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PARANOIA IS A BARRIER TO AGING IN THE COMMUNITY

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Mrs. C lived alone in the apartment in which she and her husband had raised their children. She had always been a bit distrustful. The butcher put his thumb on the scale. A teacher had it in for a daughter who wasn't doing well in school. But after her husband died, she became increasingly suspicious of everyone. She double checked the pills she got from the pharmacist. She refused to hire a new cleaning woman when the one she had had for years retired. Her daughter visited. "You bitch," she screamed, "You stole my diamond ring." The daughter was tolerant to a point but eventually insisted that her mother have help in the home, in part so she didn't have to face her mother's abuse every day. "You say my daughter sent you," the mother yelled through the door when the worker arrived. "Does she want you to kill me?" She did not open the door. Eventually, Mrs. C had to go to the hospital for treatment of pneumonia. Her daughter and the social worker agreed that, given her growing physical disabilities and her refusal of help at home, she should be in a nursing home. Mrs. C did not want to go, but she didn't have the strength to fight. She never went home again.

None of us wants to spend the last days of our lives in an institution. Sadly, many of us do. We don't say this to criticize nursing homes, all of which provide a kind of care that can be very difficult to provide outside an institutional setting and some of which provide very good care that makes life better for their residents. We say that ending one's life in a nursing home is sad simply because it is not what we want for ourselves.

There are many reasons why so many of us do not get to die at home in the company of the people we love. Lack of family or close friends, very severe illness, inability to take basic care of ourselves, lack of wealth—these are all reasons why we may not be able to live out our days as we want.

But—as we have been pointing out for some years now—mental and behavioral problems are among the major reasons for institutionalization. We have learned this from numerous conversations with people who work hard to help older, disabled adults to remain in their homes. Home health aides, personal care assistants, case managers, adult protective service workers, geriatric care managers, and family caregivers have all told us that the people they find most difficult to help to stay in their homes are those with mental and behavioral problems. They also tell us that of all of these, perhaps the most difficult problem they contend with is paranoia.

We want to be clear that they, and we, are not using "paranoia" as a technical diagnostic term. We are using it with its ordinary English meaning—suspiciousness, distrust, the sense that someone is out to get you. We are referring to a range of behaviors from people who are always reading between the lines and looking for ulterior motives on the one hand to people who believe that the CIA is transmitting signals to steal their thoughts and to implant ideas in their minds and

who, therefore, cover their heads with aluminum foil on the other. It is a range, that is, from a personality trait to full-blown psychosis.

Paranoia can be a very serious problem even among older adults who are able to manage well enough to survive without much help. They may be able to do their own shopping and cooking, to keep their homes reasonably clean, to get to doctors when they need to see them. But often they become increasingly socially isolated because of their suspiciousness. Some become convinced that their home is broken into when they are out, that family members are stealing from them or, at the extreme, trying to poison them. Family and friends become increasingly scarce under these circumstances. Sometimes paranoid people call the police or aging services programs for protection, but they reject help that is offered because what they are offered is not protection but care and support. They would have to acknowledge their irrationality if they accepted the help offered. Obviously, they become a great challenge to service programs, police, landlords, and others.

For older adults who are paranoid and lack the basic skills they need to survive independently such as the ability to manage their finances, to get out for food and other necessities, to prepare meals, to keep themselves and their homes passably clean, and so forth—for these people, distrust of those who offer help is a life-threatening problem.

What can be done to help people who are paranoid to remain in the homes they want to live in? There is, we are sorry to say, no easy answer. However, there are some steps that could be taken that would make a very big difference.

1. Specialization and training for people who try to provide help in the home: Rejection of help generally is regarded as a problem in the person who rejects help, as of course it is to some extent. But the truth is that some people are better than others at engaging people who are paranoid. People who take accusations, especially abusive accusations, personally are generally not good with people who are paranoid. People who get angry quickly are not so good with people who are paranoid. People who are impatient to get their jobs done, people who want things done the "right" way, people who demand respect—these are people who will have a hard time working with those who are paranoid. Those who understand the emotional root of distrust and abusiveness, who do not take it personally, who have high tolerance for socially inappropriate behavior, whose sense of self-respect comes from within—such people often do better at engaging people who are paranoid.

   This is why we strongly recommend that home care organizations, adult protective services, and case management programs for older adults should develop cadres of specialists to go into the homes of the people who have significant mental and behavioral problems and that special training should be provided regarding mental and behavioral challenges. It's good to find staff who are naturals at engaging people who are paranoid. But training to understand emotions, in the value of patience, in the importance of respect, and in techniques of helping someone quiet down and accept help can make a very big difference. It should be required for all who work in the home.

2. Access to mental health and health professionals with expertise about older adults with mental disorders: Unfortunately, most mental health and health professionals do not have nearly enough knowledge about older adults or about practices that work (aka "evidence-based practices"). This is a very serious problem, which we have every reason to believe will get worse as the population of older adults explodes and the number of geriatric psychiatrists and other mental health professionals as well as the number of gerontologists declines. What is needed is a workforce development initiative that includes appropriate education in professional schools, training for those already in the workforce, a vast effort to recruit new geriatric professionals, and the development of ways to incorporate retired professionals (with updated training) into the service system.

3. Research: More information about paranoia (in the ordinary sense of the word) is also critical. We have been distressed to discover that paranoia receives little attention in the geriatric mental health research community. By far most research focuses on depression, which is very important, of course, and should continue to be supported. But research, we believe, especially research that is funded by the government, should be closely connected with public policy goals. Long-term care reform—largely providing home-based care instead of institutional care—is presumably one of the primary components of health care reform in general—as a matter of both cost containment and basic humanity. It is clear that paranoia is a major barrier to aging where we choose in the community, and research should be organized to help overcome this barrier.

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