# *Educating Families*

## Concepts and Recommendations for Clinicians Who Teach Families How to Manage Schizophrenia

Carol M.  Anderson, Ph.D.
Douglas J.  Reiss, Ph.D.
William R.  McFarlane, M.D.

*Editor's Note*:   In Chapter 6, a curriculum for family educational workshops and the process for its presentation were described.  Because the  psychoeducational approach includes many coping strategies that are initially presented in the workshop, several descriptions of key interventions from previously published material are included here (Anderson et al., 1986a).  In particular, the sections of the workshop describing in detail: (1) the subjective experience and signs and symptoms of schizophrenia, (2) the experiences and responses of families and (3) more extensive descriptions of the Family Guidelines are made available for readers who undertake application of this approach.  In our use of this material in multifamily groups, we have found that nearly verbatim use of much of this educational material to be remarkably effective and welcomed enthusiastically by families and patients.  Many families have responded to the section on the subjective experiences of schizophrenia with gratitude, stating that they had no comprehension of the suffering and terror that psychosis and even negative symptoms can cause.  Often, that information has greatly increased the sympathy they feel for their loved one.  Similarly, families feel validated by descriptions of other families' responses, even when they are framed as less than helpful.  It makes them aware that they have been trying to help, but without the information necessary to guide effective action.

Note also that we have suggested using the material included in Chapters 1and 2 as explanations for the clinical and psychobiological aspects of schizophrenia and recruiting a psychiatrist or nurse to provide explanations of the currents treatments for this illness.  As mentioned earlier, we have produced an updated videotape that includes this material, either for use in lieu of medical professionals or for their use in preparing to present to families and patients.

We remain grateful, as should the field in general, for the contributions of Anderson, Reiss and Hogarty as one of the key foundations upon which the multifamily group approach is built.

## Schizophrenia: The Personal Experience

With the history and epidemiology of schizophrenia presented, the process of demystification and deisolation should have begun.  But an understanding the personal implications of schizophrenia should also be presented in order to increase empathy for the patient and tolerance for the symptoms of the illness and the slowness of change.  A description of what it is like for the patient to go through the first encounter with schizophrenia facilitates this understanding.  To make this description more relevant, it is often helpful, prior to the workshop, for presenters to be made aware of the particular symptomatic and behavioral characteristics of those patients whose families will attend the workshop so that these factors can be explained in greater detail.

The first indicator that something is wrong is often a decline in the person's ability to select "relevant" aspects of the environment to "attend to" while, at the same time, ignoring or inhibiting irrelevant cues.  Patients might feel that their minds are "playing tricks" on them.  Table A1.  lists a few of the deeply personal phenomena that patients in the throes of an early schizophrenic episode might experience.  There are literally scores of autobiographical reports which attest to the early disturbances in attention among "becoming" schizophrenic patients (e.g., Freedman, 1974).  Presenters can borrow liberally from these published reports and from the examples we offer below.  "Attention," it should be pointed out, is the most fundamental human capacity required for the process of learning and hence for the formation of one's sense of self.  Without an intact attentional capacity, we could not record or respond to the experiences of daily living, nor could we place such experiences in memory.  There would not be available for recall those important bits of information that provide us with a continuing sense of who we are.  People with a serious disturbance of attention would likely leave this workshop at 4:OO P.M. with no more information conceptualized and stored than they had at 9:OO A.M.

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McGhie and Chapman (1961) described this disturbance in attention and its sequelae.  The disturbance tends to make perception more "global" and "undifferentiated." Sensory perception becomes more diffuse.  "Willed action" is less controlled and is subject to an increased awareness of bodily functions.  Finally, concentration and thinking (in the face of distraction) become more impaired as patients struggle with and often fail to abstract those "internal associations" from incoming stimuli which are necessary to maintain logical thinking.

*Distraction*

Utilizing examples of distraction from McGhie and Chapman and other sources as well, we provide examples of what patients have actually said about this early disturbing process.

> *I couldn't read the newspaper because everything I read had a large number of associations.  I mean, I just read a headline and the headline would have much wider associations in my mind.  It seemed to start off everything I read, and everything that sort of caught my attention seemed to start off ... Bang! Bang! Bang! ... like that, with an enormous number of associations....  (Freedman, 1974, p.  335)*

Another patient remarked:

> *I jump from one thing to another.  If I am talking to someone, they only need to cross their legs or scratch their heads, and I am distracted and forget what I was saying.  (McGhie & Chapman, 1961, p.  104)*

We point out to relatives that the competing sounds in the room during the workshop (cars and buses going by in the street; the hum of the air conditioner or heating system; the drone of a fluorescent light) are representative sources of distraction.  Instead of the voice of the speaker becoming the principal stimulus, a schizophrenic patient, in the midst of an episode, might allocate equal "attention" to all these sources of competing information.

> *I am speaking to you just now, but I can hear noises going on next door and in the corridor.  I find it difficult to shut these out and it makes it more difficult for me to concentrate on what I am saying to you.  Often the silliest little things that are going on seem to interest me.  That's not even true; they don't interest me, but I find myself*

*attending to them and wasting a lot of time this way.  (McGhie & Chapman, 1961, pp. 104-105)*

*Overload*

We share with relatives that stimuli are generated internally as well.  Past events and experiences, memories of people, places, conversations, music, photographs and so forth, all compete with externally impinging stimuli.  The onslaught can be devastating.  Even Freud himself reminded us that above the reception of stimuli the human organism more likely required protection from too much stimulation.  Many patients describe this process as an "overload."  We use the analogy of a telephone switchboard operator, perhaps on the day that the *Steelers* won their first Super Bowl: Phone calls would all come in at once, needing to be sorted out and directed to their proper source.  The calls would overload the switchboard -- and the operator.  One patient, describing this process, remarked:

*It's like being a transmitter.  The sounds are coming through to me but I feel my mind cannot cope with everything.  It's difficult to concentrate on any one sound.  It's like trying to do two or three different things at one time. (McGhie & Chapman, 1961, p. 104)*

Another patient described the overload as a broken "filter":

*At first, it was (as) if a part of my brain "awoke" which had been sleeping and I became interested in a wide assortment of people, places and ideas which normally made no impression on me.  I think that the mind must have a filter that functions without our being aware of it, sorting out things and allowing only those that are relevant to a situation to come into consciousness.  I guess that this filter must have to work at maximum efficiency at all times.  (MacDonald, 1960, p.219)*

And she later concluded:

*My brain after a very short time became sore trying to handle all this information with a real physical   soreness as if it had been rubbed with sandpaper until it was raw.  It felt like a bleeding sponge.  I had very   little ability to sort the relevant from the irrelevant.  The filter had broken down.  Completely unrelated events became intricately connected in my mind. (MacDonald, 1960, p.  219)*

*Sensitivity*

In the midst of this bombardment by stimuli, many patients will often comment that the "quality" or properties of sensory stimuli have changed: colors may be brighter, sounds louder, sensory images more detailed and vivid, and familiar objects more ominous and threatening.

*I have noticed that noises all seemed to be louder to me than they were before.  It's as if someone had turned up the volume ...  I notice it most with background noises, you know what I mean, noises that are always around, but you don't notice them. (McGhie & Chapman, 1961, p. 105)*

*Colors seem brighter now, almost as if they are luminous.  When I look around me it's like a luminous painting.  I'm not sure if things are solid until I touch them. (McGhie & Chapman, 1961, p.  105)*

*Misperceptions*

With the sensory presentation of the external and internal world now dramatically different, relevant and irrelevant cues equally worthy of attention, "too many balls coming over the net," sounds, colors, shapes, experienced in an unfamiliar manner, it does not take much to appreciate the fact that patients will make "mistakes" in perceiving reality.  In many ways, the perceptual

distortions that occur are similar to the more familiar psychedelic drug experiences (LSD, PCP or "Angel Dust," "Speed").  Some researchers, in fact, have suggested that perhaps the acute psychotic process actually produce toxic chemical substances that induce cellular damage in the cerebral cortex, as does cocaine and other stimulants in large quantities and chronic use.

For one patient, the misperceptions rest between the realms of illusion and reality:

*If I am looking at something and there's a sudden noise, perhaps an airplane passing or a bus, what I am looking at seems to swing or move in front of me although I know it's stationary. (McGhie & Chapman, 1961, p.  106)*

For another patient, it is more real:

*Everything is in bits....  It's like a photograph that's torn in bits and put together again....  If you move it's frightening.  The picture you had in your head is still there but it's broken up.  (McGhie & Chapman, 1961, p.  106)*

And for yet another patient, the misperception **is** the reality:

*Everything (is) a jumbled mess.  I have found that I can stop this happening by going completely still and motionless.  When I do that, things are easier to take in.  (McGhie & Chapman, 1961, p.  106).*

Sometimes the misperceptions can fill the patient with a morbid fear:

*That's the horror! That's the horror of the great big open space! It's like something gone mad about the place.  I could never walk in the streets.  Never! It's a terrifying place, isn't it?  Soon as the houses lift off buildings on both sides of the road, as if it's flat and you could see right over it like a mad horse or something ...  it would look mad and terrifying, like it would hurt something.  (Strauss, 1966, p.  78)*

Or fill the patient with dread:

*I went to my teacher and said to her, "I am afraid.  She smiled gently at me.  But her smile, instead of reassuring me, only increased the anxiety and confusion for I saw her teeth, white and even in the gleam of the light.  Remaining all the while like themselves, soon they monopolized my entire vision as if the whole room were nothing but teeth under a remorseless light.  Ghastly fear gripped me.  (Sechehaye, 1951, p.  22)*

Obviously, these problems in perception and information processing must be terribly upsetting to patients, making them more anxious, nervous and excited.  In medical terms, one would say that patients are increasingly "aroused." Later in the workshop, we demonstrate that increased arousal, in fact, contributes very much to the growing problem of disattention and misperception.

## Schizophrenia: the Public Experience

Once the presenter feels that family members have an appreciation of the disordered process of attention and arousal, the rhetorical question is asked: "How would you act if this were happening to you?"  By this time, family members, even those who attended the workshop reluctantly, actively begin to participate in the workshop, expressing increased understanding of the patients' dilemma.

Still, it is helpful to go on to give examples of the differences in individual response to this process that have contributed greatly to the difficulties in diagnosis.  It would be convenient if everyone responded in the same way.  Unfortunately for diagnosticians, human beings insist on being individuals, yet, there are commonalities in the *process* of responding, even though the *content of* the patient's explanations might differ widely.  In order to make the following more

relevant, presenters might want to use actual behaviors which the families present at the workshop have witnessed.

*Thought Disorder*

Considering all that is going on in the patient's head, attempts to explain the experience often don't "hang together." A single word of explanation might start off indirect associations to other words or ideas. (When asked if he felt concerned that he would be deserted by his friends, one patient responded: "I wonder what's the dessert today?" (cited in Spitzer, Endicott, & Robins, 1978) This aspect of thought disorder is referred to as *"loose associations",* one of the cardinal Bleulerian hallmarks for diagnosing schizophrenia. Patients will sometimes stammer or halt in their speech. The loosely associated ideas, when strung together in sentences, make little or no sense to the listener. The meaning attached to words sometimes seem very personal and very private. It is hard, at times, for family members to follow the patient's conversation. The diagnostician, when listening to such speech, might characterize it as "illogical" or "incoherent" or private," all of which are signs of a thought disorder.

*Delusions*

At times when patients' explanations are even understandable, family members can become terribly upset when they cannot convince the patient that such explanations are simply untrue. When patients are convinced of ideas that most people around them feel are untrue, the ideas are called delusions or false beliefs. Unfortunately for families and friends, the patients' explanation of what is going on often does contain a "kernel of truth." Frequently, the psychotic process might go on for weeks or months before family and friends are convinced that, in the long run, the seemingly valid explanations just don't make sense. If patients, for example, have had a rough time with their employers or co-workers, they might be convinced that it is these persons who are "doing it" to their mind. If family relationships have become stressed and strained, patients might seize on the disrupted relationship and begin to blame and accuse the family members for their problems. Public and international events involving spying, espionage, counterintelligence and other sinister forces frequently provide the explanation and justification for the disturbing personal experience of schizophrenia. These types of false beliefs are called *paranoid delusions or persecutory delusions.* The content or reasons often change with the times. Decades ago, God was most often given as the source of the problem, later, satellites and color television. Today, "sex" is often identified as the culprit. In some cultures, "spirits" do it to the patient and in others, the patient's ancestors. No matter what the source, it is the falseness of the belief that makes it a delusion.

At other times, the personal experience of schizophrenia might be so frightening or recognized as so bizarre and unusual that patients become convinced that someone or something (e.g., television or a satellite) must be putting these disturbing thoughts and altered perceptions in their heads. *Thought insertion* is a frequent characteristic of severe psychosis. At other times, the personal sensory horror of schizophrenia might be so real, so vivid, so loud and tumultuous that patients become convinced that others can "hear it," "see it," and "sense it" as well. *Thought broadcasting and reading one's thoughts aloud* are equally severe aspects of psychosis.

*Hallucinations*

One of the frequent and tragic consequences of a breakdown in the "inner filter" of the brain may be that sensory stimuli are generated internally. In other words, there is no apparent external source of stimuli capable of accounting for the experience. This phenomenon is called a *hallucination.* Sounds, particularly "voices," are the most common internally generated stimuli

and are labeled *auditory hallucinations.* The voices might be familiar or unfamiliar, one voice or a number of voices. They are frequently threatening and terrifying in the early stages of the illness. Sometimes after recovery, a friendly voice or two might persist, especially when patients are alone or given to fantasy and rumination. We sometimes will show relatives a PET scan picture of the "brain in action," with the auditory centers of the brain "lit up" in activity, even though the patient's ears are plugged! Such examples serve to impress upon the relatives the fact that these altered perceptions and sensory images are *real,* not "made up," and not to be dismissed or argued as "imaginary."

*Withdrawal and Reduced Feeling*

Many times in the face of the personal living nightmare of schizophrenia, patients will develop ways to "block it all out." Many patients, even through the long period of recovery, will learn to avoid these sources of stimulation (e.g., heated conversations, the demands of school or work) and take to their rooms or "travel alone." Some appear emotionally paralyzed by the inner turmoil as well. Social withdrawal and a "flattened" or "blunted" affect or feeling level are important distinguishing characteristics of schizophrenia, especially when they occur in the context of thought disorder, delusions and hallucinations. It must be pointed out, however, that the world is filled with people who are shy, socially uncomfortable and have a reduced feeling level, but who are not suffering a schizophrenic illness.

## The Family and Schizophrenia

*Coping*

At this point in the workshop, family members occasionally will ask why it is necessary to involve them in a treatment program if the professionals conducting that program do not believe families play a causal role. Three main reasons are given for soliciting family cooperation in the patient's treatment. First, emphasis is placed upon the fact that schizophrenia inevitably has an impact on everyone in a family. Although most family members readily acknowledge this fact, quotes from other family members struggling with the illness are used to emphasize that other families have gone through similar experiences. The following quotes are shared to give just a few examples of statements' made by family members about the impact of the illness:

*Since he's been sick, I've had to do everything. I work, I take care of the kids. It's been so frustrating. The kids don't bring friends home. I think they're embarrassed. One of them isn't doing well at school. We all pay a price.*

*He's our only son. He won't let anyone help him. Our hearts are breaking. When he suffers, we suffer. We don't go out anymore. We can't enjoy ourselves knowing he's sick.*

*Our entire family life has been devastated. The other kids don't get our time or attention. We can't think of anything else; it's been a nightmare.*

Second, the point is made that when a family experiences the severe and chronic stress associated with living with this illness without receiving help and support, its members will be less able to continue to help the patient effectively. Even worse, it is possible that they themselves may begin to develop problems. It is common to see marital conflict between parents, acting out in siblings and depression or physical symptoms in just about everyone. These potential difficulties are mentioned at this time to underscore the importance of all family members developing and maintaining a healthy concern for themselves, not only for their own sakes, but also for the sake of the patient. Thus, it is emphasized that their presence in treatment helps them to learn to protect themselves.

Third, family members are told that our current knowledge of the patients' vulnerabilities has led us to believe that there are specific things that those who live with patients can do that may make things better for the patient. It is stressed that the suggestions which will be made are not necessarily the natural responses anyone would have to someone who is ill. Nor are the suggestions meant to imply criticism of the ways family members may have coped in the past. Even past treatment programs have not been based on some of these concepts. We stress that most relatives have tried to use the usual problem solving resources to deal with this complicated illness. However, if common sense solutions worked, neither patients nor families would need to seek help. Families also are told that while the staff of the program are experts on schizophrenia and on patients and families in general, they are experts about the patient in their family and experts on the way their family operates. It is emphasized that while the workshop will provide many coping techniques, some will not be appropriate or possible to use in their particular situation. They must be the final judges of which ones they will attempt to use.

Before providing specific coping techniques, it is also important to let families know that the program's staff have some understanding of the experiences they have been through. Family members are less likely to accept any suggestions if they do not believe the staff understand the difficulty of following these guidelines. For this reason, common emotional responses of other family members to the illness are reviewed, along with common behavioral responses. Although no active attempt is made to encourage discussion of these issues, this review often stimulates considerable sharing of personal experiences by family members. Discussion is allowed at this point based on the belief that this sharing can help everyone begin to feel less isolated and more willing to accept support both from other families and from the professionals in the program. The following specific emotional behavioral responses to the patient are touched upon.

*Common Emotional Responses*

*Anxiety, fear:* Since the onset of schizophrenia involves significant behavioral, emotional and cognitive changes, family members often will have become anxious and fearful even before it is clear that the patient is seriously ill. Watching a loved one develop strange, inexplicable behaviors is incredibly upsetting. Fears and anxiety about the cause or meaning of these behaviors, as well as about the patient's future, are inevitable. In general, professionals will have done little to alleviate these feelings since, if family members are seen at all when patients are treated, they are unlikely to have been given much information or reassurance.

*Guilt:* Lack of knowledge about the possible causes of this illness has led to a proliferation of theories, many related to ideas about the pathological impact of the family. Even those families who have not encountered these theories tend to fear that the patient's problems were caused or exacerbated by something they did or did not do. When something goes wrong, most people look to themselves to see what they could have done differently, and most people find something that they can worry about. These concerns tend to be reinforced by the messages of the popular media (magazines, TV and radio) that emphasize the connection between good parenting and a child's success. Thus, a certain amount of guilt seems to be inevitable and needs to be challenged, strongly communicating the message that family interaction cannot <u>cause</u> a biological disorder.

*Stigma and embarrassment:* People with mental illness are among the most stigmatized groups in our society. Much of this is due to fear, society's lack of understanding of mental illness and the disproportionate publicity given to those few patients who are disruptive, violent,

or criminal.  Understandably, when patients behave in an unusual manner, they often cause pain and embarrassment to their family members.

*Frustration:* When someone in a family becomes mentally ill, other family members usually try every possible way of helping that person, while also trying to keep family life stable and predictable.  Because *so* many common coping mechanisms either produce minimal results or fail altogether, most family members become increasingly frustrated.

*Anger:* Anger is a normal response to chronic frustration.  Even when family members realize that the patient is ill, it is impossible to avoid feeling angry at behaviors that are thoughtless, inconvenient, or irritating.  Anger is particularly prevalent when family members believe that patients could control their behaviors if they only tried harder, or if they were not lazy or manipulative.

*Sadness, mourning:* Most family members experience, at one time or another, a sense of sadness about the loss of their hopes and dreams for the patient.  These feelings are particularly acute when family members first realize that the patient will never be the same as he or she was before the illness.  Giving up hopes and dreams is particularly sad for parents and even worse for parents when the patient is an only child.  Nevertheless, it is also sad for spouses of patients when they must mourn the loss of a partner who was genuinely responsive to them and learn to cope with the self-preoccupation or diminished capacities of their loved one.

*Common Behavioral Responses*

*Adapting and normalizing the situation:* The most common initial response of family members to behavioral changes in patients is to adapt their routine to incorporate the behavioral patterns of the patient.  If the onset of the illness is slow and insidious, there is usually a slow, continuous adaptation by all family members that allows the patient to maintain a role in the family and "get by" in the world.  As the patient becomes more dysfunctional, however, it becomes difficult to constantly and increasingly adjust to the home environment and this coping mechanism loses effectiveness.

C*oaxing and rational persuasion:* The natural instinctive response of family members when a loved one begins to behave or think strangely, is to try to convince them that their unusual ideas and belief systems are not true, or to coax and persuade them to behave in a different, more acceptable manner.  Early in the course of the illness, the lack of any overt physical disability often leads to the assumption that it is possible for patients to have control over their symptomatology.  Thus, family members often continue to try to coax and convince patients long after it has become clear that this method of coping is an ineffective one.

*Making sense out of nonsensical communications:* As it becomes more apparent that the patient does not make sense, family members often try to discern the meaning of the patient's bizarre or nonsensical statements.  They search for the core communicative message or some element of reality in the patients' irrational ramblings or statements.  This, of course, is both frustrating and exhausting and over time might also cause other family members to develop habits of communicating in unusual ways.

*Ignoring:* When the patient's behaviors do not demand a response, family members will often try to cope by ignoring them, hoping they will go away.  Family members may even express the hope that the patient "will grow out of it," but more likely they will try to deny the significance of the symptoms, focus on other aspects of their lives, and try not to think about it.  Again, ignoring the illness only works for short periods of time, or when behaviors are not extreme.

*Taking on extra responsibilities themselves:* As patients become increasingly disabled, family members often attempt to be supportive by assuming more of the patients' tasks and roles. This coping mechanism often allows patients to survive outside an institution even when they are quite dysfunctional since this way of coping usually reduces the amount of dissension about the patient's failure to perform even minimally. There is, however, a limit to how much and how long family members can tolerate these extra burdens.

*Providing constant supervision:* As the patient becomes more disturbed, the fear and anxiety of family members often leads them to try to monitor the patient's actions on a minute-to-minute basis. Since there is a strong sense of unpredictability, continued supervision provides some protection for the patient and gives the family some sense of having control over a potentially chaotic situation. Ultimately, however, most families cannot maintain this state of hypervigilance, and this coping mechanism breaks down.

*Curtailing their own activities to care for or support the patient:* As in any crisis in any family, family members tend to plan their routine and activities so as to be able to care for or offer maximum support to the member with a problem. It is easy to see how the chronic problems of a patient slowly cause all family members to begin to base their schedules and routines on his or her needs. Either they must actually take care of the patient, providing supervision in the home for fear of harm to self or others, or family members find themselves too exhausted and overextended to use what little free time they have to do anything but the minimum tasks necessary to maintain a home.

*Ignoring the needs of the other family members:* As the patent increasingly becomes the focal point of the family's energy and attention, the emotional and functional needs of the rest of the family almost automatically become secondary. This does not mean that the needs of others lose their importance, or that other family members do not care about one another, but rather that caring for the patient ultimately becomes a full-time job. Over time, this can mean that other family relationships deteriorate, or that others will come to feel uncared for or neglected, because there just isn't enough time and energy to go around.

These are just a few examples of the emotions and behaviors that family members may develop in response to the patient's mental illness. When reviewing these responses for the workshop group, it cannot be over-stressed that they should be framed as appropriate and normal for any family coping with a difficult situation and a confusing illness. The pain associated with the gradual realization that most of these coping mechanisms are futile must be addressed before moving to the specific recommendations of the treatment program. If family members do not perceive that the workshop staff appreciates the difficulties they have experienced and that they have done their best considering the overwhelmingly difficult circumstances, they will be more likely to be defensive and unreceptive to trying new ways of coping.

Suggestions and guidelines are given to family members to prepare them for working with the staff of the program on an ongoing basis. Over time, these suggestions can be modified and adapted to specific plans for specific family situations, based on the individual strengths and problems of the patient and the family system. All suggestions are based on the assumption that a family can positively influence the course of the patient's illness.

The stated overall goals for patients are reviewed: A return to as normal functioning as possible over time and breaking the cycle of repeated psychotic episodes. The working premise presented is that if patients can be maintained on medication and not overstimulated during the time of highest vulnerability (the first 12 to 18 months post-episode), it may be possible to avoid

the full-blown recurrence of overt psychotic symptoms, leaving more time and energy for patients to enhance problem-solving skills and develop ways of protecting themselves. While it is never implied or suggested that this delaying tactic will cure the illness, it is suggested that there is genuine hope for improvement. Families are told that some patients will eventually be able to look and act like anyone else, others will have occasional problems but still be able to function effectively, and some will require ongoing or periodic intervention. Few, however, need to be either in constant crisis or continually disruptive to their families.

## What the Family Can Do to Help

The theme of the entire treatment process is explained to families as one of maintaining a delicate balance between too much and too little stimulation. Family members are asked to help by providing a relatively low-key, but not permissive, environment for the first several months after an acute episode. This low-key environment is framed as a way of "buying time" during which the patient may be able to become more tolerant of stimulation and the normal demands of life.

More specifically, it is emphasized that the goals of the first year following an episode are primarily the avoidance of another episode or hospitalization and the gradual assumption of basic roles within the family. Anything else achieved is regarded as a bonus. The goal of the second year is to begin the gradual process of starting or returning to work, school and social functioning. The following general suggestions are given to families to help to achieve these goals.

### Revise Expectations, at Least Temporarily

Temporarily modified or decreased expectations of patients enables families to be less surprised or "let down" by inevitable patient behaviors. The first half of the workshop, which described the symptoms, course and treatment of schizophrenia, usually helps to facilitate the development of more realistic expectations. Nevertheless, the need for revised and diminished expectations is reinforced and made explicit.

For families who are experiencing the patient's first episode, the point is made that, because the hospitalization may have been brief, this does not mean that the patient's illness is not a very serious one. It is suggested to family members that it would be useful to regard patients as if they had a very serious physical illness, one which required a long process of recuperation. After the initial stabilization of the patient's psychotic symptoms, a period of inactivity, amotivation, and excessive sleep is common. Even if patients do not experience these negative symptoms, they tend to have restless energy, with little ability to follow through effectively on even small tasks. Thus, the need for increased rest, sleep, withdrawal and limited activity for a period of time is predicted in advance. It is important to stress the fact that these patterns are a natural part of the course of the disorder, since some family members will otherwise tend to assume that once the acute episode has passed, patients are now healthy but lazy. If families can be helped to understand that this apparent laziness merely represents another stage of the illness, they may be better able to tolerate the inactivity and amotivation that can otherwise be extremely irritating. In fact, it may be helpful to label these negative symptoms as the body's adaptive response to a debilitating stress, since this provides some sort of explanation for a level of inactivity that seems inexplicable. Whether these symptoms are actually adaptive or not is less important than the fact that they are predictable and difficult to influence. Most patients do become more active and interested over time. However, to aid in coping with these symptoms while they persist, the family clinician is established as someone who will offer

support and help family members make specific judgments regarding the symptoms of the illness as opposed to possible malingering.

To enable family members to tolerate the slowness of change during this period of low expectations, the idea of using an "internal yardstick," is presented. As patients begin to recover from an acute episode, both family members and patients are encouraged to compare the patient's current behaviors to those of a month ago, rather than to someone else's current behavior. This yardstick concept was, in fact, generated by a patient to help herself. She was a very bright young student who was extremely frustrated after hospital discharge because, although she did extremely well, she found she couldn't keep up with the other people in her class. She was unable to do the very things she used to be able to do with ease. After spending months getting repeatedly depressed and furious because she didn't have the control or ability she once had, she learned on her own how to gauge change. She said, "I have to compare myself to where I was 6 months ago, not to where my brother is today, not to where my peers are today, but to where I was 6 months ago. I have to ask myself "Am I better now than I was then?" If patients and families and even the professionals treating these patients, can learn to use this way of measuring success, they can develop a greater tolerance of the slow progress inherent in the recuperative process. The idea is to help people to see and appreciate the "inches" of movement as they occur, thus decreasing feelings of discouragement and hopelessness. The appreciation of very small positive changes may also eventually help patients to have more appropriate expectations for their own behavior.

### Create Barriers to Overstimulation

Families are helped to see that they can influence the course of schizophrenia by learning to modulate the level of stress within the home. Decreasing stimulation and stress is labeled as central to an eventual decrease in patient vulnerability. The family is told that the diminished stress tolerance of the patient includes a diminished tolerance for the interpersonal stresses common to family life. The results of studies of the post-hospital adjustment of schizophrenic patients (mentioned in Chapters 1 and 2) are shared. These results have demonstrated that relapse is often related to the amount of stimulation in the patient's environment, including the amount of intense affect or conflict within families. While the details of these studies need not be shared, it is suggested that conflict, simultaneous and multiple interactions, unclear power structures and diffuse generational or interpersonal boundaries will be difficult for patients with schizophrenia to manage. Thus, decreasing stress implies decreasing the emotionality and intensity of family life.

Families are helped to see that certain instinctive behaviors common to all families in crisis are generally not helpful in dealing with schizophrenia because of the particular nature of the disorder. Generally, these less helpful behaviors can be put into three categories:

1. Conflict and criticism between family members in general and toward the patient in particular.
2. Extreme involvement with the patient, (whether positive or negative).
3. Decreased involvement with each family member's own social network or other potential supports or gratifications beyond the nuclear family.

Thus, a series of suggestions are given to help family members to limit interactions that could constitute overstimulation for schizophrenic patients. Much like the Muzak heard in department stores and dentist offices in which the range of tones is compressed, family members are told that they will be asked to modulate the highs and lows of their family interaction. In

other words, they are encouraged to minimize the negatives of nagging, rejection, fights and conflicts, as well as the positives of extreme concern, encouragement and enthusiasm. An example of the upsetting nature of both of these extremes, provided by a patient early in the project, is shared. He described his upset when his mother would continually nag him to take out the garbage. He also described at least as much upset, however, when she not only stopped berating him, but rewarded him excessively ("That was wonderful") when he did carry it out. As he stated, "I knew it was no big deal to carry out the garbage. I just knew how much I had been letting her down when she made such a big deal over nothing." These examples are used to underscore the importance of benign, relatively neutral responses, however difficult they may be. The idea is to create distance without rejecting the patient.

It is also suggested that families allow patients to withdraw when they seem to need to do so and learn to recognize which patient behaviors signal the need for "time out" from interaction or activity. Operationally, this may mean simply allowing patients to keep the doors to their rooms closed, to have a room in a quiet part of the house, to eat dinner away from the rest of the family, to know in advance when company is coming and so on. To help avoid complete withdrawal of patients during this phase, families are encouraged to offer patients opportunities to engage in activities, such as going to a movie or going bowling, but to accept patient refusals if they seem unable to participate or need to be by themselves.

It is emphasized that this sort of attitude may initially seem artificial, difficult to implement and unfair to both family and patient so soon after an acute episode, but that it is of great help to patients. In general, messages demonstrating an awareness of the difficulty of all these suggestions are important since they reinforce the notion that the staff truly appreciates the problems families will have in carrying them out. These messages also allow the staff to emphasize that suggestions are only made if they are considered extremely important for the patient's recuperation or the family's emotional survival.

**Set Limits**

Another method of decreasing the likelihood of overstimulation of the patient and overextension of family "coping resources" is the creation of reasonable rules for living together and their reinforcement through setting limits. Families are instructed not to confuse the need for low stimulation with permissiveness. Because patients are sick does not mean that families can or should do whatever they ask. The emphasis placed on creating rules and limits often confuses family members. Thus, time must be taken to explain how limits can help to maintain a low-key, predictable home environment and how they can be set without increasing stimulation or conflict.

Families are helped to understand that external limits are reassuring to patients who are feeling overwhelmed by the chaos in their own minds and that these limits also are crucial in preparing patients to live in the real world, a world that will be less tolerant of bizarre or symptomatic behaviors. It is also emphasized that limits are important in helping to keep the level of stress placed on other family members within tolerable bounds. It is never helpful to permit patients to engage in unusual rituals or strange, irritating behaviors if they unduly upset others in the family. The following guidelines are given to help families to set reasonable and effective limits on most behaviors.

1.  Decide ahead of time on the minimal conditions or rules necessary for the patient to come home to live with the family. In making these decisions, try to separate behaviors that are just irritating from those that are intolerable, and establish priorities based on a consensus

about what upsets the patient and other family members the most. Family members should never tolerate abuse, but other behaviors can be left negotiable dependent on the family's reaction to them. For example, one patient required his entire family to remove their shoes when entering the house. For his parents, this was a tolerable, if somewhat inconvenient request. For his adolescent brothers and sisters, who had to explain the ritual to friends who visited, this was very irritating and extremely embarrassing. Considering the needs of these siblings, then, this ritual became a priority for parental limit setting.

2. Set limits clearly and without detailed discussion. It is best to avoid discussions of why a limit is being set or how everyone feels about it. A direct statement such as "that's not acceptable" is preferable to a detailed explanation since it is both more clear and less stimulating.

3. Keep requests specific. Try to avoid asking the patient to follow general guidelines or multiple suggestions given simultaneously. For example, don't ask patients to "help out more." It is better to say, "Your job is to carry out the garbage twice a week." Since lack of initiative is a common problem, when the time comes to carry out the garbage, another specific reminder is in order.

4. Set limits before the tension builds. Excessive anger undermines a low-key environment much worse than limit setting. Thus, when possible, rules should be established beforehand, or limits set as soon as something begins to brew.

5. Don't be guided by the patient's chronological age. It may seem unreasonable to establish rules and chores for someone in their 20s or 30s. Nevertheless, if patients cannot behave as adults, it is important to supply the structure they need rather than to wait for them to "grow up."

6. *Avoid threats.* Before setting any limit, family members should ask themselves, "Can I follow through on this?" They should never set a limit or consequence if they are not prepared to insist on compliance. If what is being asked of the patient is impossible to enforce, then it should be put aside for the time being. Eventually, the treatment team will attempt to find ways of helping family members deal with these more difficult issues. This policy is important in that it serves to avoid struggles that cannot be won, thus decreasing the likelihood of frustration, anger and eventual burnout.

7. Expect limits to be tested. Establishing reasonable control of a patient's negative behaviors takes a while, especially if the behaviors have existed for a long time. Many families too soon give up a stand they have taken, feeling it has failed because they tried it once and it didn't work. It is important for family members to be able to take a consistent stand and give it some time before deciding it has failed.

8. Admit it when limits are primarily for the needs of other family members. Don't try to convince patients that everything that is said or done in the family, especially in the areas of limits, is exclusively for the patients' own good. Sometimes limits are set on the patient because it is important to consider the needs of others in the family. Patients must learn to live with the fact that they and their needs cannot always be the center of family life.

9. When in doubt about whether or not to set a limit or in need of support in doing so, use the clinical team. The setting of comfortable and effective limits should be as much a

collaborative effort as other aspects of treatment.  The treatment team is available to help in this process.

The topic of limit setting is given a good deal of time since limits are so crucial in providing structure, maintaining a low-key environment and establishing a home atmosphere everyone can tolerate over the long haul.  Particular emphasis is given to setting limits on psychotic, violent, or bizarre behaviors since these are not only very upsetting, but also the least accepted by society.  The only exception to setting limits has to do with paranoid delusions.  It has been our experience that if family members attempt to *directly* confront or limit a paranoid idea, patients tend to become more agitated and may even begin to believe that particular family members are a part of whatever plots they believe exist against them.  In these situations, it is suggested that the family respond to the anxiety beneath the statement rather than the statement itself.  For instance, they might respond to a patient by saying, "That doesn't make sense to me, but I can appreciate how upsetting it must be to you if you believe it", or just, "It sounds as though you're really feeling like it's you against the world.  It must be tough."

**Selectively Ignore**

Not focusing on everything at once is an important guideline in determining what limits to set and what goals to strive for.  Without carefully established priorities, it is extremely difficult to maintain a suitable environment.  No one can change everything at once, and attempting to do so only makes everyone feel overwhelmed and hopeless.  Thus, family members are encouraged to choose one or two issues as their initial focus, with others to be selected after these first issues are managed successfully.  While ignoring negative behaviors is almost always difficult, most families are able and willing to do so if they have established their own priorities, if they can see progress in other areas and can believe that the other issues will be addressed eventually.

It is important, however, that families never be encouraged to ignore violent or psychotic behavior.  Inevitably the question of what to do if violence is threatened arises during a workshop, more frequently stimulated by media representation of mental illness than by personal experience.  In response to questions about violence, families should first be reassured that the incidence of violence among schizophrenic patients is not great.  The majority of schizophrenic patients are, in fact, remarkably unassertive.  However, in the event that particular patients have threatened to be or have been violent, families are given a number of suggestions.  First, because violent acts may be precipitated by delusional thinking or hallucinations, rational discussion rarely is effective in toning things down.  Rather, a good deal of violence can be avoided by establishing and maintaining a structured environment and agreeing in advance on the limit-setting procedures already described.  Patients who are not overwhelmed by stimulation are less likely to react catastrophically.  Families who *have* experienced violence are asked to review the precursors of these past experiences in an attempt to identify precipitants.  Signals of impending violence, as well as events that touch it off, differ in every case, so it is important to be very specific in reviewing these events.

When it is possible to identify precipitating behaviors and events, plans for dealing with it can be made *well in advance of* a crisis.  For example, if the beginning indicators of potential violence are at all predictable, a cooling-off period can be planned in advance and instituted at the first sign of trouble.  As a first resort, the family can ask the patient to go to his or her room.  If this is ineffective, it may be possible to have the family member directly involved go to another part of the house or leave the home for a brief period, just to give time to reestablish some sense

of control.  In order to work, however, this maneuver must be implemented early, before either the patient or family member has become agitated beyond the point of control.  If patients tend to be responsive to clinician influence at such times, families are encouraged to call the clinician (see Chapter 5).

Once a patient actually has lost control, however, very little can be done unless someone in the family is sufficiently larger and stronger to either intimidate or physically restrain the patient.  This is not particularly desirable, and, in most families, it is also not the case.  Therefore, if extreme behaviors cannot be avoided by the techniques discussed, it is important that family members get help as quickly as possible.  If immediate harm seems a possibility, the family is encouraged to call the police.  In smaller communities, it, is sometimes possible to develop a positive and collaborative relationship with police, who come to know these patients over time.  In some communities, however, police avoid contact with mental patients or give these calls a low priority.  In such cases, it may be easier to get police to respond to a request for help if the caller reports "an assault in progress," rather than asking for help with a psychiatric patient.  Finally, in situations where there is the potential of sudden or unprovoked violence (based on past history), family members are asked to take preventive measures such as removing or locking up obvious weapons such as guns and knives.  While this does not offer total protection, since almost anything can become a weapon under the right circumstances, it sometimes decreases the seriousness of spontaneous outbursts.

Suicidal threats or behaviors also cannot be ignored.  Suicide is a genuine risk with these patients; if family members are concerned about this issue, they are encouraged to call the treatment team immediately and to directly supervise patients until arrangements can be made to keep them from accidentally or intentionally hurting themselves.  Although suicidal talk or behavior is frightening, families are given the message that a calm response is likely to have better results than intense reactions that could trigger an impulsive gesture.

**Keep Communication Simple**

While communication training is not seen as appropriate for families dealing with this disorder (if only to avoid the metacommunication of family etiology), specific advice regarding a limited number of communication skills may be given.  The philosophy of providing these suggestions is based on the patient's vulnerability to stimulation and thus on the belief that the content of family interactions matters less than the clarity and simplicity of the messages sent.  Thus, family members are asked to keep their communications simple, with an appropriate amount of detail and a moderate level of specificity.  Rigorous training in effective communication skills is avoided since such a task is thought to be too ambitious, frustrating and anxiety provoking for both family and clinician at this point.  Thus, only three themes relating to communication skills are emphasized.

*1. The ability to acknowledge the statements of others and to accept responsibility for one's own communications.*  In any family, a certain amount of "mind reading" occurs.  That is, family members make the assumption that someone else's thoughts are known even if they are not expressed.  These assumptions can cause particular difficulties and create distorted communications.  Thus, family members and eventually patients, are not only encouraged to speak for themselves, but also to avoid assuming they know what others want or need and to accept and respect what others say even if they don't agree with it.  This communication skill, once learned and practiced, helps to reinforce interpersonal boundaries.

With patients who have difficulty in processing incoming stimuli, pauses and delays in communication responses are common. Family members therefore often develop a habit of stepping in to speak or respond for the patient. Unfortunately, this not only allows patients to become less and less responsible for their own messages, but it also undermines their sense of being separate, autonomous adults. Thus, it is important to help family members learn to wait and to respect the patient's ability to contribute to the conversation.

*2. The ability to keep things at a moderate level of specificity, avoiding excessive detail or too many abstractions.* When families are experiencing times of crisis, it is not appropriate to discuss highly charged and rarely resolved issues. The meaning of life, sexuality, religion, or politics are issues that tend to be highly emotional even when things are going well. Thus, families are encouraged to avoid topics such as these while the patient is ill.

In addition to these upsetting topics, some communication styles can be particularly confusing or misleading for patients. For instance, a family member may have an obsessive style, frequently becoming involved in detailed discussions about even neutral topics. Such a style would not be likely to cause problems in other circumstances, but schizophrenic patients are more likely to find detailed discussions stimulating or confusing. Problems can also occur if family members get involved in inappropriate conversations with patients as they search for a core element of sense in a patient's delusional statement. In general, it is best to encourage family members not to attempt to discern the hidden meanings of bizarre communications. Others in the "real world" will not take the time to translate strange messages, thus patients should be helped to make themselves clearly understood.

In  discussion of communication issues, the staff reinforces the need to limit psychotic communications and to help patients to be more clear, while at the same time offering understanding about the frustration families experience when they must deal with such strange messages on a day-to-day basis. These instructions give the implicit message that patients are capable of communicating more appropriately, given support, structure and time.

*3. The ability to express and emphasize positive messages and supportive comments.* Over the course of the illness, family members are likely to become increasingly sensitized to problems or potential cues that difficulties are developing. This sensitization can lead to a focus on the negative aspects of the patient or the home situation as positive interactions and accomplishments are minimized or ignored. Thus, helping family members to focus on and reward small, positive behaviors is an important goal. Examples of what other families have learned in this regard can help to make this point.

The ability to recognize small steps of progress and to appropriately reinforce (but not over-reinforce) them is an important skill for both family members and professionals to nurture. Recognition of these accomplishments offers hope to the family and courage to patients to continue to expend the energy and commitment necessary to attempt positive steps.

**Support the Patient's Medication Regime**

Because families can facilitate or impede the implementation of a medication program, information about the benefits and risks of drugs is shared early in the workshop, with the goal of increasing the likelihood of the family's support for medication compliance. At that time, the use of medication is explained as one way to decrease the patient's vulnerability to stimulation and relapse. At this point in the workshop, it is emphasized that most patients are ambivalent about taking medication. Some are uncomfortable with the side effects, while others wish to stop medication as soon as they begin feeling better, since they associate taking medicine with being

sick.  Unfortunately, or fortunately, the positive effects of medication can take several weeks or even months to fade after the medication has been discontinued, while the negative side effects diminish more rapidly.  This creates the *appearance* that medication was not why the patient was doing well and in fact was actually causing additional problems.  Without this understanding, it is often very hard for either patients or family members to appreciate the connection between medication and well-being.  For this reason, time must be devoted to help each family member to understand the way these drugs operate (particularly the time delays between initiation or cessation of drugs and the effect of these steps) and the possible benefits of a medication regime.  In this regard, statistics demonstrating the relationship between medication compliance and community tenure are reemphasized.

When patients are resistant to taking medication, the support of family members often helps to improve compliance with the drug program.  Nevertheless, there are negative side effects.  Families must be helped to weigh the possible costs and benefits of a drug program (including the possibility of tardive dyskinesia), so that they can make a truly informed decision about whether or not they wish to support the role of drugs in the patient's treatment program.

### Normalize the Family Routine

During this portion of the workshop, discussion should also focus on the need for family members to normalize their own routine as much as possible in preparation for the demands of a long-term illness.  It is suggested to family members that they not center their lives around the patient.  During an acute illness in any family member, of course, it is necessary for the rest of the family to focus their attentions and their energies on the patient.  However, in any long-term illness (like diabetes, heart disease, or schizophrenia), patients must learn to live with their limitations and life must go on for those around them.  If this does not happen, the impact of illness can become debilitating to families.  In fact, family members may experience so much stress that they will be unable to offer ongoing support to patients and may even incur additional problems of their own.  Good parenting, as one of our colleagues says, begins by taking care of ourselves as parents.  This is also true in marriages: Being a good spouse begins by taking care of your own personal needs.  In any family then, enlightened concern for self is a core part of each individual member's ability to care about others.  Furthermore, if other family members begin to be negatively affected by the patient's illness, patients can come to feel guilty and responsible, thereby experiencing their family as a burden, not a support.

The importance of maintaining contacts outside the immediate family is stressed for three reasons.  First, social contacts can be useful as temporary distractions from experiencing the pain of the illness and in providing general support and recreation to occasionally relieve the tensions of family members.  Second, having social contacts can make it easier to divert the concentration of too much energy and attention on the patient.  Third, social contacts can help family members in times of crisis by providing instrumental and practical support.  Unfortunately, the effort to see people outside the immediate family requires motivation and time.  Over time, coping with this illness tends to decrease the motivation necessary to maintain these contacts.  Giving encouragement and providing these explanations may help to motivate family members to reestablish some of these  links.

It is difficult for many family members, however, to concentrate on their own needs and their own social network.  Many consider their own needs as minimally important when another is in crisis.  Therefore, it is essential to emphasize that family members must consider their own needs for survival *so that they will be able to help the patient.*  The point is made that if they

deplete themselves, in the long run they will be less able to help one another or the patient.  For instance, the need to attend to other children in the family is emphasized.  The disproportionate amount of attention needed by the patient in a chronic illness often occurs at the expense of the needs of other children.  Siblings of patients frequently complain that their parents side with the patient no matter how unreasonable he or she is, while they always are expected to understand and avoid conflict.

In general then, while ongoing familial, social and work activities are often impossible to maintain during the acute phase of the illness, family members are encouraged to see the need for an expanded repertoire of management techniques for the "long haul." These management techniques must include a life style that does not entirely center on the patient and his or her needs.  In this regard, the need for each family member to find time away from the tension within the family is stressed.

It is also common for patients to have become socially isolated and lack any activities or support systems outside the immediate family, especially those who have been ill for a long period of time.  Family members often point out that it is the absence of friends that forces the patient to spend an inordinate amount of time at home, thus increasing the likelihood of family conflict.  It certainly is possible that patients with fewer or less available social supports outside the immediate family are more vulnerable to family intensity and family stress since they are more involved in and dependent on their families to meet their multiple needs.

During the latter part of this section of the workshop, the issue of the vocational and social potential of patients is discussed.  Although no promises are made, the success of the program in helping some patients to develop vocational skills and even to attain employment is shared.  It is made clear, however, that these goals only can be achieved after the patient's illness has been controlled and only then after a good deal of time and hard work.

**Learn to Recognize Signals for Help**

The family is asked to develop an awareness of those behaviors that tend to signal the experience of increased stress or difficulty for their ill family member.  Over time, when possible, the family and the patient together will be helped to identify which behaviors require the family's help or support and which behaviors simply signal the patient's need for increased psychological space.  The family is told that the staff will help both patient and family to become as aware as possible of any early indications of decompensation and will help them to mobilize their resources to modify the environment and/or control symptoms.  To decrease family anxiety and over-responsiveness, emphasis is placed on the fact that some signals, such as withdrawal, are not always negative, but at times are the patient's adaptive response to the threat of being overwhelmed.  A review of the significance and meaning of possible signals helps family members to avoid the tendency to respond to every symptom as if it meant a patient was getting sick again, or conversely, to "keep the peace" at all costs by ignoring potentially vital messages.

Although these "signals" differ from patient to patient and must be further defined during future family sessions, the message given to family members is that there may be a number of warning signs that could allow early intervention and avoiding a major psychotic episode.  This, in itself, can decrease anxiety in family members by giving them a better sense of having some control of the situation.  It should be noted, of course, that some patients do not have definable early warning signs and that the symptoms of the illness in such patients can arise suddenly.  Whether or not signals exist, family members are taught to initiate fast and appropriate contact

with professionals as soon as trouble occurs in an attempt to avert a full-blown psychotic episode.

Family members are specifically advised to use professionals when they have questions or concerns. A lifeline must be established because the progress of the patient is likely to be very slow. In our particular program, we have found it most beneficial to limit actual family sessions to once every 2 to 3 weeks except during times of crisis. Therefore, it is important that family members be assured that they can reach their clinicians between sessions should they be uncertain about the appropriate response to a given situation. Some families require encouragement regarding the use of this resource, since they have learned not to alienate clinicians by imposing on their time. Thus, workshop time is used to stress the availability of the family clinician and other members of the treatment team for emergency phone and in-person contacts, as well as the clinician's desire to continue to play the role of ombudsman for the family in relation to other therapeutic and rehabilitation systems, services and personnel.

## Wrapping-up the Workshop

Finally, the importance of every family member's constant input into the patient's treatment is stressed repeatedly. It is predicted that some stages of treatment will seem slow and painful, causing both patients and family members occasionally to wish to discontinue treatment. The role of preventive and maintenance work in avoiding future episodes and crises is stressed, as is the importance of an ongoing commitment.

The final section of the workshop is left open to allow family members to bring up questions that may not have been covered during the formal presentations. Most family members use this time to ask about ways of handling specific situations that have troubled them for some time. Others again raise questions about possible causes or treatments after they have had time to think about the morning presentation, raising thoughts and fears they have not previously expressed. All questions are dealt with as honestly and clearly as possible. Finally, at the end of the day, families are asked to evaluate the workshop and make suggestions which are incorporated for the benefit of future workshops, making this a truly collaborative program over time.