About a year ago, a colleague told me a heart-wrenching story. Her son, while in graduate school, began demonstrating what was first thought to be an anxiety disorder. As you might guess, the anxiety was the first symptom of what developed into schizophrenia. The diagnosis would be enough of a burden for most, but the treatment received by the family was the most distressing. Her son was given written information that his family caused the illness. How could this still be happening in the 21st century?

My colleague asked me why those of us in mental health care are so against families. I tried to explain that we were family advocates; our behavior, however, told her another story. Her son had a family who was willing to help in any way possible, yet they were blocked from all communication and healthcare planning. He was referred to a group home. Interestingly enough, he ended up living with his parents. The decision to involve his parents was not made based on best solutions but on the fact that he had a dog. So, the ownership of a dog he was not willing to give up became the deciding factor, not open communication and planning with his family.

Those who have followed JCAPN over the years know a number of editorials have promoted family-centered care. Could it be that we still have a long way to go in the collaboration with families to provide holistic care? My colleague’s experience brought to mind many other stories of families we all have heard. It is as if we often hold families away from their family members when they need them the most. When a child—no matter the age—is hospitalized for mental illness, why do we view family involvement different than if the child had a traumatic injury or a problem such as a fractured leg?

Anyone who knows the science of the brain and mental illness knows that while there is a genetic link to many mental disorders, we have evidence that the family does not cause the illness. How could it be that we still blame the family and restrict their visiting? We all could give examples of difficult families, but so can nurses who work in cardiac units or orthopedics. Open visiting has been the norm for quite sometime in all inpatient settings except psychiatric. Is it the stigma associated with mental illness that has colored our view of the healing power of families?

There are many laws and regulations that protect privacy, but have we in mental health turned those rules into a wall we can hide behind? I have long been appalled when I hear mothers complain they cannot even talk on the phone to their hospitalized adolescent or adult child because of privacy issues. I know whose privacy is being protected and, in my mind, it is not the son or daughter. Then there is the “age thing”: When a child becomes an adult based on the number of years he has lived instead of ability to care for himself, we have been blinded again. Most psychiatric programs have a goal to promote independence of their clients. That is a goal I have worked toward my entire professional career, but with the understanding that the degree of independence will vary with the disability and desires of the individual and his/her family.

I recently heard a story of an adult who was in a group home and doing very well. Some well-meaning, I am sure, healthcare provider decided this woman with no cooking skills and no transportation should be more independent. So, over the protest of her parents, this woman was moved from a group home with 24-hour supervision and life skill support to an independent apartment, where she was isolated with no meals. Her mother had to get a court order to have her placed back in the group home. This may seem to be a drastic example, but it is not an uncommon theme: independence at all cost. What happened to asking the individual and family what they want and making an assessment of the person’s level of functioning? What happened to different approaches for different situations?

Do we find it strange for a child with a fractured leg to be cared for by his family? Do we see this as strange if the child is an adult? Why is it that we often do not see the same support as helpful if the child has a mental illness?
What is it about our clinical area that separates individuals—even young children—from their families? The nature of a chronic mental illness is that there are peaks and valleys. Families are the consistent resource for these folks, and we need to build them into the treatment plan. Certainly we have made some strides in collaboration with families. We have evidence that wrap-around programs and family involvement lead to better patient outcomes, but too few systems have changed. Too few systems view the family and all of its resources as a partner in the healthcare treatment.

In another example, a woman with an anxiety disorder needed to be off her medication during both her pregnancies. Following uneventful pregnancies and the delivery of her babies, she went into severe postpartum depression before she was placed back on her medication. Her mother and husband were turned away repeatedly by the healthcare system when they made frantic attempts to get her immediate assistance. They were told the woman had to seek the assistance on her own: independence again. Why was the mother of a grown woman calling for mental health assistance for her, the mother was asked? Well, anyone who remembers how one feels just after delivering a baby, let alone severe depression, should have some understanding of why the mother and husband were seeking assistance for her. Where is the continuum of care and where is the family involvement? Where is the common sense?

These examples are not unusual incidents. I know from personal experience. We have a 30-year-old son who lives at home with us. He is mentally retarded and attends a day program with a wide continuum of available services. This situation meets his needs very well at this point. We feel fortunate to have such a wonderful resource. He has severe communication difficulties and functions at a low developmental level. I explain this very personal example because I am weary of those well-meaning professionals who try to push him into another more independent living arrangement. We are well-informed parents who have spent his lifetime advocating for the services he needs. Where is the assessment of the best living situation for our son and his family? It seems to me that any assessment of needs should be based on developmental functioning and not chronological age. There is no room for assumptions and personal biases when working with families such as ours. Our son has parents and a sister who need to be involved in all planning of his future. Why is this a foreign idea? Why are we labeled as unrealistic or difficult?

My wish for the future is that we live up to our rhetoric and include families as partners in care. I imagine that every treatment facility’s mission statement includes partnering with families. I hope we would assess each individual situation and work toward the best solution, instead of basing our recommendations on false assumptions and personal biases. Who are we kidding? In today’s healthcare system, families may be the only constant resource available to many in need of mental health services. We should be embracing the resource of the family and collaborating with them as equal partners in meeting the needs of that family and all of its members. We need to prepare them for the future and the caretaking that they may need to provide.

I talk with my colleague about her son from time to time to offer support. Her dealings with the mental healthcare system have not improved much, but she has been able to match medication and living arrangements with her son’s needs. I can only listen and offer my condolences for the battles she had to fight. I told her I would tell her story and ask for your assistance in changing the mental healthcare environment. I hope you will not let her and others like her and me down. Partner with families in all the care you deliver.

Linda Finke, PhD, RN
Associate Editor
lindaf@stti.iupui.edu