing adult offspring and the need to study them. Also there need to be studies in terms of distinguishing, and not only in terms of distinguishing generalized trauma from the specific experience of growing up with mental illness, but also along the lines of different diagnoses and the different kinds of experiences people have. We have single parent households, two parent households, foster care, economic situations, supports, sibling relationships—these distinctions need to be looked at.

The clinical issues, which are outlined so I'm not going to go through them all, they are outlined on the paper. But I think that what's most important is that we recognize that this is a *group*. Adult children of alcoholics had to work to identify themselves as a community and a group. Clinicians and people who treat people need to recognize that so that then when someone comes in and they're showing certain behaviors and symptoms, they can know this is an experience the person might have. So what are these common experiences?

Identity formation is a big issue if you've grown up with a parent with mental illness. Often the illness takes the parent away in a sense --they're there but they're not there— and there is the lack of mirroring. So there is also often a lack of sense of self, or a creation of a false self: 'if I act all good and do what I'm supposed to do, maybe Mommy won't be sick.'

Sometimes the parent's psychosis can pull the child in, so that they have learned behavior in terms of how to please the parent—and don't get a chance to do the childhood thing of expressing their needs all the time. Depression and psychic numbing, is another big symptom. Dissociation, often brought on by trauma which can create that feeling of dissociation. And there are other factors in terms of inappropriate boundaries and relating issues that are outlined in the sheet. And perfectionism, I've found from talking to people, is often a common and big issue for many.

Another one that connect to —somebody said to me (she was doing a paper about something else) and she brought up the concept “ambiguous loss” to me, which apparently was used to identify families who dealt with people who were missing in action over in Vietnam, or maybe it was before that. And that just absolutely struck to my core. The idea of ambiguous loss—which some people have outlined, so that it’s not always clear; the child doesn’t know what’s happening. Your entire identity is formed through this lens and you don’t know that you’ve lost anything because it was always there. And yet there is a sense that the loss—you know that there is loss. So to have that phrase has been healing for me.

So I’ll just end here with some of the research—the paper that I wrote, and what I was looking at. A lot of the studies that are out there are very important. They also have titles like “Anguished Voices,” “Hidden Victims,” “Troubled Journey.” and just like when I said I connected to these friends in college, I felt like, you know, I’m really proud of my mother. I’m really proud of my family. I’m really proud of myself. It’s been hard fought, but I think, some of the people I know who are mentally ill, because I’ve worked with people with mental illness for many years, and the children, are some of the most fun loving fabulous people that I know. And why is it so dreary and awful?

And yet at the same time, people often romanticize mental illness—stigma busters deals with that all the time. So to me, it was, how can we get away from romanticizing something on the one hand, and making it this dreaded awful plague on the other? And to look at resiliency and what the specifics of that are. So I came up with four things in my paper that would correspond to my experience and some other peoples’. Please make a note, that depending on your situation it may be more or less true to you.

The first one is creative orientation. My mother is schizophrenic and she’s an artist. She thinks in metaphors, she’s playful with words, with imagery. That gave me a great creative orientation toward the world that I take with me in everything I do, such as the ability to make associations and flights of imagination. The second is a tolerance for difference and challenging the status quo. A lot of people throughout history have been called mentally ill because they challenged the power structure. So I think a lot of times, they are willing to—it’s like, they’re already stigmatized and say, ‘I’m going to say what the truth is, and I don’t care about the power structure.’ So there’s a freedom in that. Emotional expressiveness—my mother was expressive, she would say things other people wouldn’t. And I felt—people that I saw who were in households where you had to keep everything under the surface, I didn’t experience it that way. And I feel thankful for that. And a sense of humor. Gallows humor for any group of people. I’m sorry, I know I probably went over.

So I think people need to look at these more, and people need to tell their stories, and the more we do, people will come together on it. So thank you Joe and Maggie, and everybody.

[Applause]

**JOE DONOVAN:** Next I want to bring up Maggie, because she’s actually helped to do something which we’re probably hoping to get more of in NAMI, which is—I guess back in February, NAMI Metro New York City actually created a new support group specifically for

daughters and sons who have a parent with mental illness, really to try to develop some more bonding, and Maggie wanted to talk a little bit about that. And once she's finished with that, we'll move to questions and answers.

**MAGGIE JARRY:** Also, Heather, the videotape is about to go out, and you're the one who knows how to do it, and since we've gotten to this point. I was supposed to be watching the video to change it just in case we needed that.

So I'm just going to speak briefly because—as you noted in your packet, and as a wonderful woman in the audience helped out, I think Susan here, I typed up the list from the University of Chicago and I was in a bit of a rush, and there are a few typos. So please forgive me, but I did list the web site so you can find the appropriate sentences. Some of them say things like “Fear of Having Children.” It's supposed to say fear of having children but it might have a few extra words in that sentence. And it's certainly one that I could talk about for about an hour and a half.

But what I wanted to note also is that there's a double sided photocopy of a promotional flyer that a woman named Stasia and myself had created in New York for our Daughters and Sons support group, and on the opposite side of that you'll see the old name for the Washington State NAMI, and you'll see that the Washington State NAMI had a support group and has had one going for adult children that I found out about last year. Three years ago, or four years ago, I had approached NAMI Metro New York and said, you know, I know there are a lot of similarities between siblings and adult children, but I also know that both of my parents suffered from mental illness, my stepfather suffered from mental illness, and sometimes I just don't have any parents to talk to at all, and sometimes sitting in a group with siblings is hard for me because they're talking about their parents. And I really need to talk about the fact that I don't have a parent to call. It's a subtlety, but it's a difference. And I really feel like adult children need to have our own group. But they said, well, maybe there's not enough need. Stasia, another member of NAMI New York City Metro and a Family-to-Family instructor also felt that a group for just Daughters and Sons was merited. I ended up moving on to other projects, but Stasia continued to work tirelessly to start a group.

And as time has gone on, what's been evident is, there's a very large population of people like myself, many of whom may come to NAMI and never stay around, because they don't find what they need. And so, after three years of kind of continuing to invest time and trying to get something started, I started communicating with people all over the country, people in Australia, just started going on line and saying: what's out there? And I found a lot of people like myself who said they'd been to NAMI and they didn't find what they needed, so they went somewhere else, and they're still searching. Or they're trying to create resources for themselves because they can't find anything. But my feeling is that NAMI is well placed to start Daughters and Sons groups. And we're calling them Daughters and Sons instead of adult children, because we feel like it's an affectionate term, it embraces our love for our parents, and it just gets away from the 12 step program kind of baggage. [laughter] I don't personally have that baggage...

What is really great, is due to Susan Smiley's film, and I want to credit that, the film that's going to be shown later this evening at 7:30, there's been a greater awareness of the need for support for people in our part of the family system. And NAMI Metro New York called me and Stasia

after a couple of years of us banging at the door and said, we'd like to start a group. So we've started one, it meets every month, and we've had 20 people participate since February, and it's once a month. And what we've found is that we get about 7 to 10 calls a month from new people who are interested in the group. So I want to encourage you that—kind of like a “Field of Dreams”, if you build it they will come. And we're really talking about a core membership of NAMI—potential future donors. [laughter] OK? Thanks. That's it. Now I'm done.

[Applause]

**JOE DONOVAN:** OK, now it's your turn. I guess this is the only mike we have so I'll have to repeat...

[Inaudible audience]

**CHRISTINE KOTULSKI:** I will try in my own words. OK, I'll try to repeat your question in my own words. I think what you're asking me is, as a parent now, that we're a child of someone with a mental illness, the “stigma” that we face within our society, and the fear our children have of developing an illness, when an illness is stigmatized. Is that kind of what you're asking?

[Inaudible audience]

**JOE DONOVAN:** I can do that one. My mother's first hospital admission occurred when I was about two years old. And this was early 70s, my father had no clue what this schizophrenia thing is. He denied it, he decided he was going to work late, he's going to stop at the bars on the way home, he found other women who were interesting. So divorce occurred when I was six. And it really was an issue, because my mother had also remarried a couple of different times and then divorced a couple of times. There's a large overlap. There are a large number of us daughters and sons who are children of divorce. And that's a reality. Because the tension of these illnesses does—spouses aren't prepared to deal with them. And a lot of times its safer for that spouse to say, I'm leaving and its up to someone else to take care of that. So a lot of us are children of divorce, so we all have some challenges with that.

**MAGGIE JARRY:** I want to make a comment about the question parts, I just want to note, someone just asked me. If you've written down a question, I think you should try to ask it also. Because we just knew there would be so many questions, we wanted to collect them so that we could respond to them in writing. You're free to ask it and to write it down.

**CHAI YING WEI:** Can I just make a note on that question? I think I can assure you that even if your parents are not divorced, and only with mental illness, things, difficulties in your relationship will still happen. Because my parents are still married now, so, you know from my story you can still know that I felt that way.

**MAGGIE JARRY:** I just want to respond to that too [Inaudible] Joe and I talked about this very early on, we started talking about this a year ago, and our personal thought was that we got a large number of our community that come from divorced homes but I don't think there's been

enough research and this is exactly one of the things we need is, is we need to understand our community, [inaudible] and we need to know, what's the percentage.

**JOE DONOVAN:** First of all, this gentleman here.

**AUDIENCE MEMBER:** I've heard everyone speak and I'm not sure that any of you are, it's a trite expression, but, are you claiming ownership of mental illness yourselves? Or are you simply saying, I was impacted by a mentally ill parent? With that rhetorical question, I like Daughters and Sons, rather than adult. Because I'm an adult, and I never married and I don't have children. When I become, when I'm an adult of a non-diagnosed, and particularly one parent was mentally ill, but never diagnosed. And that had a very severe impact on me. I'm not ashamed of being mentally ill, I'm not proud of being mentally ill, but I do take great pride in the long hard struggle to lead a more meaningful life, from the nadir I experienced 22 years ago. And again, I just want to get a sense, do you acknowledge symptoms of mental illness in your own lives that you've overcome? I'm not suggesting—you all worked hard, you struggled and you arrived at this point in life, but surely you must have come from a much darker time that you had to struggle to get through because mother or father or both were mentally ill. And the last point is this, NAMI has a predisposition, indeed a bias, towards parents who have mentally ill children, and therefore their inclination is to say, don't blame the parent, because my child is mentally ill. Well hopefully each one of us arrives at the stage where we no longer blame our parents, and we understand it indeed as a blessing—

**JOE DONOVAN:** Can we get to a specific question?

**AUDIENCE MEMBER:** The point is, there are dysfunctional parents that cause dysfunctional children. To suggest that parents—its' not a question of blaming them—but of understanding parents and mental illness, and the destructive things that parents do to children that they bring into their adult lives.

**MAGGIE JARRY:** One of the things I want to say that I've said before is there's a diversity to the population that are children of people with mental illness as much as there's a diversity to people with mental illness. My mother has schizoaffective illness but I have another friend whose mother's diagnosis is schizoaffective and you know, sometimes we say, this doesn't seem like the same diagnosis. You know what I mean?

I suffered from depression, severe depression, when I was twelve, I've suffered from post traumatic stress disorder, and I have a great therapist. And, I'm not on medication, but I don't think that I necessarily think of myself as ill or not ill. I've lived with it fearfully. I've thought—I've hyper analyzed every move, every thought, every time I get nervous, every time I have anxiety, every time I put this much effort into trying to do a project, I think oh my god, I'm ill. [laughter] And I really think that we have to get beyond the fear. It's ok to be ill. We have to get to the point where we embrace recovery. I think that's where we're at.

My mother is an excellent parent and I love her dearly, and I'll talk about her in the next panel when we talk about children growing up. But I have been thinking about this a lot. And I also really have felt like I'm walking around and going up against these invisible brick walls. And



I'm trying to understand, I know I'm not alone, I know there are hundreds and hundreds of people I've been in touch with who feel like me and are in my group. But yet we're not being acknowledged, and I think it's the fear that if we talk about this it will stigmatize the people who are our parents, if we talk about this it will somehow bring us back to the 1950s when parents were blamed for their kids. And that is not the case. I think that we have to just all embrace who we are and the way in which it affects us and the children of parents with mental illness are floating out there and they need to connect with NAMI. The other thing is that they have to go through a process in order to become at peace with their own life experience and understand it in their own way. So, there's just so many labels and it's just so painful. I just can't, we could talk about it for hours and each one of us are different. Joe, you want to say something?

**JOE DONOVAN:** I do acknowledge my own mental illness. I do have manic depression, and I take meds all the time. And I went through a long time of not being diagnosed, of self medicating with all sorts of illicit substances, it took me a long time before I was able to do my own work. And that didn't happen until I found NAMI. When I first found NAMI ten years ago I learned more. And it was finding NAMI that allowed me to go deeper into what I am and to learn about my mental illness, my mental wellness, my self, that's allowed me to do this. So it is a broad group that we're talking about. Back there? You.

**AUDIENCE MEMBER:** I have two children, I've been ill since my children have been very young. My older boy, when he was fourteen, suffered from a severe case of adolescent depression. I got very ill and tried to kill myself, and he looked at it as the ultimate abandonment, and twenty four years later, he still is very very distrustful of me, he won't talk to me, he won't let me into any aspect of his life, and he's moved half way across the country so that he doesn't have to be with his family. My other child is a NAMI advocate. I told my older boy about NAMI many years ago, I found the affiliate in his community, I asked him to go to support groups for children whose parents who are mentally ill, because I feel he has a burden, and I wrote him a letter explaining my illness, and how I know it affected him and how sorry I was about it, and he ignored it. What do I do to get through to him, to let him know that he is loved, and that we can't change the past but we can build on it?

**CHRISTINE KOTULSKI:** For me it was simple. I had to love myself first, before I could love my mother. That in itself for me was a journey. And maybe your son is simply wandering because he confused about his own life and questioning it. Maybe he's not questioning you at all. Maybe he loves you very much. And maybe he just doesn't know how to express that.

[Inaudible audience]

I think you've already done that. But...never forget his birthday. [laughter] And never forget Valentine's Day, because a son to his mother, there's a bond and there will be a bond long after you are gone, and he is 90 years old, there will always be a bond between a mother and a son.

[Applause]

**JOE DONOVAN:** I also want to address that too, because...I'm the son. And it is my mother. And Tina really said it better than I could, because it is—you know, I needed, when I was

younger, I was in a place where I needed to run away from my childhood. Because, I was a teen, I didn't know what was going on. I attended 14 different public schools as a kid. A lot of moving around, a lot of that. So the first thing I did when I was 18, I joined the Marine Corps, found my own life, I basically turned my childhood away, I needed to take ten, fifteen years away from my childhood family to find myself. It wasn't until later that I had to reexamine myself, had to find out, had to rebuild some bonds with my mother because of some challenges, had to rebuild some bonds with my sister—my bonds with my sister and I are still kind of shaky, because for so long as children we were together and we experienced this together, but once we became adults, we grew apart because of that. So some of this stuff, you're just going to need to take some time. And you're just going to need to love him

**MAGGIE JARRY:** There are a couple of people that have had their hands up in the back and I want to get to them, you can write them down and we will collaboratively write the answers, because we did know there would be a lot questions. [Inaudible] One, two three.

**AUDIENCE MEMBER:** I'm Debra, I'm a mentally ill parent and a single parent for many years. And I always had emergency plans for my child because I knew these complications can happen, and they did. Unfortunately, during those times of trauma, my child was often given misinformation by the well-meaning people that I had entrusted to take care of him when I was not able. I would always try after the fact to give him correct information, but it has never had the impact on him that the information he received at the time had. Do you have any ways that a parent can address that?

**MAGGIE JARRY:** The next panel is actually going to talk about that in depth, so you should stay for that. And that's the Invisible Children's Project, We're going to talk about that.

[Inaudible audience]

**AUDIENCE MEMBER:** Hi, as an adult child myself from two mentally ill parents and a niece, I was in a household of my mom's brother he was also ill. Do you ever get over the grief? I feel like I've done the Family to Family and I thought that was very healing, but when it comes to periods of getting married or buying a house, how to get your parents to be there—I'm finding it hard not to be resentful of my friends who have that help of the "normal healthy" parent, if that's possible. Do I ever get over that loss? And I guess Mary Ann would be the best person to...I hate to discriminate age wise. [laughter] Does it ever get easier because it seems like I just keep grieving, like the never ending funeral sort of, that's still alive, its very...

**MAGGIE JARRY:** Susan, do you want to answer that? I said people could call on you in the audience. [Inaudible]

**SUSAN SMILEY:** Well, I think no. [inaudible] I don't think you ever get over it, what I think is you learn how to manage it. I think you learn how to sort of compartmentalize it, and recognize it when you're feeling depressed or at a loss or angry or whatever. Recognize it for what it is and not let it rule your life for you. That's my personal opinion. But I think for me, what freed me up most was knowing [inaudible] that feeling of sadness and loss of not having the mother that I always wanted, and that's ok, because just being aware of it kind of frees you up.

**MARY ANN WIDENHOUSE:** One of the things in teaching the WRAP, we talk about grief, and the trauma of losing a parent or whatever the grief happens to be around. And it's come several times, people have said, when she starts to feel that sadness for the loss of her child or whoever it is that they've lost, she allows herself so much time to grieve. She allows herself. And this summer—I'm probably going to cry—I lost a grandbaby. And I've allowed myself to do that. It's been helpful and very healing for me to allow myself for a period of time, she said set the timer for twenty minutes or an hour, and at the end of the time, you know, start going about your business, but allow yourself that time to feel that sadness and acknowledge that sadness. Because it's tough. It's very hard to acknowledge and feel that and allow yourself to do that. Sometimes it can be healing. But I've not had the grief that a lot of people have, my parents were in my life, my mother is still in my life, and she's very much a part of my family right now.

**JOE DONOVAN:** And we have one more.

**AUDIENCE MEMBER:** To start off, I just wanted to thank you. It's so wonderful to see fresh new faces, young faces, at NAMI. [laughter] and I wanted you to know that ten years ago my sister and [inaudible] and it taught me a lot about how to care for people, and my dad taught me a lot because he stayed with her [inaudible] and ten years ago when we came to NAMI we said, do you have a group for adult children? And they said no, but we do have a sibling group and you can go meet with them. So I just want to thank you.

**MAGGIE JARRY:** Thank you. Thank you very much. Because there have been a lot of times when Joe and I think, are we doing this for the right reasons? And then so many people come out and say, this is so important and we're so happy that you're really active on this. I want to also recognize that developmental grieving is part of life and a part of loss and I think that children of parents with mental illness need to be recognized as grieving and need to be able to grieve because it's part of the healing process. And parents also grieve and they grieve for their children. I think parents with mental illness are some of the best parents. They just care so much. Now, not everyone is the same. There are parents who may not be as functional and able as others, but there are a lot of parents in this audience, and I just want to say that your parents may be feeling grief but they love you a lot and we all love our parents a lot and together we heal, and we recover. So god bless you.

[Applause]

**JOE DONOVAN:** Alright. Thank you again.

**PANEL TWO:  
SEPARATING FACT FROM MYTH:  
CHILD WELFARE AND PARENTAL MENTAL ILLNESS**

**MAGGIE JARRY:** OK. Hi everybody. I think I see some familiar faces in the audience. I see people who were here for the last panel, and I am so appreciative because I know when you sit for a long time, it can be tiring. I think that's a sign that a lot of you care really deeply about the topics we're talking about. This panel is the second panel of the two panels under the umbrella of Daughters and Sons. This is "Separating Fact from Myth: Child Welfare and Parental Mental Illness."

We're extremely fortunate today, because we have some of the best people I think we could possibly have in the country on this panel to talk about this. I'm going to introduce them all as they speak. But I'm just going to go over it briefly: Kate Biebel from the University of Massachusetts, Lucinda Sloan-Mallen, the founder of the Invisible Children's Project, Jim McNulty of NAMI, and Anand Pandya—Jim and Anand both having various roles past and present on the national board of directors.

I want to also note that like the last panel we have this packet out there with handouts. One side of that packet had information for the first panel. The second side has some sheets you can find on the National Mental Health Association's Web site related to the Invisible Children's Project. This is just one example of a program that is happening, and the intention is for NAMI to think about what are some of the unique ways NAMI could be helping on some of these issues. And I think on the last part of that there is some discussion about grief and loss and children, which had come up in the last panel.

Again, we have the question cards which Joe will be collecting, and we will respond in written form to any written questions, and you can also ask any questions that you write down, you can also just hand in a card to give us your information if you're interested in what happens next. I also want to note that I think it's at 7:30 that Susan Smiley's film "Out of the Shadow" is going to be screened. [Inaudible audience] 7:15. Location? International Ballroom. So we really just wanted to mention that again.

OK. The first person who will be speaking today—and I'm a little discombobulated because we were so involved in the last panel discussion, everybody's running around—is Kate Biebel. Kate is—I'm just going to read this bio—is a researcher at the Center for Mental Health Services Research of the Department of Psychiatry at the University of Massachusetts Medical School. Kate has done extensive research on the topic of parents with mental illness. Kate works tirelessly as an advocate and educator to increase support for parents with mental illness and their families. Among Kate's list of recent publications and research are, "The Invisible Children's Project: A Family Centered Intervention for Parents With Mental Illness," "Interventions for Families Living with Parental Mental Illness," and "Building the Bridge from Service to Science: A Commentary on Community Mental Health Care for Women with Severe Mental Illness Who are Parents." Kate's list of recent articles and research on the topic of families, especially young families living with parental mental illness, is extensive. And I welcome her to come up here and give you a presentation. Thank you.

[Applause]

**KATE BIEBEL:** I think you must have doctored my bio or something, I don't remember writing that. But I appreciate you writing that.

I'm really happy to be here, this is actually my first time at the NAMI conference. I've been doing this work for about six years and the group of people I'm representing from the UMass medical school have actually been doing this work for about 15 years. And NAMI, we have not always had the best time connecting with NAMI, so this is a great opportunity for us to share some of the work we've been doing. Jim sort of gave me the kiss of death before we started, when he said, "Oh you're an academic, you're doing that PowerPoint thing." And he's right! [Laughter] That's OK. Well, he's partially right, that is true. And I was trying to think—especially after the first session, if folks saw that, which were these very wonderful heartfelt stories of peoples' experiences about being in families where a parent has a mental illness—and I thought, "Oh, I have to go up and present data, wow, that's not always as exciting."

However, I think the selling point should be is that—and I think Lucinda will corroborate this—is that data sells. If you want to get somebody interested in thinking about the issue of parents with mental illness, the first question they're going to ask you is, well, who are you talking about? And they are going to probably say to you, "Oh, well the folks we work with aren't parents." And I know Lucinda, who I've known with for a long time, has had both those experiences. So think about that when I'm presenting the data.

This area of research is pretty tiny. There aren't very many folks around the country or even around the world that are really thinking specifically about families where a parent has a mental illness. And I just wanted to list for you some of the reasons how we come to thinking about this issue. One is because we know that for adults with mental illness that being a parent is very common. And I'm sure for many of you in this room that is no surprise. But I can tell you for many of the places where we go and talk, it is very surprising, and unfortunately, it is the places where you really want people to hear it, such as your state mental health commissioner, executive directors of large advocacy agencies, etc. So, that's one of the main reasons.

A second is that parenting is a really meaningful life role. And I'm sure anybody who's here in this room will say that if they are a parent, that is probably the primary way they identify themselves, and that is the same for a person if you happen to have a mental illness. And that we know that when, if parents do better, that children do better. And that now more than ever before that there are really effective treatment and rehabilitation strategies, so we should really be thinking about how to support families where a parent have a mental illness.

And finally, that there are times when unfortunately there can be very tragic consequences when supports aren't available.

So this is that first question: how many parents with mental illness are there? This is a question we have been asked for a really long time and until recently we really had no way to answer this. There were no national data that were asking folks about their parenting status as well as asking

folks about their mental health status. This is not a handout, but let me put in a shameless plug. [laughter] We have a Web site, it's [www.parentingwell.org](http://www.parentingwell.org), parenting well is all one word, and I have cards afterwards that I can hand out. On that Web site are a series of papers that we've done that Maggie mentioned. Also, this presentation I'll put on that Web site, as well as other fact sheets etc. So everything we're doing and thinking about you can see on that Web site.

[Inaudible audience]

It's [www.parentingwell.org](http://www.parentingwell.org). Also, you can Google me, and it's the only that will come up about 12 times, which I was professionally very excited about but personally a little deflated. [laughter] Doesn't everybody Google themselves? [laughter] Thank you Maggie, thank god you're here.

So here's the first question you need to answer as a provider, as an advocate, even as a researcher: how many parents are there with mental illness? And for a long time, as I said, we didn't know, so we just said: millions. We just assumed it had to be a lot.

Recently, however—well, a few years recently—we actually did some analysis of the National Co-Morbidity Survey, which is a nationally representative sample of the U.S. What this means is that it is normed to look like the U.S. So that when we look at results around parenting and mental illness and this, we can say that these are generalizable to the United States. What we found in these data were that 45 percent of American women and 30 percent of American men, have a lifetime prevalence of some sort of psychiatric disorder. Of those 45 percent of American women, 68 percent of them are mothers. Of those 30 percent of American men, 57 percent of them are fathers. We also have data that aren't on here, which discuss the 12-month prevalence, you know, asking, within this 12 month period of time—and the numbers are similar. They're high.

If you look at this chart, what this shows you is the prevalence of parenthood between three categories. The one on the left, the blue one, that 62 percent, that's for how many individuals with no diagnosis are parents: 62 percent. You see that having any diagnosis—I'm looking at the women right now—bumps you up to 68 percent, and that having serious and persistent mental illness, which is identified by diagnosis and functioning, I believe, is also at 67 percent.

With the men, I think those data are particularly interesting, because I think there is a myth, to think about the myths, which is the title of the workshop, that men with serious mental illness aren't fathers. And according to these data, that is not the case. And that's actually a significant difference between men with any diagnosis and men with serious and persistent mental illness.

The purpose of this slide is to shock you, I suppose, to really let you see that parenting and having a mental illness really are prevalent and go together. So, the take home message there is that women and men with a lifetime prevalence of a psychiatric disorder are at least as likely to be parents as adults without psychiatric disorder. Yes?

[Inaudible audience]

You're talking about the sample size?

[Inaudible audience]

I don't know off the top of my head. I know for the men that it is a small sample. The sample that this is working from is about 3100, because there wasn't a direct—too direct questions, they were subset questions, the data came from sub samples. I can get you that information, though.

[Inaudible audience]

But your point is well spoken about the sample size. And I know for men particularly that it is much smaller than for the women. The other thing that we see in the data is that the prevalence is high across diagnostic categories. I think this is also a misconception that we think that folks with psychosis, for example, are going to be less likely to be parenting. But, as we see across the board, we still have pretty high prevalence rates regardless of diagnosis.

Maggie also wanted me to talk a bit about children and what we know there. So when we think about how many adults with mental illness are parenting, the next obvious question is, well how many children are living in those families? And again, there are no national data looking at this particular issue. So we figured that if parents had 2.5 children, if there were many millions of parents, there has to be many more millions of children, either living in these families or having parents who have a psychiatric disability.

We do have some data, however. These data, and I don't know how well you can see the numbers there, but these are from the SAMHSA, Center for Mental Health Services. They have currently 92 systems of care sites around the country that serve children with serious emotional disturbance and their family. So they have a big pool of data where they are actually evaluating those programs and there are some family history questions in there. So these data are for children who have a serious emotional disturbance, and we see that 45.5 percent of those children have a biological family member with a history of mental illness. 62 percent of those children have a biological family member with a substance abuse problem. And 18.8 percent of those children have a parent who has had a psychiatric hospitalization. These data are actually a little old, we have more updated data which I didn't bring with me, but I do know that the numbers are higher in all three of those categories. But they are pretty high anyway.

[Inaudible]

These are children from the SAMHSA Center for Mental Health Services national evaluation, these are children who have serious emotional disturbance who are being served in these 92 centers around the country. It's the closest thing we have to any sort of large dataset where we can look at kids and their parent and family history.

And actually, most of what we know about parents and mental illness comes from the children's literature. Parental mental illness has been waved around as a risk factor for children with poor outcomes. And I'm going to talk about that in a second, too. We do know that children who have a parent with a mental illness are at greater risk for developing their own problems. That is true. The data seem to indicate that, in the general population, and in this sense that means the

population where there hasn't been a parent identified with a mental illness, that about 20 percent of those children will have some of their own problems. And that if you add in having a parent with a mental illness, that that percentage goes up to anywhere between 30 to 50 percent. So your risk does increase as a child.

However, I think the story that doesn't get told very often, but that should, is that 50 to 70 percent of those children are resilient and are actually doing well. And so I think what's important to remember, and what we try to do in our research, is try to recognize that child outcomes are due to a variety of factors and not simply: having a parent with mental illness, direct arrow, causal relationship, having a kid with poor outcomes. There are actually multiple factors involved. And that many of these families are living together. I think it used to be thought that there are parents with mental illness here, there are kids over here. And that is true for some families, but there are also families where these folks are living together. And I think that's what Lucinda's going to talk about, that there are actually programs that work with all those kinds of families.

So here's the old thinking. The old thinking was that a parent's mental illness was that direct line to poor child outcomes. The newer thinking is that there are actually many things that are influencing a child outcome, a parent's mental health being one of them, but also family situation, parenting style, the stress and support that family is receiving, the characteristics of the child. And so it is important to think about all those things when we are trying to figure out how to support families.

The last lesson being that what this actually provides us with is many opportunities to provide support and resources to parents, but to families as well. And I think actually, it says child outcomes on there, but I know in the work that we're doing, we've really moved away from thinking about parent and child, and we're really much more interested in thinking about families, and how parent and child live in those together.

That's it.

[Applause]

**MAGGIE JARRY:** Kate has been very sensitive to the fact that statistics are, you know, tiring, so she wanted to focus just on helping with the prevalence issue—I think she could speak to us for quite a long time about these issues. So again, please talk to her after, and we'll get some questions after, please write them down. I'm going to invite Jim to come up here, and I have a little thing I'm going to read about Jim. Jim McNulty is immediate past president of the NAMI national board of directors, having stepped down on July 1, 2003. He is a longtime NAMI member and activist, which is a nice word for a troublemaker. [Laughter] And is currently serving as Director of Consumer and Family Affairs for the Division of Behavioral Health for the state of Rhode Island. Jim McNulty has been living with bipolar disorder for his entire adult life. Not diagnosed until his mid-30s, when the illness began to manifest itself in a particularly devastating way. He has two sons, Patrick and James, who went through this part of his illness with him. Most parents worry about whether they have done right by their children, and those



who live with mental illness often wonder what the impact has been. This is what Jim will discuss today. And here he is, Jim McNulty.

**JIM MCNULTY:** Thank you, and I'm going to ask your indulgence. This is emotional for me.

Being a father is a very important thing. My sons were both a support to me and they were taken away from me when I was hospitalized. And I don't believe I ever recognized the pain that that caused me until I talked to Maggie Jarry, and she explained what she was doing, and what Joe was doing with his project, and I thought it was an extraordinarily good idea. I loved the title of "invisible children," but families are invisible too.

My boys are fine. That's the good news. And there are some funny things that happened along the way. They did finally get to come and visit me in the hospital. My ex-wife fought that bitterly, because she said, "Oh my god, can you imagine, they'll catch what you have." The doctor said, "Look it's not infectious." She said, "Well it's dangerous." The doctor said, "Look, if I thought it was dangerous, I wouldn't let them come in and visit—you know, kids come in all the time."

She fought, but they came in and visited me, and I still remember the look on their faces. I think it was very reassuring for them to see me, that I was not in some surreal environment. It was pretty normal, it looked like a living room. It was a pretty nice hospital—I mean, it was a hospital, and they locked the door and they didn't let me go out when I wanted to leave—the usual amenities of a psychiatric facility. They were little, nine and four. And I wondered what was going through their minds. So I asked them after you talked to me, "What the hell was going through your minds?" My younger son said, "Well, I really don't remember that that well."

He's a sophomore at Northeastern University in Boston, he's doing quite well. I do worry about him, I think there may be some of that genetic prevalence, because he's a lot like me, he has the same problems with sleep that I did, that were a symptom of my disorder. My older son seems to be remarkably normal, because he bore the brunt of my illness. The younger boy really didn't experience it to the same degree that he did. Although they both bitch about the time—I was living on my own after I got out of the hospital, and you know, bachelors are not very good about things like keeping milk around because it tends to go bad. And you know, you pour out spoiled milk in your morning coffee and it's a really rude experience. You just don't want to do that. But it was Christmastime, and I had eggnog in the house, and I had some corn flakes, so I said, hey, eggnog, cornflakes, you know, it works. They have never forgiven me for that. [laughter] They are still very suspicious about any meal that I serve them that has been prepared by me.

I talked to my older son because he, as a ten year old/nine year old, went into caretaking mode, care-giving mode. My wife basically threw me out, and said, "I can't deal with you any more." And that was hard, but I got through that. But my son, when he would come and stay with me, after we finally got through the legal nightmare of my being able to visit my sons—which took an enormous amount of time and energy and I was actually surprised that I prevailed and got visitation rights, so was my lawyer—but he would worry about me and he would take care of me. He would calm me. He was the parent. It was wild.

The good news was, that as I got better and better—my illness was at its worst for probably about four years, so he was probably about fourteen when he started to really come back. And he became a regular teenager, which meant that he was extremely difficult to live with. And he went on, and it was remarkable because I actually had to go see a social worker to figure out what was going on because I had no idea what he was going through. Remember, I was not a custodial parent. I was separated from that part of my children. And that—that’s a big loss, because you don’t get to see your kids grow up.

[Pause]

I didn’t think this was going to be this hard. Maggie asked me if parenting was important to me. And it is. It’s the most important thing I’ve ever done in my life. And people with mental illness feel just the way every parent feels. You love your children. You hurt for you children. You’d die for your children. And the system doesn’t really encourage any kind of familiarity. They don’t encourage togetherness. I never had a doctor ask me, “How are your kids?” I never had a therapist ask me, “How are your kids? How are you getting along with your kids?” The only time one did was when I paid a therapist to tell me why my son was being so difficult. And he said, “Well, how old is he?” And I told him. And he said “He’s separating.” And I said, “What do you mean separating?” He says, “It’s time for him to grow up. He’s declaring independence.” I had no idea. Probably most parents don’t know that. I only know what my experience was, and I had to pay somebody to tell me what it was. Probably a pretty good decision, well spent money anyway.

But at no point did anyone talk to my children about my illness. No one sat down with them and said “He’s going to be OK.” No one said, “You know, mental illness is not necessarily the end of life.” And that’s what they both said: that they never really knew, until they saw it. They had to go through four years of hell. Because they didn’t know that I was getting better, really. I knew I was getting better. I could feel it. Because when you’re the person living with the illness, you kind of know what’s going on inside. It’s hard, you don’t get better—it’s not “I’m sick, I’m better.” It’s “I’m sick, I’m sick, I’m sick, I’m sick, I’m better.” And it took this immense period of time—it seemed like it was immense—if I had known how hard it was going to be to get better, I probably would have just laid down and died. But I’m glad I didn’t, because of my sons.

And by the way, the other thing I have to tell you is that they kept me going when nothing else did. That’s what they meant to me. Because I saw those little faces, and I just said, “I cannot, cannot, leave them.” So, my relationship with my children today is pretty good. It’s a little distant with my older son because he—I think my ex-wife had a little bit more impact with him, and she’s still pretty down on me. When she found out I was the elected president of NAMI, she said, “You’re essentially turning out to be a professional mental patient.” And I said “Thank you dear, that’s a real vote of confidence.” She’s real recovery-minded. [laughter] I speak highly of her, too.

But she—she did not help the relationship my older son and myself. But this was very wonderful, because it made me sit and talk to him and find out what was going on, and that, I

think, is going to help me proceed to heal. Because I still have a big scar inside of me that you can't see, but I can feel. And I just showed you what that is.

For those of you who are children, the only thing I can tell you—showing love by a parent is hard. But we really do love you, we really do. But when your mind is spinning out of control, it's real hard to express that. [Pause] And I will worry everyday for the rest of my life whether my kids are going to come down with what I have, or whether my grandchildren will, assuming I have any, and I think I will, the older boy's getting married. By the way, your data was very well presented. It was one of the best PowerPoint presentations I've ever seen. I have to tell you that—I apologize, I never realized how much this was going to affect me. But it really does. And I think that this is a very important issue. And I would encourage you, I would implore you, to keep on going with this project. Thank you.

[Applause]

**MAGGIE JARRY:** It seems very unfair to have time frames to be able to have to present information in, especially something this important. And, while Jim was speaking—and I'm so grateful to you for being so willing to be here and to share so openly. When I was thinking about this, and I haven't scripted very much because I've been so busy trying to create everything support wise and organizing, I was in the shower, you know, in the shower, and you start thinking about what you're going to say on some sort of occasion, and I started thinking about my three parents, whose names are Elizabeth, Raymond, and Mike. My mother Elizabeth has schizoaffective illness since I was 2 and my father suffered from chronic depression and he's now deceased and my stepfather Mike suffered from schizophrenia. And there are people who I love very very much, and I am who I am because of them. I am not always an easy person—I'm so passionate about life. But what I learned from them was that passion, and there's a lot of pain and a lot of confusion sometimes, but I know there's this beautiful thing called living and I learned it from them. And I just wanted to share that.

And I also wanted to share that I was working in a foster care agency one day, and I heard a story about a woman who was taken away by the police in our foster care agency because she wasn't compliant. And the foster care agency workers, who I think are wonderful people, thought this mother didn't love her child enough to become compliant to medication. I asked, "Did they have a good bond?" And she said "Yes, a very good bond." The daughter was a twelve year old girl, and they had to place her apart from her mother and the foster care worker didn't know anything about what therapy the mother was getting, and everybody was talking about having the daughter given away permanently from the mother. And I knew that I had been in foster care twice as a child and I thought "Well, I think things must be better than they were in the 1970s." Actually in the case of this girl, her mother had been taken to a hospital by her neighbors, at the hospital they admitted the mother, never asking whether she had a child and the child was left alone in their apartment, with the neighbors looking in on her to care for her.

I think there needs to be a lot more attention to these systemic issues and NAMI has a lot to do related to it. So I'm going to go on now and introduce Lucinda Sloan-Mallen. Lucinda Alden Sloan is a dynamic, dedicated, and passionate advocate. In 1991 she embarked on a strategic effort to mobilize a public response to the unrecognized issue of serving families where one or

both parents have a mental illness. Lucinda's passionate and intelligent activism, together with research spearheaded by the Mental Health Association of Orange County, New York, influenced policymakers at local, state, and national levels. She developed the Invisible Children's Project, currently replicated throughout the country and hailed as the model of professional, effective response to families coping with mental illness. I think it's being piloted in nine cities right now. A noted national public speaker, Lucinda has received numerous national, state, and local awards for her distinguished and extraordinary efforts in mental health. As the chairperson for national committees addressing mental health issues and the executive director of the MHA of Orange County, New York, for twenty years, she had devoted her professional career to ensuring the needs of children and families affected by mental illness were addressed. Her work was inspired by her mother, a single parent who suffered from bipolar depression. I welcome Lucinda to the podium.

[Applause]

**LUCINDA SLOAN-MALLEN:** Jim, you said earlier in your remarks that you liked the name “invisible” and I guess I want to point out that I am invisible no more. [Laughter] Isn't this a wild outfit folks? I decided you know that—for my whole career I had to wear blue business suits and my hair was in a bun and I did not dare look anything but professional. And today I am here to model Art Threads, which is for sale out in your...what do you call that room, that huge room? NAMI land. And because I am modeling this today, I have been told that fifteen percent of all the proceeds that anyone here in this room decides to give the woman who makes these lovely things will go to NAMI. So I encourage you to get out your holiday shopping list, they have gloves, they have scarves and you know—live a little. Which I am now doing, but it was a long road, I have to say, from numbness to living, and along the way I learned a tremendous amount. And I have met the most incredible people, and I am so thrilled, I truly am, to be with you today.

I have worked with some members of NAMI before—many years ago, and I have spent most of my time working with the National Mental Health Association, as Maggie mentioned. But I will share with you, not for sympathy, but for reasons of joy, that I wasn't sure I would ever be able to stand before an audience again and speak, as I do have mental—I probably mental illness too, I don't have a diagnosis yet, that's a Freudian slip—I have multiple sclerosis. And three years ago I was unable to continue my work as I was paralyzed for a while and in a wheelchair and really was highly dysfunctional in terms of my ability to communicate. So Maggie invited me, she tracked me down, apart from my professional career, and found me, and I celebrate some kind of rebirth with you and I thank you. And I will tell you that being away from it for three years has given me some new insights that I'm excited about sharing with some of the researchers later. So I applaud each of you for coming here today, and I particularly thank you Maggie and you Jim.

I will tell you that the “invisible children” name was born at the New York State NAMI annual meeting where I was the keynote speaker in 1991. And I was asked to speak about a variety of mental health issues because our mental health association was quite extensive and we did many many different kinds of things, including serving quite thoroughly and completely I think, the service needs of adults who had mental illness, apart and aside from their role as parents. And at

the end of my presentation, which was very well received, I dared to bring up the issue that you are talking about today. And I spoke about these parents, and I could feel the silence in the room. And it was if I had said something stigmatizing. I spoke about *parents* who had a mental illness.

It was at that moment that the name “invisible children,” for me, was coined. Because it became so clear to me, in a very crystallized way, that these children were completely invisible. Invisible not only to the people in that room, many of whom were grandparents, they were in fact the parents of an adult who had a mental illness, absolutely invisible to our policymakers at all levels, but they were invisible many times to themselves. That sense of shutting down. That sense of numbness. That sense, as Susan says, of coming out of the shadows. And I was approached after the speech by the then president of NAMI for New York State. And she was very agitated. And she said, “Well, you know I liked what you said, however, why did you have to bring that up at the end?” Because there is a very limited amount of money, and that’s true, and if you start lobbying for money to service whole families, its got to come from somewhere, and it’s going to come from this pot. That pot being money for persons who came in the category of serious and persistent mental illness.

It became very clear to me that I had some homework to do in order to persuade the powers that be. And I did go to the commissioner of mental health New York State who was very innovative, and his name was Commissioner Richard Searles. And this is back again in the early 90s and he said that it wasn’t an issue. It was an absolute non-issue that people with serious mental illness basically did not have children, it was a rarity. And I thought, oh wow, 60 miles from New York City, I’m up here in Orange County, we must have something in our water, because the folks that we serve here in our mental health association, by and large are parents.

And so together with the Middletown Psychiatric Center and our local department of mental health, our local mental health association did a survey of everyone for six months who was in that public mental health system. Now bear in mind that does not include people who were outside the public mental health system. And of course the numbers were similar to what you’re seeing on these slides and finally we have this national information. But it really served as a wonderful tool to garner support, because it’s evidence, it’s black and white evidence.

It wasn’t necessarily stories, like you’ve heard today, because people like myself at that time, we were not really hip on the internet, we weren’t reaching out to each other in that manner. And I certainly wasn’t going around telling anyone that my mother had a very very serious mental illness, as did too my father and stepfather. You know, we all have a lot of these parents in the picture, because I was very ashamed to say it, even in my position. So I applaud all of you now because time is shifting and people are being honest about it.

So armed with this ammunition we got approval to go ahead and try to do something. But the money did not come from the New York State Department of Mental Health, it came from the health department, because the health department recognized that children who are in families who have certain risk factors are more inclined to have a developmental disability. And it occurred to me that these risk factors mirrored the risk factors I was seeing in our own population, i.e., divorce, we talked about that already, poverty, certainly a big one, homelessness,

perhaps drug addiction, and guess what: for us, we had mental illness on top of it. So imagine the needs in these families, and again, not being addressed at all.

The Invisible Children's Project was born, it was a quilt, a patchwork quilt of sources of funding. I mentioned the department of health, we got \$250,000 from them to do an innovative research project for three years that was studied by the psych institute in New York. And we got money from United Way. Because you know, when you talk about it, this is not rocket science. Well guess what folks: people who have illnesses, including mental illnesses, make every effort they can to have quality of life. And that includes having children, so they are in our community, so United Way should fund this kind of initiative. It was not hard at all to get funding from them. And Jewish Federation for Families supported it. It was just a matter of talking to people.

Because as each person has said, parents want to be the best parent they can be, regardless of whether or not they have an illness at all. They want to be the best parent they can be. And it is that desire, that love that you have heard articulated from children, daughters and sons, from Jim, from Mary Ann, from others. It is that strength, I believe, that against so many amazing obstacles—that one would think would shut down somebody—that they manage to persist in what I consider to be a courageous and heroic manner.

That does not mean that there aren't sometimes very, very difficult and sometimes very, very damaging situations in families. And I have experienced them. And I too have my scars. But, what I like to think about is, what we're doing now. And when I have time I think about—I allow myself to think about—the difference that the kind of programs like Invisible Children and what you're trying to do through NAMI, what kind of difference would that have made for me. And what kind of difference would it have made for my own sister, who suffers from mental illness.

And I look forward to the day when my children are parents themselves, I have two sons, Kir is 21 and Anders is 18. And Anders was diagnosed when he was 5 with obsessive compulsive disorder. And in fact, I'm proud to say, he was one of two children that was invited to the White House for the White House mental health conference, and he and I sat in the front row next to the Cabinet, with Mike Wallace, with Tipper Gore, with the vice president, the president, with Hillary, you name it. There we were in the front row, my son, who never before that was willing to talk about OCD because he was so embarrassed, but writing a composition which I managed to share with the national office prompted that invitation. And who was in row 12? Jim Stone, the commissioner of mental health and Richard Searles, the man who said "I don't think it's really an issue." So I took great delight in the fact that we had some recognition there. [laughter]

But my son is an awesome, awesome young man. He's in college—he fits a profile of kids who are going to be resilient. He's smart, he's funny he's handsome he's intelligent and he's a fabulous athlete. But he really, really has an illness, I mean, a serious illness which affects him. I was going to say every day—it affects him all the time. He spoke at the National Press Conference here in Washington when he was 13, about what it was like to be in the classroom. What it was like to try to pay attention and wonder if the person in front of him had lice, and if the girl sitting next to him coughing was going to make him sick and then he would die. He's now at college, joking about "Oh my god mom, what am I going to do, because people are going

to want to sit on my bed.” He literally has a fit if you sit on his bed, he’s so afraid that the germs are going to do something to him. But we talk about it, and he and his girlfriend laugh about it. This will always be part of his life and he as a father will absolutely be able to talk to his children about it and he’ll be able, when he can, to joke about some of the strange little behaviors that he has. So I look at my mother, a woman who was runner up for Miss America as Miss Pennsylvania, who was a gifted artist and so amazingly kind and loving and wonderful. And I look at how her life was completely, I mean completely, destroyed by bipolar depression. Because there were no supports for her in the most important role of her life, which was being a mother, nor for her children, and then I look at my son, and the picture looks so much better.

The Invisible Children’s Project recognized that you have to have a very comprehensive array of services to serve families most in need. And what I did was interview the parents, most of whom were women, at our clubhouse in Orange County. Many of them had lost their children, because this was a number of year ago. And I asked them what they thought might have made a difference in their life. And they had the most obvious answers—again we don’t need huge research projects to figure out what people need. Well maybe if I had a place to live that was safe they wouldn’t have taken my children away. Well maybe if I had childcare when they said I had to go to these therapy appointments, I would have gone to these therapy appointments. And perhaps maybe if I wasn’t terrified that if my social worker found out I had a mental illness that my kids would be removed, I would have gotten help. And maybe, maybe, if the clinical social worker at the state psychiatric facility had ever asked me once, not how my children were doing Jim, but if I had any. They did not even ask that question.

And I will tell you, as someone hospitalized for multiple sclerosis for over a month at a time and routinely in the past three years every two months for a minimum of a week, my caregivers were very concerned about the effect on my children. They were keenly aware that the absence of me in their life was significant and moreover, they were certainly smart enough to know that my desire to be with them and be able to parent them and be able to walk again and be able to think right was much more beneficial to me in terms of recovery than abinex injections or chemotherapy or anything else that I went thorough, because I wanted to be with my kids. I wanted to mother my children. And discharge planning, they always included—how are your kids going to get to school if you can’t drive now and you need to rest in the afternoon? Who’s going to take care of them? These things should be automatic. They should be automatic in any family where someone has an illness. Discharge planning, as someone mentioned before, emergency planning, respite, child care, art therapy for children, speaking to kids about what the illness is, helping them—I’m getting the look from Maggie so I’m going to wrap it up.

You can read about the Invisible Children’s Project, it’s in your folder. I just want to say in conclusion that it is so wonderful to have NAMI eager to embrace this. And I certainly expect that you’ll all leave here and think about what you can do as a devoted member of NAMI to make something happen in your community. Especially as the former president is now putting it high on his agenda.

**MAGGIE JARRY:** I actually wasn’t really looking at you that way, because I was both distracted by the fact that I knew I had to be concerned about time and at the same time thinking about how incredibly well you’re able to articulate these issues.

I have a book here from Australia and there are resources you can get on the web from Australia that are related to parent planning and children having emergency plans. You know like, being more realistic, saying, you know, Mom's doing really well right now but if there's another emergency, let's work through what would be the emergency plan for the child. This is not something that we have to create in the United States, it's not something that we need to create in NAMI, it's just that we need to talk openly about it and know where the information is and how to access it and how to work collaboratively to support people. And in this book from Australia, *Children of Parents with Mental Illness* by Vicki Cowling, there's a quote of a mother who's being interviewed by a social worker and she says, "I joked nervously that, 'This is like a job interview for the most important job in my life. I told myself silently. A job I've already got.' And the social worker stared at me with somber eyes and said, 'Yes, it is.'"

I'm going to introduce now Anand very briefly. Anand Pandya is on the board of NAMI national now, and he is also the founder of Disaster Psychiatry Outreach and someone I came to know last year. We've had a couple of conversations, and he is a psychiatrist and I invite him to the podium to just speak a little about the psychiatric profession and where they are at with these ideas.

**DR. ANAND PANDYA:** Thank you. I'm sorry to have to follow the other speakers, not only because I think what I need to talk about is a lot drier and not nearly as personal, but also because I think it's unfortunate to end something that is as powerful, moving, and, I think, hopeful as this workshop, on a low note. Unfortunately, I think the state of the psychiatric profession in my own experience, and the state of most mental health professions in my own experience, is not one to give great hope and optimism that there is a lot of places to get help if you are an adult with mental illness who has a child, or a child with mental illness with a sick parent.

Just by way of background, I do not have parents with mental illness, nor do I have children. When I was in sixth grade, my uncle, who had been suffering from mental illness for many years, killed my aunt and then committed suicide. And his three children, my cousins, came and lived with us. And I guess that experience of dealing with my cousins, their reactions to what their father did, and their reactions to what the family did, and did not do, is part of the reason I'm part of the NAMI family.

Psychiatrists in my experience often take a point of view based on where they are within the system. And I encourage, when thinking about how much to talk about your role as a parent or as a child, to think carefully about what is the job of this specific psychiatrist you're seeing. Jim was just saying that the outpatient psychiatrists in his experience do not ask about this. I think that's quite common. In my own experience outpatient psychiatrists do not ask about this. I think this is probably true of all outpatient mental health professionals, but probably more so for psychiatrists than social workers or psychologists.

On the other hand, the model in outpatient psychiatry is one that is based on a certain degree of confidence that your patient, your client, has capacities, and that you're there to nurture those capacities. It's probably a safer place to discuss these things. Unfortunately the place where



altogether too often your issues of being a parent or the issues of being the child of a sick parent come to the light of the mental health system is in the ER.

Let me explain the job of a psychiatric ER. Their job is not to fix problems. Their job is to make one decision. That decision is, does the patient in front of them need to go into the hospital or out? Just one question: in or out. So whether there's a child there or not is a matter of a complication. A side question. They are not there to try to fix the whole system. They are just trying to figure out whether the problem is complex enough so that it needs to be fixed on an inpatient unit. Thus, the question of, can I help this parent be a better parent, does not come up for an ER psychiatrist. The question is simply, is this child safe or not. The interventions then, are either calling protective services, or not. If any of you have had encounters with the child protective services of your localities or states, you know that they are not usually the people who are best able to help. They are more often the problem.

So clearly, psychiatric ERs are places where—I hate, as the psychiatrist, to give advice about being circumspect or hiding information—but it is a place to be circumspect, it's not a place where your problems are going to be necessarily solved. Jim has had a better experience in inpatient settings than my own. My own experience in inpatient settings is that they are usually much like outpatient settings. They usually do not ask about children. I do believe that they can be safe places to discuss, to some degree, problems that you are having at home, both as a child or as a parent—that, you need to suss out on an individual basis. If I make generalizations about outpatient psychiatric, psychiatric ERs, or inpatient psychiatrists, you need to use your own judgment to a large degree to see whether your own psychiatrist is in any way like other psychiatrists.

Finally, to talk about the differences between professionals. Clearly social workers are far more trained to consider systems as a whole. Psychologists are trained to consider the range of behaviors of humanity, not just within disease models. I find that by and large, my colleagues within these other professions have been more open to discuss issues like this.

Those were the points that I wanted to make. And I think we're practically out of time. I know that people have been writing down questions, so I'll leave time for that.

**MAGGIE JARRY:** Anand, before we go to questions, and because we have actually run to the time of this end. But I want to say some things, and I want to make sure that I do have a chance to say them. I also want to say that I'm so happy that Anand came, I feel it's so important to hear what he just said. We do have to understand the system and the purpose of the people that we're working with. And we need to think about how can we help this system, and where can we lend support as NAMI?

So I would just like to say a few words. One thing I promised myself I would do, and I absolutely must do, is share with you a very short story. My mother, when I was sixteen—and I've shared this on a couple of occasions with people—I had this wonderful experience of breakthrough, and it was like an adolescent understanding that their mother is their mother but also a person, and a recognition of my mother on a very deep level. I was sitting around a table with my mom and a friend from our church, and I said something, joked about her illness. And I

want to preface this with the fact that I lived for many years with my mother hearing voices, I suffered from severe depression, I didn't bathe myself for weeks, I missed a good amount of sixth grade. I moved ten times between six states before I was twelve, and I had disassociation as a coping mechanism. And my mother understood this. And when I visited her in psychiatric hospitals, I couldn't grieve, because I had to be strong. And my mother knew this, but I didn't understand it. And I cared so deeply for my mother and I was so afraid for her and I saw the places where she was and she would get out and she would be better for a while and then she'd start hearing voices and nobody was around, and I would take care of the house until somebody came to help us. And that went on for a long time.

So when I was sixteen, and my mom was doing well, and she had been doing well for a couple of years—that's an important context—and we're sitting at the kitchen table with a friend from church, and I said something like, you know, "insanity runs in the family." You know, I used to say things like that—I would joke, they weren't severe jokes, they weren't biting. And I want to mention also that my mom, even when she was hearing voices, never ever criticized or hit me, it's amazing. She's just so loving. But this friend from the church said, "Oh, you shouldn't joke about your mother's illness, I never let my children joke about anything that happened me." And before I could say anything, my mother stepped into the conversation and she said, "No you have to understand, this happened to Margaret too, and she needs to laugh about it. And sometimes it hurts my feelings, but she needs to laugh about it."

I didn't understand that I was hurting my mother's feelings, because she had never told me that I was hurting her feelings. She stayed up with me for thirteen months when she was well—she counted the months—so she tells me that for thirteen months she stayed up with me every night until one or two in the morning and I cried every night. Because I had that period of time where I could actually grieve, because my mom was well enough to let me grieve.

Anyway, you know these are very complicated issues, and I think that story really articulates the fact that, on the one hand, I was always trying to be strong and I didn't understand what I was lacking. Other people around me could see that I was lacking things or that I wasn't having a childhood. But I didn't know, I didn't know that it was not right that I wasn't playing, that I wouldn't go outside and play with people, that I was afraid to have friends. I didn't know how to have friends.

So, I think, you know, it's just really important to see the children. Virginia Holman, last year, we had a conversation, and she said "I feel like families, sometimes, they get so focused on the ill relative that everyone is hyper focused on the ill relative and the children just don't get any attention." And we're talking now, we've talked a little bit about the system and I mentioned that I was in foster care twice. But I was also raised by my grandparents, and my grandparents were really worried about their daughter. And I think it's really hard and confusing for them to understand that their daughter was really ill and she was going to be ill for a while. So it just went on, but during that period I was little, you know I was growing up, those were developmental years.

So I guess my piece of this is that I think NAMI is well placed to help grandparents who are raising grandchildren understand what their grandchildren are experiencing. I believe that NAMI

is a place where families that don't end up in the system, maybe have financial resources—we didn't, I grew up on welfare—but families that aren't getting access to certain types of aid, grandparents who are able to take care of their grandchildren, that they could come to NAMI and find NAMI is a place that they feel at home with, that they find peers with. And this is a really good place to get literature to them about grandchildren, what they might be experiencing, and how to talk to children about their parents' mental illness.

So that's one of the things I believe that NAMI can do. And I also believe that NAMI is an important place for those satellite children, that, like myself, had been trying to learn how to take care of myself after I couldn't live at home anymore and found NAMI, like we talked about in the last panel. So I really feel like there are some special things that NAMI can do, and I hope you can all be a participant in this as we go forward. So that's it from me. And Joe wants to collect questions, and I think it's only fair if we go over a few minutes for a few questions. This gentleman's been raising his hand.

[Inaudible audience]

Where do you live?

[Inaudible audience]

I just want to mention that Anand has told me that he has to go, so I apologize. That's all right, go ahead.

[Inaudible audience]

That's a very good point.

[Inaudible audience]

And Kent, I want to also comment, as you were commenting, among the many emails I've received in organizing this, I've received many emails from mothers and fathers who were losing custody of their children, and their mental illness was being used as a reason to take their children away. One of the people who couldn't be here but who planned to be here is man named Barry Ackerson at the University of Illinois. And Barry has been doing studies on the need for better assessment tools of parenting skills. This is very critical, I think, as a solution. So when we're talking about this, first of all, you're not invisible to me, and my mom, dad, stepfather, are not invisible to me, it's the system that finds us invisible. Which I think is kind of interesting. Because your kids always know that their dad is very important.

[Inaudible audience]

What I wanted to mention though is that in the packet you'll see a list of resources and you'll see some articles by Barry Ackerson and, just to piggyback on your comment, assessment tools for parenting. This is another really good key thing that we can as a group in NAMI talking about in terms of encouraging the creation of better assessment tools so that parents can have fairness and

justice. I'm going to take only one more question. I'm going to take it from the man in the back. Because I just want to do that. And I'm just going to choose that. So there you go. Yes...OK.

[Inaudible audience]

I want to answer that, and then I'm going to give this microphone to Kate, because she does this thing called the Parenting Well Center, and I think they have a book, right? *Parenting Well When You're Depressed*, and its very, very good. And there are also a number of things about preparation, you know. I think this is really about us all working together with the tools that we have, right? No matter what challenges we've been given in life. And there are tools that have been created in the last ten years to help parents so that you can be successful and we need to keep supporting those tools. And I want to mention that I credit my mother with my wellness, because she let me cry, and express myself. And because, of all the parents I had in my life, she didn't ever put me down. She gave me high self-esteem, and my father did—these are the resilience factors. And when you look at the packet you'll see that one of the pages I took off the internet from the National Mental Health Association are the risk factors for children, and its going to show some of the resiliency factors: high self-esteem, knowing that you're loved—these are some of the key things that children need, that all children need, and being a parent with mental illness I think you're well placed to give that.

**KATE BIEBEL:** I don't know if I'm the best person to respond to this, but I can give it a first shot anyways. Well I think first that you're incredibly lucky, if you have a partner, you know, where you can actually plan for this and you're being thoughtful about it at the get go. I think that's not a very common experience. Because I think people aren't talking about. So I think you're lucky, and you have a tremendous opportunity to do this as best you can, and you're being really thoughtful about it. So that's great.

I'll just mention that, as Maggie said, the folks I work with, wasn't me actually, but folks that I work with have written a book called *Parenting Well When You're Depressed*. And the depressed part is just because that's what the publisher wanted us to do. I think its really useful skills and it's very action oriented practical things that parents can do, regarding being with their children. And it's across all ages. So you might want to think about that. That's on the Parenting Well web site.

But I can tell you from our experience of spending time with families, and this won't necessarily be right at the beginning, but that talking with your children was one of—when we talk with children, that's the biggest thing. Kids were able to understand what was going on what was going on for parents. But I think the best thing you can do is exactly what you're doing, about being thoughtful, about knowing that there are going to be these x number of times a year, figuring out what are the supports that you're going to need during that time, that your partner is going to need during that time, including as many supports that you can have around you to help you and your partner and your child in that process.

**LUCINDA SLOAN-MALLEN:** I just want to say congratulations.

**MAGGIE JARRY:** Amen, and that's they way it should be.

[Inaudible audience]

I want to mention that Jim McNulty just left, but he encouraged people to stop him at anytime in the next day. He had to leave but he said he would like to talk with people, and if anyone wants to stop him over the last day of the convention, he would be more than happy to talk to you about things that he shared

I'm going to draw this to a close, I'm sorry we didn't have enough time for questions, and please write them down if you have anymore that you'd like to share. Thank you.

**(End of Transcripts)**

## APPENDIX A

### DAUGHTERS AND SONS OF PARENTS WITH PSYCHIATRIC DISABILITIES

#### 2004 NATIONAL CONFERENCE, WASHINGTON D.C. NATIONAL ALLIANCE FOR THE MENTALLY ILL

#### PANEL PARTICIPANT BIOGRAPHIES

##### CO-COORDINATORS

**Joe Donovan:** Joe Donovan was first introduced to public-funded human services, after the divorce of his parents 30+ years ago. In addition to being a single parent, Mr. Donovan's mother has struggled with the symptoms of schizophrenia. At a young age, he gained considerable knowledge of the policies, which regulate these services (Medicaid, SSI, AFDC, etc...). He did not, however, receive any information concerning the nature of mental illness. As an adult, Mr. Donovan would later acquire a psychiatric diagnosis, bipolar disorder, of his own.

After a 15-year career as an information systems professional, and having developed computer systems for both private and public clients, Mr. Donovan found himself working with the systems responsible for managing the Medicaid, TANF and Food Stamp programs for the state of North Carolina. He had come full-circle. At that time, Mr. Donovan decided to use his unique blend of personal and professional experience to become an advocate for persons with disabilities. He currently serves as a Peer Advocate for the Alliance of Disability Advocates, a Center for Independent Living, in Raleigh, North Carolina.

Joe Donovan has been active in NAMI since 1995. Joe has served on the Boards of Directors of NAMI-Wake County and NAMI North Carolina. Joe has participated in NAMI's Consumer and Veterans Councils. Since Fall 2003, Joe Donovan has partnered with Maggie Jarry, to raise awareness of the support and educational needs of daughters and sons of persons with mental illnesses.

**Maggie Jarry:** Since May 2003, Maggie Jarry has actively worked to increase resources in the United States for daughters and sons of parents with psychiatric disabilities, their parents and extended family. Maggie's work has focused on assisting the National Alliance for the Mentally Ill in building its capacity to meet the needs of adults and children who have a parent with a psychiatric disability. Throughout this effort, Maggie has built a network of stakeholders, including daughters and sons of parent with psychiatric illness, researchers and community leaders in the United States and abroad. Since the Fall 2003, Maggie Jarry and Joe Donovan have been working as partners to develop these panel discussions and other resources.

As a daughter of a mother, father and step-father with psychiatric disabilities (schizo-affective illness, chronic depression, and schizophrenia, respectively), Maggie was raised by my parents, grandparents, two foster care placements, teachers in my schools and the community at large. However, Maggie was never given any specific resources related to her parent's illnesses. Through the discovery process of this effort, Maggie has found that since the mid-1990's

resources have been developing for children of parents with psychiatric disabilities. These resources that have been helpful to her and to many people like her who she hopes will engage with NAMI.

Maggie Jarry is currently Director of Disaster Recovery and Advocacy at New York Disaster Interfaith Services where she coordinates long-term recovery programs in response to the September 11, 2001 attack of the World Trade Center. As of December 2005, Maggie has completed the requirements for a Masters in Nonprofit Management from the Milano Graduate School of Management and Urban Policy, The New School, New York City. She has Bachelor's degrees in Art History and Religious Studies from the University of Arizona. Much of Maggie's work experience has included program development and community organizing.

**PANEL ONE:  
THE THIRD GENERATION: DAUGHTERS AND SONS OF PARENTS WITH  
PSYCHIATRIC DISABILITIES**

**PANEL PARTICIPANT BIOGRAPHIES**

**Tina Kotulski:** Christine Kotulski is currently working on a memoir about growing up in a family torn apart by schizophrenia. Her mother, Mildred Smiley, whose life is seen in the documentary “Out Of the Shadow,” suffers from schizophrenia. Millie went undiagnosed for many years before the pieces of her life were put back together when the illness that started in her young adult years was given a name. Tina’s story follows her years growing up with her sister Susan in a single parent household and tracks the course of Millie’s illness through a first person narrative about how one family nearly slipped through the cracks. Like many living with schizophrenia, the survivors, the families and the sufferers, Tina and her family have had to navigate the often frustrating and complicated maze of today’s mental health system. Through her experiences, Tina deconstructs the shame and stigma the disillusionment and fear and reveals an underlying story of survival which at the very least provides a sense of hope, a way to heal, and the long difficult road to forgiveness. Tina and her husband have been married for seventeen years and have three children. They now live in Minnesota.

**Chiaying Wei:** Originally from Taiwan, **Chiaying Wei** is has a Masters in Clinical Psychology at Columbia University and works at New York State Psychiatric Institute. She has been working closely with the NAMI national office and, since living and working in New York, is eager to assist in local affairs. She takes the opportunity to serve on NAMI-NYC Metro’s board as the most honored privilege.

As the daughter of a mother who suffers from major depression, Chiaying has engaged in various mental health related activities. In addition to her work with NAMI, she translated two books from English to Chinese and helped them be published in Taiwan this year. They are "*When Someone You Love Is Depressed*", by Drs. Laura Rosen and Xavier Amador, as well as "*I am Not Sick. I Don't Need Help.*" by Dr. Xavier Amador and Anna-Lisa Johanson. "*When Someone You Love is Depressed*" is indeed the first book in Taiwan that targets on helping families deal with their loved ones’ mental illness.

**Mary Ann Widenhouse** currently lives in Otto, in the beautiful Smoky Mountains of far western North Carolina, with Carroll, her husband of 39 years, (on September 10th), her son Daniel, the youngest of her four children, and her mother Grace, who had her first encounter with some very intense psychiatric symptoms when she was 16. Grace is now 92 and is in recovery from her last episode 7 years ago. It is because of this last episode that Mary Ann became acquainted with NAMI, and has since served as a Family to Family teacher for 6 years, a past affiliate president, a member of the Board of directors for NAMI NC for four years and currently is an In Our Own Voice: Living With Mental Illness (IOOV) presenter for her affiliate, frequently co presenting with her mother, also a trained presenter. A mental health consumer herself, she intimately understands both the perspective as a daughter and that of a parent. By profession, Mary Ann is a registered nurse, graduating from Lenoir Rhyne College in Hickory, NC in 1965, but is not currently working as such. Instead she has spent this past year assisting



Smoky Mountain Center, the local public mental health system serving the far western seven counties of NC, a very, very rural area, with the implementation the recovery focus required by the state mental health reform effort. Because of this opportunity, she has become certified as a Peer Support Specialist and WRAP (Wellness Recovery Action Plan) Facilitator, one of the first four in this area to be trained. She will be employed soon by Smoky Mountain to facilitate WRAP classes in the community.

**Heather Despres Burack:** Heather Burack is a licensed social worker with an eclectic background. She spent 6 years working with people with mental illness through the Clubhouse Model of Rehabilitation at Fountain House in NYC and then as assistant director of Club United, a new clubhouse program in Harlem. She has more recently worked with youth in after-school and youth development programs and in family counseling in Brooklyn, New York. She also conducts empowerment workshops in a variety of contexts, with youth and adults. She often integrates creative arts, particularly dance and video, for healing and community building.

Heather Burack is also interested in exploring the meaning and ramifications of growing up with a parent with mental illness (She is herself an adult child). She has done research into conceptualizations of mental illness and into the lives of these adult children. Ms. Burack's particular interest lays in the subtler and --the often ignored-- redemptive aspects of this challenging and unique experience. She wishes to share with others so that together we can shed light on our experiences and inspire each other.

#### **Participating from the audience:**

**Susan Smiley** produced, directed and wrote the just-completed film *Out of the Shadow*, which premiered at NAMI's 2003 Annual Convention, to a packed audience and standing ovation. This hour-long film chronicles Susan's mother, Millie, and her family through the ups and downs of Millie's struggles with schizophrenia, and her trials within the public health system. By the time she was 25, Millie was a single mother with two small children. In the years that followed, she was plagued by the symptoms of schizophrenia. As the chaos of Millie's life unfolded, Susan and her sister Tina realized they had to mother her, even though they themselves were children. When they left home, Millie's life unraveled completely. After 20 years of transience and inadequate treatment, Millie finally has a stable group home placement, and for the first time in 25 years, holds a job. She is a portrait of dignity and courage, due in no small part to her daughters' love and perseverance. Susan, who has traveled the world producing television documentaries for PBS, Discovery, MTV and The History Channel, has found not only healing but a sense of mission in making *Out of the Shadow*.

**PANEL TWO:  
SEPARATING FACT FROM MYTH:  
CHILD WELFARE AND PARENTAL MENTAL ILLNESS**

**PANEL PARTICIPANT BIOGRAPHIES**

**Kathleen Biebel, Ph.D.:** Kate Biebel is a Research Instructor at the Department of Psychiatry Center at the University of Massachusetts Medical School for Mental Health Services Research. Kate has done extensive research on the topic of parents with mental illness. Kate works tirelessly as a advocate and educator to increase support for parents with mental illness and their families. Among Kate's list of recent publications and research are: "The invisible children's project: A family-centered intervention for parents with mental illness", "Interventions for families living with parental mental illness: Building the bridge from service to science", a commentary on "Community mental health care for women with severe mental illness who are parents." Kate's list of recent articles and research on the topic of families, especially young families, living with parental mental illness is extensive.

**Jim McNulty:** Jim McNulty is immediate past president of the NAMI national board of directors, having stepped down on July 1, 2003. He is a longtime NAMI member and activist, which is a nice word for a troublemaker. [Laughter] And is currently serving as Director of Consumer and Family Affairs for the Division of Behavioral Health for the state of Rhode Island. Jim McNulty has been living with bipolar disorder for his entire adult life. Not diagnosed until his mid-30s, when the illness began to manifest itself in a particularly devastating way. He has two sons, Patrick and James, who went through this part of his illness with him.

**Lucinda Sloan Mallen:** Lucinda Alden Sloan is a dynamic, dedicated, and passionate advocate. In 1991 she embarked on a strategic effort to mobilize a public response to the unrecognized issue of serving families where one or both parents have a mental illness. Lucinda's passionate and intelligent activism, together with research spearheaded by the Mental Health Association of Orange County, New York, influenced policymakers at local, state, and national levels. She developed the Invisible Children's Project, currently replicated throughout the country and hailed as the model of professional, effective response to families coping with mental illness. I think it's being piloted in nine cities right now. A noted national public speaker, Lucinda has received numerous national, state, and local awards for her distinguished and extraordinary efforts in mental health. As the chairperson for national committees addressing mental health issues and the executive director of the MHA of Orange County, New York, for twenty years, she had devoted her professional career to ensuring the needs of children and families affected by mental illness were addressed. Her work was inspired by her mother, a single parent who suffered from bipolar depression.

**Anand Pandya:** Anand Pandya, M.D. is an Assistant Clinical Professor of Psychiatry at New York University School of Medicine. He is the co-founder of Disaster Psychiatry Outreach, a charity that provides psychiatric care in the wake of disasters. He also serves on the New Research Subcommittee for the American Psychiatric Association Scientific Program Committee. Dr. Pandya received his bachelors degree from Harvard College with Honors in Mathematics and Philosophy. He received his medical degree at New York University School of

Medicine and his psychiatric training at Columbia University/New York State Psychiatric Institute where he served as chief resident. He also is a board-certified forensic psychiatrist. Dr. Pandya has served on the board of NAMI-New York City Metro and NAMI-New York State and has served on the executive committee of NAMI-New York City for more than six years. Dr. Pandya continues to teach medical students and psychiatric residents and is the Director of Ambulatory and Community Psychiatry at Bellevue Hospital. Dr. Pandya received the Kenneth Johnson Memorial Book Award for editing "Disaster Psychiatry: Intervening when Nightmares Come True."

## APPENDIX B

### Part One

**From the University of Illinois at Champaign-Urbana Website**  
<http://www.counselingcenter.uiuc.edu/Brochures/parents.htm>

#### **When Your Parent Has A Mental Illness**

Growing up in any family can be challenging at times, but there are often special problems and challenges for families in which one or both parents have a mental illness. Children in these families often have to deal with instability or unpredictability. Often there is confusion in family roles and children have to take over many of the adult responsibilities, such as taking care of younger brothers and sisters or managing household duties normally managed by adults. They may even have the responsibility of taking care of the emotional or physical needs of their parents.

Children in these situations do not always receive the parental care and nurturing they need. Often they feel ashamed to talk about their situation with others and consequently may withdraw from relatives or friends who could help them or support them. Often unable to articulate their needs, even to themselves, these children frequently feel isolated and alone.

Children of mentally ill parents may also experience added difficulties as adults. These may include:

- **Relationship difficulties:**
  - difficulty in initiating relationships, and experiencing feelings of isolation
  - difficulty in romantic relationships
  - difficulty in maintaining friendships
  - difficulty with trusting self and others
  - difficulty balancing level of intimacy (excessive dependence or excessive avoidance)
  - difficulty balancing taking care of self and taking care of others
- **Emotional difficulties:**
  - guilt, resentment
  - shame, embarrassment
  - depression
  - fear of inheriting parent's mental illness
  - fear of discovery by partner, friends
  - inability to express anger constructively, angry outbursts or repressed anger
  - confusion about one's own identity
  - negative outlook on life
  - inability to deal with life unless it is chaotic or in crisis
  - overly responsible or irresponsible in many areas of life such as commitments, money, alcohol, relationships, etc.
  - self defeating thoughts, attitudes, and behaviors such as & "I don't matter; I'm not worth much; It's no use trying."
  - Self-defeating themes involving a tendency to equate achievement with worth as a person, such as: & "Maybe I can matter if I can excel at something, be perfect in school, my job, my relationships. But if I fail, I'm worthless and it's terrible."

## Part Two

**Adapted from *When Madness Comes Home* by Victoria Secunda (pp.191-192)**

“No matter how loving, enlightened, or educated the family is as a group, no matter how well they may have adapted over the years, offspring and siblings of the mentally ill will nevertheless emerge from the experience with certain wounds. Family survival required that these young family members take a back seat to illness. And while many of them willingly did so with poignant awareness of their staggering burdens, most of these young people bear scars inflicted by that very invisibility.” . . . “Adapting to illness is not the same thing as adapting to life beyond home. And it is beyond home that the legacies of their experience will emerge.”

Some of the legacies include:

- Fear that they (we) are next in pathological line.
- Fear that they (we) will be “put away” if they do anything wrong.
- Fear of the mentally ill relative him- or herself.
- Fear that they (we) will one day have to take care of the sick relative.
- Fear of having children.
- Fear of telling lovers or friends about mental illness in the family.
- Guilt for feeling angry at their parents for not paying more attention to them.
- Inhibition and lack of spontaneity.
- Inability to set limits—not knowing how much is enough.
- Lack of pride in ones own talents and skills.
- Pressure to be perfect.
- Embarrassment or shame about a relative’s peculiar behavior.
- Sorrow over the loss of the ill relative’s mentorship, or companionship, or competitive spark.
- Grief over never having had a childhood.
- Uncertainty about how to be involved with the families of origin and in particular with the ill relative.
- Anger at being denied, by virtue of “wellness,” the same importance to mental health practitioners and policy makers that the ill relative receives.