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MY AUNT AND ME: IMPLICATIONS FOR GERIATRIC MENTAL HEALTH POLICY

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The theme of this issue of *Mental Health News*—family mental health—got me thinking about struggles with mental illness in my own family and particularly about my aunt and me. We had quite a time of it after she became seriously mentally ill in her early 70's, and I think what we went through a decade ago unfortunately illustrates problems meeting the needs of older adults with mental disorders and their families today.

My aunt lived a life she enjoyed until she was about 70. She worked until 62; she never married, but she had friends with whom she went to shows, concerts, and restaurants. They sometimes stayed in and played Scrabble or canasta. She played the piano well enough to please herself. She liked a whiskey from time to time. At 70 her mother—with whom she had lived most of her life—died. Her life began to unravel. She started to depend on me and a cousin to take care of day-to-day problems. After a few years both of us moved away. She had her first psychotic break—immobilizing fear. She recovered quickly. But over time the psychotic episodes became more frequent. I went with her on many ambulance rides to crowded, noisy emergency rooms where she would wait for hours. Her best friend died. She stopped inviting other friends over. She became more depressed—a pity case to her friends, not a person to be with for fun. She tried a roommate, got paranoid about her, and threw her out. Over time she stopped going out except to the doctor. We arranged for health aides—lovely people but completely at a loss when she became psychotic. I visited regularly but not often. My cousin pulled back. He'd burned out taking care of his mother. I handled the crises when she refused to eat or drink or became psychotic. This dragged on for years. I arranged for psychotherapy at home. Once a week didn't make a dent in her isolation, and the therapist knew nothing of cognitive-behavior therapy, which would have focused on getting her to go out of her apartment, to do something, to reclaim her life. I arranged for a friendly visitor from the synagogue. Once a month didn't make a dent. And it was charity, not a real human relationship. I should have spent more time with her, but I worked 12 hours a day, had a family, and lived more than an hour away. Over time I burned out. None of the help givers involved with her noticed. No one suggested that I should get help. Eventually I agreed with her doctor and the social workers at the hospital that she had to be in a nursing home. She lived five more years in a state of indignity and with few people to talk with except the people paid to care for her. They were very kind, like warm, nurturing parents with their child. She died in their care while I was out of town visiting colleges with my daughter. They told me proudly that they had done all they could to revive her. I thanked them and didn't mention the Do Not Resuscitate Order written in huge letters on the front page of her chart.

I tell this story because I think it illustrates some of the major facts about older people living with severe mental illness.

- (1) Many have had good lives. I think those of us who try to help too often forget that the sad, old person in front of us once led a good life—and might have the potential to lead it again.
- (2) Losses of family, friends, and work can have a devastating impact on people. Life as one knows it is gone. Shaping a new life is incredibly difficult for some people.
- (3) Mental illness is a major contributor to social isolation, and isolation and inactivity fuel mental illness. People become depressed, lose interest in the things that used to give their lives meaning and pleasure. They lose hope. They become anxious, convinced that no one wants to be with them, fearful of the streets, of crowded places. People become suspicious and distrustful; some develop full-blown paranoia.
- (4) It is difficult for people to get treatment. Few home-based services are available. Transportation is often a problem. Co-pays can be more than a person can afford. Few bilingual professionals are available for people who are not comfortable speaking in English. American professionals are frequently not skilled at engaging people from ethnic and racial minorities.
- (5) Because I knew my way around the system, access was not a major problem for my aunt, but poor quality of treatment was. She might have benefited from one of the forms of evidence-based treatment for depression, but the mobile mental health service I found for her sent a well-meaning person with out-of-date clinical skills. In addition, my aunt relied more on her primary care physician, whom she had known for years, than on the psychiatrist who would visit from time to time, but was a stranger. I tried to pass information back and forth between them, but as far as I know, they never talked with each other.
- (6) It is also striking that the home health aides who lived with my aunt much of the time did not have a glimmer how to deal with her psychotic episodes. These women were among the most caring people I have ever met in my life, but they were not prepared. They didn't even know when they had to call for help, couldn't recognize the psychotic episode as it began.
- (7) For my aunt, an alternative level of housing—something between staying in isolation at home and being placed with people with whom she could not communicate in a nursing home—might have helped. We need housing alternatives that can help people who have become socially isolated to develop social connections that are meaningful to them.
- (8) For my aunt being treated with the dignity owed a mature person rather than with a patronizing semblance of respect could have been very helpful. Once, for example, I visited her at the nursing home shortly after Halloween. A very young rehabilitation specialist proudly showed me a photo of my aunt—who looked very glum—dressed as a pumpkin. A nice idea for a child. For a depressed woman who had once been a competent adult? I don't think so.

(9) I think that my aunt's case also illustrates that family caregivers need support. I was viewed as intrusive by the mental health professionals involved with my aunt because I had strong views about how she should be treated and insisted on being involved in treatment decisions. It never occurred to either the social worker or the psychiatrist whose opinions I questioned that I was reaching a point of personal desperation, that I might be depressed myself, that I needed help. I was just a pain in the behind who didn't visit enough. I am entirely clear in retrospect that ultimately my aunt went to a nursing home at least as much because I burned out as because of her physical and mental infirmities.

(10) One last thought—I had enough money to arrange whatever my aunt needed. Still it wasn't good enough. I hate to think of what befalls people without money. Medicare and Medicaid do pay for some services, but there are huge problems financing appropriate services.

Clearly, this is not just a story about my aunt and me. The issues that defeated us are among the major issues that most older adults who are disabled by severe mental illness and their families routinely encounter. And it is clear—isn't it—that these are cross-system issues, straddling the mental health, health and aging systems. And isn't it clear as well that these are family issues as well as issues for individuals? Family members provide 80% of the care for people with disabilities. They do the bulk of the job, but they need—and deserve—help to do it.

We have made some progress in New York State towards getting the service systems to work together. But there is so much more to do and so little time to do it before the elder boom hits in force. We really have to move faster.

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