

A Parents' Tale

Donald L. Madison, MD (with Victor and Johanna Smith)

VICTOR AND JOHANNA SMITH LIVE ON Harbor Island in Wrightsville Beach, North Carolina. Their gray house on stilts backs against the Banks Channel, a narrow sound that separates them from the outer barrier island and the beach proper.

Both Smiths are now 63. They moved to the greater Wilmington area 15 years ago when Vic left his customer relations job with Burlington Industries in Reidsville.

"We had thought about retiring here at some point," he says. "We came down a little bit early."

Soon after they arrived Vic started a small, unfinished furniture business, which he ran for about 10 years. Johanna, who is a former teacher, kept the books.

"But now," she says, "we advocate for the mentally ill."

Their reason is a familiar one: "Our youngest child took sick."

This is their story. It tells of a family's misfortune, of negotiating North Carolina's system of mental health services, of challenges faced, setbacks experienced, and ultimate perseverance. It is also a story of advocacy and service to others who walk the same path.

My conversation with the Smiths touched, too, on the topic of "reforms"—those needed, enacted, implemented, and not implemented. I have elected to address that topic only indirectly, insofar as the Smiths' story touches on it. Others have covered mental health reform and policy in North Carolina repeatedly and well, both elsewhere in this issue of the *Journal*, and, notably, two years ago in the *Journal of Common Sense*. ("The Unhealthy State of Our Mental Health" is the title of a multi-contributor report that appeared as a special double issue in the winter of 2000/2001. It can also be found on the web at <http://www.common-sense.org/journal/>). I commend these sources to the reader.

Vic and Johanna Smith have four sons. The three oldest live in Raleigh, Atlanta and Florida. Their youngest son, Reed, carries a diagnosis of schizo-affective disorder. He is 27 and lives in Asheville.

The Smiths tell the story in their own words. I have edited the transcript only slightly for clarity and continuity, but not for style; the voices are theirs.



Victor and Johanna Smith

Dr. Madison is a professor of Social Medicine in the UNC School of Medicine and Contributing Editor for the *North Carolina Medical Journal*. He can be reached at donmad@med.unc.edu or at the Department of Social Medicine, UNC School of Medicine, CB# 7240, Chapel Hill, NC 27500-7240. Telephone: 919-962-1140.

JOHANNA: We thought we were dealing with a rebellious young person. All of our four sons had always been well disciplined. So when Reed began behaving irresponsibly... Vic became angry. And I was confused over the change in his personality. At first we thought he was just frustrated with school. He would say that he wanted to drop out of school and go to Alaska and lay pipeline or that he was going to be a professional boxer, ideas that now look a little manic but at the time seemed like excuses to not go to school. Then when he couldn't sleep at night he would go out, but he wouldn't leave through the door, he'd climb out the window, and when he came back in the morning he would miss his bus to school. And he would get in trouble on the school bus and say things like, "There was a fight going on in the back and I had to straighten it out." Then he'd blow the bus driver out for not keeping the bus in tow, and she'd have to turn him in, and he'd get a note home that he was expelled for a day or two. And what we'd say to him didn't register. His logic was gone—cause and effect was gone.

VIC: A teacher would accept him, and hook up with him, and want to help him and do well with him, but he would self-destruct with that teacher and do something that would ruin the relationship.

JOHANNA: Then he ran away. He rode his bicycle to Winston-Salem by way of Myrtle Beach, and we didn't know where he was. Eventually, he caught a bus to Atlanta. He was picked up there by a kind of urban ministry type organization. They found him without any clothes or any money or food. But they managed, through family services, to trace him back to us—even though he almost didn't know himself. They called and asked, could we send money for a bus ticket? Well, they bought the ticket, I think, to Wilmington, Delaware (instead of Wilmington, North Carolina). But when he came through North Carolina he knew he was supposed to get off the bus. And so he got off somewhere north of here, and called us, and we went to pick him up. We knew then that he was going to have to see a psychiatrist. And he did agree to do that.

When we went to see the psychologist—he was in private practice—he told us, basically: "He's as sick as anybody I've ever seen." We didn't know what "sick" meant, and so we asked him, "Does it mean he might be dangerous?" "Well," he said, "that depends. Does he play with guns or knives?" I said, "He probably has a pocket knife." "Well," he said, "He'd have to stab somebody a lot of times with a pocket knife to really hurt them." "Well, what should we do? Can he live on his own?" "Well, that depends..." So we didn't get very much. The psychologist sent us to a psychiatrist, who gave him medication. We only saw him for about ten minutes.

So we got him a trailer, close enough to walk to his job at Harris Teeter as a bag boy, and close to our store. And then people began to come to the trailer, and take over, and take all of his things away. And he missed a lot of appointments; if I didn't take him he wouldn't have got there at all. For most of that time he was functioning at a high level. But there were other times when he would call in the night—and he might be at Carolina Beach, confused, and not knowing how to get back to the trailer, and scared, saying that people were after him and

that he didn't want to get into a fight or anything, and could I come get him?

One time he threw shoes out the door at me, and that was when I said, "Reed, we have to get to the doctor." I knew he wasn't taking the medicine, or maybe someone was taking the medicine away from him, I don't know. But I did have a container with medicine in it that he had not taken; by then he should have been through with the series. Then I asked to go in with him to see the psychiatrist—and they did allow that. And so after the psychiatrist and Reed finished their discussion, I said, "I do have something to say here, because I don't think he's been taking his medicine properly." And the psychiatrist looked at Reed and said, "Are you taking your medication?" And Reed said, "Yes, sir." And the psychiatrist looked at me and said, "I'm going to give Reed the benefit of the doubt here." And that was the end of the conversation.

A few weeks later Reed cut himself all along his arms, superficially, in order to get into The Oaks, which is the psychiatric unit of our hospital (New Hanover Regional). He knew that to get in there you have to be, appear to be, a danger to yourself or to someone else. So he went to the emergency room and into The Oaks. He had just turned 18. We were upset because we didn't know whether we were going to be able to afford The Oaks. It was like \$500 a day at the time, something like that. But since he was 18 he could apply for SSI and SSDI and all. And they were going to see to that, to the application.

Meanwhile, we felt like since he was safe there, in the hospital, that we would get the other boys together—one of our boys was getting his graduate degree in Minnesota—and take a trip; we got the other two and went up to see the one in Minnesota. And when we got back—we weren't gone long—Reed wasn't at The Oaks. I didn't know where he was, and when I called The Oaks they didn't want to tell me whether he was there or not there. So I went over there, and realized he wasn't there, and I, of course, wanted to know where he was. They didn't know. I was just frantic. Finally, after I don't know how many days it was, Cherry Hospital called, and they said, "We've got your son here." He had left The Oaks and had gone to this fellow's apartment to spend the night. And this person had a gun, and that scared Reed. He cut himself again on both his arms, went back to the emergency room and tried to get back in The Oaks. But they said no. They shackled his hands, shackled his feet, which is standard safety precautions—I understand that—and took him to Cherry.

VIC: The ironic thing was that I felt very comfortable when we first took him to The Oaks. I didn't know much about it, but there was a pamphlet there out in the waiting room that described what a state-of-the-art facility they had, how they included families in the treatment, how he would have a counselor in the house there, and that they would always confer with us and discuss with us. Well, since he had just turned 18, that didn't happen. They wouldn't talk to us. We couldn't get any answers from the medical profession. They wouldn't tell us what was going on. When we did see him he was in a fetal position smoking a cigar. So we got a little up tight there, just over the fact that they wouldn't talk to us. And even one of the psychiatrists there

said, "Because of confidentiality, we can't reveal any of his medications." He said, "If you want to know what he takes, you can ask him. But remember, he probably won't give you the right answer, or he might lie—if he knows you." It was just so exasperating! But the psychiatrists asked *us* things. They got a lot of information from us. *That* wasn't confidential."

JOHANNA: It wasn't secrets that we wanted to know. It was about the treatment program, what we could do to support him in his recovery. If I'm in charge of picking him up, I should know what medication he's supposed to be taking, so that I can read about it, so that if he begins to have side effects I can report that. And, you know, the nature of the illness doesn't allow the person affected to communicate, often, with any type of logic. And so if the professionals will not relay the information the family needs, well... In the long run, over the long haul, the family will be the caretaker for the rest of the person's life, whether it's parents, siblings, spouses, children. And to not educate that parent or family as to what has happened... It's a huge disservice not to bring all of the people together—the doctors, the families, the person who is ill—and tell them what has happened and why. You would do this with diabetes, with heart disease, with cancer. We're not trying to condemn this facility. What we're saying is that because there is no communication—parent after parent after parent will tell you this story—is why the whole reform came about.

Anyway, Reed was in Cherry. After about six weeks he was released to a rest home (nursing home) in Morehead City. Because that's the way the state pays for your SSI and disability care. You've got to get it through a rest home. So that's where he was—at age 19. His roommate was 91. He was there a year or so. They changed his medications, and his teeth began to fall out. He lost four teeth. His gums were bleeding so bad he couldn't eat. So then he cut himself again to get back into Cherry. And that's the point where I told him, "This is three times! You don't have to cut yourself to get back in the hospital."

Because he would always commit *himself*. Thank God—most of the time the parents have to do it. Then you have to go down to a magistrate and prove that he has gone off the page. You've got to watch him get shackled or arrested there in front of you. He hates you—or she hates you. Your heart is breaking. And when you go to the magistrate—because you're afraid of what your child might do to himself, or run away or disappear—they say if you don't have an address where they can go and pick him up, forget it. But how long is he going to sit out in your front yard, naked and yelling obscenities?

Well, when he cut himself and walked to the emergency room in Morehead, he told them, he said, "Don't shoot me up with drugs or anything. Please get me back to Cherry." So they did that. He was at Cherry about six months, probably.

This time he was released to a rest home in Jacksonville. They had 180 patients. His "girlfriend" was Miss Sudie. She was 83, the one he could talk to, who was the sanest. He ate with the old ladies—he was probably 20 now, 21 maybe—and cut up their food for them. By this time he was having trouble eating, too, I think. He stayed there, probably, a year and a half.

While he was at Jacksonville we went to see him regularly,



since it's real easy to get to. Then he calls me one day and says, "Mother, they're calling me from across the street. They're yelling at me." He says, "I can't go out any more. I can't go have my coffee at McDonalds." And I said, "It sounds like you're not getting your medication or you're not taking it." Before I could even get up there, the director of the rest home calls me and says, "Reed walked out the other day. He had his television with him." And I said, "Wait a minute. Where did he go?" "Well, we don't know where he went." And I said, "Didn't anybody feel like there was something going on with Reed? He just called me and we were trying to get up there and see what we could do." And she said, "Honey, I had three people die last week. I've got families I've got to deal with. I don't know where he is." Well, he had readmitted himself. He had walked to the hospital in Morehead. He didn't cut himself. And they sent him to Cherry.

DM: So this was his third admission to Cherry?

JOHANNA: Third and last. This time he went into what they call the "Unit One Program." They had offered him that before, but you have to stay a year, and he wouldn't do that, he wanted out. But this time he told me he was going to stay, and he told them he wanted to be in Unit One. You work yourself up to different levels, you know. You start down at a certain level, and if you do certain things consistently over a period of time, and take courses, and all, then you go to a higher level. There was a team that treated him, and the team had maybe seven members: they had a dietician, a pharmacist, a case manager, a nurse, a psychiatrist, and so on.

VIC: And these were all caring people, involved people. And they involved us. They gave advice on meals. They encouraged him to stay in touch with us.

JOHANNA: Sometimes he would call and say, "Please, please come see me." And, of course, I'd jump in the car, and by the time I got up there he would have done something that he would get that pass taken away. And about the third or fourth time that happened I finally drew a line in the sand. I

said, "Look, Reed, I'm driving up here, and I'm sitting in this tiny little room with no windows, and I get to see you ten minutes because you've misbehaved; I'm not going to come any more." So, he reached the next level, and then the next, and about the third level you get passes where we could take him to a movie and things like that. And deep down Reed wants to please, and I think most all of those that are sick do, unless the family gets to the point—and a lot of them do—where they can't handle it any more.

Anyway, after a year and two or three months, he was discharged the last time, and sent to Wilson, to a family care home.

VIC: He was in the best shape then that he'd been in three years.

JOHANNA: Yes, he looked good. His hygiene was good, he was very optimistic, and we were just tickled to death.

Now, there's a lot of different categories of family care. Some are regulated by the state, some aren't. Well, Reed went to this home, and the plan was that he would have a prescription for enough medication to last until his first appointment with the area mental health program in Wilson. Vic was going to see his mother in Bristol, Virginia, and I told him to go by way of Wilson. "Check this house out," I said. My other son was with him, and they went by this house. And Vic said that when he opened the door there was a body behind it. The house was just...

VIC: It was run by one man. It was really deplorable, but Reed seemed to be fine there. It was in a bad neighborhood. But he said, "I'm OK, I'm good with this." The problem was that the man didn't have any credit with the pharmacy to get Reed's medications.

JOHANNA: Well, what happened next was, I get a phone call, and it is Debbie. Now Debbie is significant because she used to be the director of the first care home that Reed was in, in Morehead. She had left that place to go back home to Virginia and look after her mother, who was dying. After her mother died she got a job in another care home in Fremont (which is a small town between Goldsboro and Wilson). She called me and said, "Do you know where Reed is?" I said, "Where?" "I have him here." Well, we went to Fremont and went to this rest home where I thought he was. And when I walked in, everybody there was bedridden.

VIC: The man in Wilson had dropped him off there at that rest home because he didn't have credit at the pharmacy and couldn't get his medications. So he took Reed to this rest home where he knew he would get his medications.

JOHANNA: Debbie in the meantime had gotten a phone call from the lady who ran this rest home, with severely ill patients, all bedridden. And this woman called Debbie: "I have a young man over here who does not belong here. Do you have anything in your rest home for him?" And Debbie said, "I'll make room for him; send him over here." When he went over to Debbie, she recognized who it was. It was Reed. See, she had a son who was mildly retarded, and he and Reed had really enjoyed being with each other at her rest home in Morehead, before she left. So she was fond of Reed. So when we went up

there, after she had called and said, "I have him," we just happened to go into the wrong rest home, because that's the one he had been in; it was deplorable, a nightmare. But we found him across the street at Debbie's. She had only about nine, maybe. It was very small. And there he was.

He had been out of Cherry about 30 days, total, and he was the worst we had ever seen him. He had not shaved, no haircut, same clothes day after day. He didn't know where he was. He kept saying, "The guy said he was coming back for me, he's coming back for me." He had told him, "As soon as I get credit for your medicines, I'll come get you."

VIC: Well, we thought that when they let him go (from Cherry) they would put him someplace that was appropriate. And when I called the lead nurse at Cherry, who had been very cooperative before, suddenly it was a "confidentiality" problem. "I can't tell you because of confidentiality." When they don't want to answer the question, it's because of confidentiality. But it's funny. Some time before this we had the director of Cherry down here for a speaking engagement. So we happened to know him. I wrote him a letter, and explained all that had happened, and asked, "How could this happen at your hospital?" (You know, we think it's a great hospital.) And he wrote us back and apologized, and said, "The system broke down; it just failed."

JOHANNA: When we found Reed in Fremont, and he was in such terrible shape, we brought him home. It was early December. After Christmas I asked Vic to get in the car and drive west from here to see if we could find any kind of supervised housing for the mentally ill.

VIC: I went to scout first. But we went all over the state, because we didn't have it here; there are no facilities like that here. I went to North Wilkesboro and looked at some apartments there, and at another little town near Wilkesboro; and I went to Hillsborough. And then I went on to Asheville.

JOHANNA: We had just had a young girl move down here from Asheville, who had worked up there in mental health. And when she got here—she was going to be in charge of the psychosocial day care program here—she said, "Oh, my lord, this is just a mess." She said, "We work as a team up there, and we have this and this and that." So she gave Vic a name. And he went up there.

VIC: Well, they have a lot of private facilities there that have assisted living. A young man and his wife run it, and the father-in-law builds the facilities. So I talked to the man and asked him, "Would you accept our son into your facility?" He had certain rules, which he explained to me. He's very strict. But I think that he liked me, and his facility was nice, and so I asked him, "What's the next step, then?" And he said, "I've got an opening coming up, and if you're interested, give me a deposit and we'll go from here." So that's what we did. And I came home and told Reed that I wanted to take him up there (by this time he had been home a while and was in pretty good shape). But he didn't want to go. He said, "I don't know anything about that," and it's too far from home and a couple of different reasons. But I said, "Reed, trust me on this. We're going to go. These people know how to deal with folks like you." So he went

up there and entered the assisted living thing and progressed on from there until now he's in an apartment.

JOHANNA: Each house (in the assisted living) has room for six. Each has their own bedroom. They have 24 hour—well, a lady that gives them their medications and cooks for them. And the man who runs it tries to keep all of them within the same age range—there weren't any as young as Reed there yet, though. And, of course, when he entered the assisted living he got hooked up with their mental health system up there (Blue Ridge Mental Health). The director of the mental health center there has involved all of Asheville. He has a group home, which we don't have here. That was the next step for Reed—a group home.

But in the assisted living, that housemother—she was living with him 24/7—would call us and she would say, "Reed is trying me. He says he doesn't want to eat with some of these others because he's not as bad as they are," and so on. Then we would call up and say, "This is your last hurrah up there." And that would bring him back around. And she was very concerned about Reed, and when she would call and say this was happening, or that was happening, she would try to call the director of the mental health center and talk to Reed's psychiatrist or his case manager. And then she would call me and say, "I have an appointment with his case manager; I wish you would be here." And we would drive up there.

But once he goes to the group home and learns some skills, and meets the other criteria they have set, then he is eligible for an apartment. And after about two years, Reed progressed to that point. He had a wide choice of apartments. He chose to go to the Vanderbilt Hotel downtown, which they've restored into apartments. So in December of this past year, Reed moved to the Vanderbilt.

VIC: We had our doubts. We didn't think that he was going to be able to handle that. And there are rules for the apartments. You have to keep them clean. It's a secure place. They have an on-site manager and a security guard.

JOHANNA: And they don't administer his medications. We were concerned, because he must take ten or twelve prescriptions. He knows them by size, by shape, color, and he will take them. But when he's here, and they are in a medical box, he'll have them all over the floor. Well, that's where the ACT (Assertive Community Treatment) team comes in. This is a group of mental health workers, a part of Blue Ridge Mental Health. They stay as a team and stay in touch with the ill person in the environment in which they live. And whatever problems come up they're there to help with. Well, the ACT team picked Reed up when he moved from the group home to the apartment. He will see a psychiatrist only about once every three or four months, and then only for just a little while for his prescriptions. His counselor and his case manager are the ones who actually talk to him. And they will often talk to the doctor about his medications and make recommendations, like, "It looks like this needs to be adjusted, or that needs to be adjusted."

VIC: Blue Ridge Mental Health has a real good relationship even with the city, which was accepting of these people. It's a different environment from here. We think that the reason it's different up there is the director. He's gone to the community,

he's gone to the hospitals, he's gone to the schools....

But now that Reed has been through all of this and is in an apartment, he says that Asheville is the greatest place on earth. He's as happy as he's ever been. He's functioning well. It's just been a miracle, actually. And for a guy who didn't want to go up there to start with, now we have to fight to get him home. We bring him home two or three times a year.

He doesn't have a job, and that's sort of the next goal. But he walks the streets. He goes into the restaurants there and has coffee and doughnuts. And he has a girlfriend now.

JOHANNA: She works three days a week at Taco Bell. And that's about all that Reed will be able to do. He can't seem to do anything consistently. She has the very same problem that he does. He goes to a psychosocial day program, and they have a transitional employment area there. What they do is they train four or five in a job. That way, if one or two are having a problem, then they send the third guy. And if all of them are having a problem, or going on a field trip or something, then the job coach takes the job—just so the employer can be assured that there will be somebody working there all the time.

SOMEWHERE DURING THIS TEN-YEAR SAGA, Vic and Johanna became advocates. The services that Reed and other young people with similar problems needed haven't been available in the Wilmington area, or for that matter in most of North Carolina. So the two read, listened, talked, negotiated, attended meetings, and for a time took the lead in trying to get supervised housing in Wilmington.

JOHANNA: We have builders who can get credit for building certain units for the mentally ill. And so they're more than willing to do this. But we've got to find the property. And if you go to where it might not bother anybody, then you can't meet the federal standards, which say that there has to be a bus stop nearby, and city water and sewer, and all. We don't have that housing here yet. Well, we have one old, old place that a man whose son had mental illness gave. But the Volunteers for America were here and they offered to build it; and so did the Mental Health Association of North Carolina. But our director of mental health here told his board that he didn't want to be in the housing business.

Vic started working on the housing problem in 1993. I've got documented letters, year by year. In 1993 he left his job, his business, and started in looking at designs for supervised housing. When he got to the point where he had the design and we decided that's what we wanted and needed, he went to the director of mental health here, wrote grants, met with developers in Raleigh and other places, and sought out properties and everything. And it's now 2003. We closed on the property, I think, last month. I mean he got to the point where it was one step forward and six back.

VIC: We intend to do it, and we have the money to do it. But somehow it just won't get off the ground. We can't seem to make it happen.

We found some property. And we were going to put the apartments there. It was great, everybody loved it. The mental



health center also needed a new place for their psychosocial day program, and we were going to put that there, also. It was going to be a little community, like a campus. The lender says, "We love this idea; we'll give you \$50 thousand to promote this thing. Well, then one of the staff members for the psychosocial day program says, "That's a bad section of town. People get shot and raped and murdered over there. We don't want to have our psychosocial day program there." It was right next to the child development center. It was their property that they sold to us.

JOHANNA: There was this petition signed by a lot of people that were claiming the location was dangerous—even though all of the agencies had come by to take a look at it, and they all OK'd it—the police, the housing person. The entire package that the lender had approved depended on the psychosocial day program being part of it.

VIC: So the director of mental health comes up and says, "OK, we won't put the psycho-social thing there. We won't put you all in harm's way." We'll let the apartments go there "in harm's way," but we're not going to put you there. I could have choked him. He didn't want to deal with it, with the whole issue. And that's what delays this whole thing.

JOHANNA: Well, I saw what was happening to Vic, and I said, "You've done everything you could possibly do, everything. Let's leave it alone now."

My area is education. And I was going to the police and the Rotary, and the churches, and I was trying to teach the Family-to-Family course. And I was an officer of our local affiliate here of the Alliance for the Mentally Ill.

And then the phone calls. Oh, my goodness! For five years we've been at it nonstop. We've got file cabinets just full of letters we've received and written.

DM: It sounds as though you've been spending nearly full-time on these issues. Just how much time, would you say?

VIC: This is a... It becomes a problem with your marriage. I got into it real strong. And then she tried to curb me back. It was having an adverse effect on the family. Now she's in it real strong; but now she's backing off a little bit.

JOHANNA: I've cut back. But the one thing I won't give up is talking to that parent when they call. Because I know the days when I was in my pajamas at four o'clock in the afternoon wondering what is going on with Reed. And there are just so many.

One lady I've recently been working with, whose son is in Arizona, in the high security part of the jail there... And she has taken her life savings to fly out there, and has taken his history, because they don't realize that he has been treated for mental illness. She thinks this might help. But we needed to get a lawyer to tell who to send the history to. And we needed to get her a ticket to get back. We did what we could. And she said when she got back that it's

really a minor incident that he's in for, and they've got a lawyer out there working on it, too, to try and get him transferred to a place that's not as harsh. She was only out there from Wednesday to Monday, and they kept putting her off; they told her to come Thursday and then come Friday. And she never got to see him until Sunday late, when she got to talk to him through a window. I don't know how that will work out.

It's just so sad to see what the parents have to do. Another example: An older woman—she's in her 70s—called me from Brunswick County, and she said, "My son is schizophrenic, and I'm having problems because I know he's off his medication." He was swimming without his bathing suit in her local area pool there. And she said, "I told him he had to go back to the doctor." She said, "I think he's committed himself to The Oaks, but I called there, and they won't tell me, and it's worrying me to death." I said, "They need to be able to tell you that." I said, "NAMI (National Alliance for the Mentally Ill) worked hard and long to get a law that says that they can tell you if the person's been discharged, relocated, or left." And I said, "That's not confidential, and they should be able to tell you that. Quote this law, and tell them what the number of it is." "OK," she said, "I will do that." So she calls back and says, "Thank you, thank you, so much; they told me and he is there. Oh, I'm so relieved. Thank you." All right, so then, he's out. She calls me and she says, "Oh, Dear, I hate to bother you again. I'm looking at his medication, and they have got him on all different stuff, and the one medication that helps him more than anything else, he doesn't know if it's here, and they won't talk to me over there; they say they can't talk to me, and I don't know who is following him, and he's saying that two or three doctors saw him, he thinks, and one of them, he thinks, is so

and so, and one, he thinks, is such and such.” I said, “OK, those names I recognize. They are with the local mental health agency. Let me get you in touch with them.” She calls back and says, “Nobody will talk to me there.” I said, “Give me a minute.” So I called the assistant director of the agency, and I said, “Can you please, please get in touch with the doctor and see if he will see this man again because he needs a different medication. This one isn’t working.” And so the person I talked to said he would do that. Then the mother calls back within a day or two and says, “Thank you, thank you, thank you. They called me back and they said they will have the doctor (do whatever).”

VIC: Another problem is denial of mental illness. We had a very prominent man in town, an attorney and public official and so forth. And his mother called us to find out about mental illness—because her grandson was at Cherry Hospital. They wouldn’t tell anybody, didn’t want anybody to know. It was an embarrassment. The official didn’t want to say, “I have a son who has schizophrenia.”

JOHANNA: And the child’s grandmother called, and she said, “Oh, Johanna, I heard that your son was at Cherry.” I said, “Yes, he was.” And then she whispered, like this: “Well, my grandson is there, and I don’t know how to get in touch with him.” And I said, “I think I can tell you how.” And she said, “Oh, would you? Because my son won’t admit that there’s anything wrong and that they had to take him up there.” Now that child was a brilliant young man...

VIC: And this was a situation where the dad could have made so many inroads, by making that public, helping people understand about it and what it was, that it wasn’t something they needed to be ashamed of or to fear.

JOHANNA: I went to a workshop not too long ago at our AHEC here. And one speaker, he was a psychiatrist, was very much against the reform: “You know what’s going to happen,” he said. “There’s just going to be more homeless walking downtown with one shoe on and dragging a blanket,” he said. He was very bitter. “Who’s going to look after them? This community’s not going to put up with that.” Well, I think that some of them—the professionals—have gotten kind of lazy about this.

And we are so callous. Reed, one time, said: “Oh, mother, I’d rather be in jail; I’d rather tell people that I’m in jail than that I’m crazy, that I’ve got schizophrenia.” But when you have someone who becomes mentally ill, and they’re in med school or an artist—you know, some of the brightest of our people have mental illness—it looks to me as though you could sit down and tell them that this is going to be an ongoing thing (just like you would with diabetes) and how they will have to work with this thing.

I talk with parents who have spent every penny they have and have suffered all of this disruption, and they don’t know what they’re dealing with. They still think they just have someone who has gone berserk because they’re rebellious or something. They can’t imagine that this young man, who has

just graduated valedictorian two years ago... A family we know well, their son killed himself. The suicides—just that alone. We have another good friend with two sons, and they’re both sick, and one of those sons killed himself. And we have another that we know of. And another and another. These are our children, and some of them are so bright. If we can remove that stigma so that they can accept being schizophrenic—We’re sorry you are; I hate that you have diabetes—but you’ve got to learn to live with it. And then to have the family in on it, that would solve a ton of problems that have caused all this homelessness and this revolving door, and this continuing suffering. There has to be a better answer.

And the police need to understand it. Memphis, Tennessee, has a “crisis prevention team” and they’ve been trained especially for mental health problems: if there’s a domestic crisis, sometimes that’s mental illness; if there’s a problem with children, sometimes it might be mental illness. Well, that’s their crisis team. Tipper Gore had a big television thing on mental illness, and the Memphis police were on it showing their state-of-the-art program. And so I ordered the video, and went to our police, and said, “Can we do this?” “No. No money,” they said. “We already know about that program.” Our intervention team from the police here, when they go to an apartment, where the problem is suspected to be mental illness... It’s literally a SWAT team—masks, helmets, guns. That’s the way they dress.

You asked how much time we spend on this. We’re trying to turn over some of the local calls to another family. But we get calls because someone, maybe in Raleigh, says, “You’re in Wilmington; call the Smiths.” Or maybe we’ll get a call from a parent of a student here at UNC-Wilmington. Sometimes the first break occurs in college. And then we had a mother call from Oregon, and her son had left his family—seven children—and his business, and she said, “The last time he called he was in your area, and he was wearing a long beard and carrying a sign that said ‘Walking for Jesus.’” She was so intent on finding his location! There was that desperation and that fear. If Reed had not been found by this urban ministry type organization, that had really put their nose to the grindstone in Atlanta, I don’t know that we would have ever seen him again.

VIC: We go up and lobby at the legislature. That’s another frustration. I went up to a hearing one time, and I sat down in the audience and ran into a friend of mine. He’s an attorney and he used to be in the Legislature. But now he was a lobbyist in Raleigh. He wondered what I was doing there, and I said, “Well, I’m trying to stump for mental illness and get a little help.” And he said, “Well, I’m fighting it. I’m a lobbyist for the insurance people and I’m fighting it.”

DM: All those roadblocks must be discouraging for you.

VIC: Well, frustrating sometimes. But we’re optimistic. And one reason is that we’ve seen what can work. We’ve seen it work in other areas—around the country and in North Carolina—and so we know it can work.