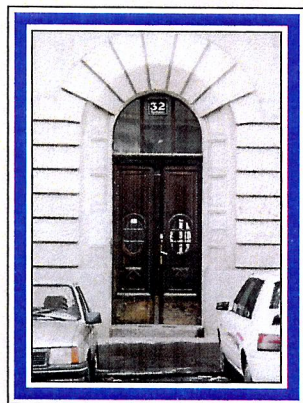

PATIENT/FAMILY EMPOWERMENT

VIENNA'S SCHOOL FOR LIVING



WITH SCHIZOPHRENIA

If you regard patients and their families as partners in trying to cope with schizophrenia—not as dependent clients to whom only professionals can give advice—you tap an enormous amount of energy and creativity from a large body of experience.'

Heinz Katschnig

Unnoticed here on a street called Hardtgasse is a large walk-up flat named "Pension Bettina." In the schizophrenia community, it lies somewhere between two ends of a spectrum—with professionals who treat with drugs and psychotherapy on one end, and on the other end, self-help, which often leaves people frustrated and dysphoric—sometimes anti-professional—as they struggle with everyday life. To passers-by, it's just another large flat, while inside, 10 "revolving-door" schizophrenia patients, most dependent on their often contentious families, are turning into autonomous members of society—relatively independent of their families.

For a decade, this "School for Living (with Schizophrenia)" has involved professionals and families in year-and-a-half programs that have reduced hospitalizations by more than 80% and enabled 80% of its graduates to live away from their families (vs. 14% who had lived outside the home before the program).

Making the patient independent of family—and the family independent of the professional system—comprise the ultimate goal of the program, according to its founder, Heinz Katschnig, MD, professor and chairman of the Department of Psychiatry at the University of Vienna.

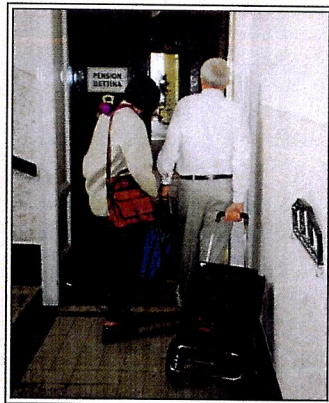
"Schizophrenia usually strikes when young people are just becoming adults—a time when it is a natural process for them to be weaned from the family and become independent," he told *Living with Schizophrenia*.

'Revolving Door' Residents

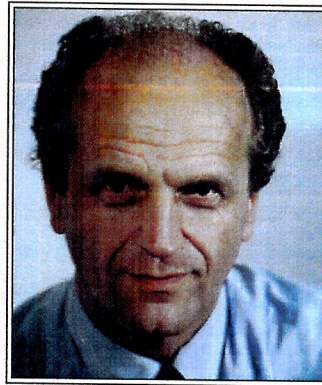
Those accepted for the school are truly "revolving door" schizophrenia patients who have been in and out of hospitals for a couple of years and are still living with their families, according to Katschnig. "They get home from the hospital, the family can't cope, tensions arise, then crises, problems, conflict, relapse, back to the hospital, where acute treatment with antipsychotic drugs helps. So they get out of the hospital very quickly and back into the

family, where no one can cope, and the revolving door keeps turning."

So the school focuses on the family. "They all have to learn how to live with the disease," Katschnig explained.



'PURE DISEASE!—Free from family conflicts, Father A returns from shopping with daughter of Mother B (above). JUST ANOTHER FLAT—But inside, 10 "revolving door" schizophrenia patients are turning toward autonomy (below).



"It's not primarily intended to do away with the disease—although this might be an effect—but we would like to provide the possibility of learning how to live with schizophrenia."

The 10 patients move into the flat at the same time and live there for 17 months—Monday through Friday. Weekends, they go home to the family and Pension Bettina is closed. "This is not unlike some regular school systems," Katschnig noted, "where being away from the family during the week can be beneficial for normal children—as well as for their parents!"

Professionals provide some formal treatment activities, such as family therapy and group sessions. But mainly it's a place of learning, Katschnig stressed. "The distinction between treatment and learning is a blurred one: The best psychotherapy is where you provide the patient the opportunity to learn on his or her own, and not just to be taught. In Pension Bettina, it's learning by doing."

During the week, a member

Heinz Katschnig, MD, believes the family is the schizophrenic patient's best asset. He became aware of the power of self-help advocacy groups in 1974, when he worked with John Wing, MD, at the Institute of Psychiatry in London. The National Schizophrenia Fellowship (see *Living with Schizophrenia*, May/June 1996) was born in England at that time, with Wing's help. When Katschnig returned to Austria, "the first thing I did was tell them to form an association like that. And they did—in '77—two years before the National Alliance for the Mentally Ill (NAMI) was founded in the United States." He is the author of *Die Andere Seite der Schizophrenie: Patienten zu Hause (The Other Side of Schizophrenia: Patients at Home)*, Fourth Edition, 1997, available only in German from Psychologie Verlags Union, Germany, Tel: +49 6201 60070; Fax: +49 6201 17464; Post Box 100154, D-69441 Weinheim, Germany, at 78DM. Contact Professor Katschnig with questions or for related materials in English: Fax: +43 1 40 400 3605; e-mail SKATSHE1@AKH-WIEN.AC.AT.

of each family comes into the flat for a few hours and spends some time with patients other than his or her own son or daughter, according to Katschnig. "For example, on Tuesday afternoon, Mother B comes in, and goes, say, shopping with son of Mother A and daughter of Father C. So the parent gets the experience of the *disease* without all the biographical conflicts—the many tensions usually present in these families. Not just the positive symptoms, which they recognize, but also the negative symptoms, such as withdrawal.

'Is He Bad? Or Mad?'

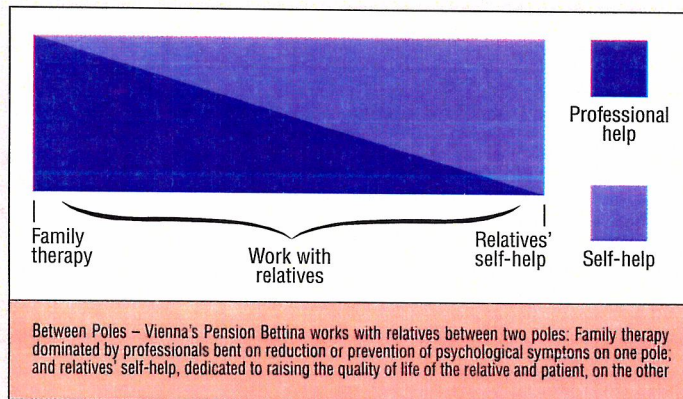
"It's often difficult for parents to decide, 'Is he bad? Or is he mad? Shall I treat him as bad and get him out of bed? Or shall I decide he's sick and leave him in bed?' We often find an atmosphere of conflict in these families. Perhaps 40% of them display high expressed emotion—criticism, over-involvement. Once in the program, parents can have real contact with patients of other parents—without (turn to page 8)

these personal conflicts with them. They just have the disease before them—pure disease—so they can learn, not only theoretically by psychoeducation, but by doing. By interacting with someone who hallucinates, is deluded or withdrawn, but who is not their family member.”

Katschnig said it's also the same process, the other way around: “The patient can communicate with the father or mother—who's not *his* father or mother—and interact with the *role* of the father without the conflicts which are often present with the *real* parent.”

A parent is also obliged to do night duty at the flat once a month, which means the mother or father is there alone for the night with 10 schizophrenic residents (“We don't call them patients,” Katschnig said). “They can keep me if there's a serious problem,” he said, “but it rarely happens, since most of the problems arising can be solved without professional help. The residents always tell the duty mother or father when they're going out. After all, it's not a hospital or an institution, it's a place to live—and learn to live.”

Any problems encountered by families during weekends are aired at regular Tuesday evening meetings of the relatives. While one mother complains about her son's lying around all weekend in



bed and not helping with household chores, another mother will say, “That's not true! When I come into Pension Bettina Wednesday and do the dishes, he's so helpful.”

“They're talking about the very same kid,” Katschnig said. “So these parents get to know that environment matters, that attitudes matter, and they start to look at their own behavior in light of what may be helpful for the patient.”

The last few months of the program are spent planning for what happens to residents when they leave. Where will he live? What will she do during the day? Where will they go? To a day hospital? To a workshop? Maybe even employment, which some have managed.

Four-Star Manager

“One of our alumni has become a reception manager of a big hotel,” Katschnig boasted. “He started at a one-

star hotel and now he's at a four-star!” Sadly, there are bad examples, Katschnig recalled, as he described one fellow whom he has seen wandering around the streets of Vienna. His father, his only caregiver, had died, “so he had no one left to care and somehow the hope has drifted away.”

When the program comes to an end after 17 months, Katschnig said many of these families would like to continue. “There's so much burn-out with schizophrenia, and when you take the relatives and patients as people who can contribute and bring in their ideas, it's extremely positive and ‘anti-burnout.’ Some of them even say, ‘It's fun. I've never laughed so much!’”

Some groups of families stay together after the program, pool their resources, hire an apartment somewhere in town, and groups of three or four of their sons and

daughters with schizophrenia live there. Parents visit but don't stay. “It's ‘intimacy at a distance.’ And it's all organized by the parents—not by professionals,” Katschnig beamed. They might come back to ask advice, but basically it's pure self-help—they're now providing services for themselves.

By now the School for Living has spawned six such self-run group homes in Vienna—an effect totally unexpected when the program began.

“But I don't paint it all in rose,” said the Viennese professor. “Some families like each other; some don't. That's the strength of it: We are not a psychiatric hospital, we are a normal place where you have conflict, the problems of everyday living, and you can learn to live with these problems.”

“Relatives and patients like to be taken seriously, to be taken as persons in their own right, not just as receivers of advice. They know—better than we professionals—what the problems of living are. And they like to be taken on as a player in the management of the disease. That's empowerment.” ■

SUMMARY REVIEW

1. Why does a parent spend time with residents other than his or her own son or daughter?
2. What do many parents do when the school is finished?
3. How long (in months) is a School for Living session?