

In Psychiatric Illness, Families Must Be Our First Responders

By Lloyd Sederer

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No mental health system will ever be able to identify serious behavioral problems as early as family.



Memorial tree in Newtown, Connecticut [CraigRuttle/AP]

Time is beginning to soften the shock of the Newtown massacre. As their community returns to the routines and rhythms of everyday life, much debate -- some reasoned and some polemical -- still rages around gun control.

There is no question that something must be done, but the answer is not to become an armed state.

I am a psychiatrist, a physician, and offer my ideas as a mental health professional. I believe there is one immediate action (among others that can be taken) that can reduce the risk of similar searing pain being rained upon families and communities in the future. We must employ an early warning system -- one that is already in place. I am referring to the families of people with mental illness.

These are families who see a loved one begin to become different from the child or spouse or sibling or parent that they knew: To isolate themselves from family and friends; to show persistent changes in sleep, eating and hygiene; to say or do odd

things that suggest their thinking is off, maybe hearing or seeing things others are not; to be moody or irritable or intolerant of the slightest of questions or statements; or abusing alcohol and drugs. Families see these changes first, notice them subtly, and it is they who typically call out for help particularly to mental health services that is seldom then provided them.

The plight of families that recognize a member is becoming mentally ill, and at risk to harm themselves or someone else, can be truly agonizing. Their loved one often will not accede to their entreaties to go for evaluation or treatment. Sometimes this is because the illness is so serious that it interferes with the person's ability to recognize they are ill -- often denying any difficulty and blaming others for their fears or anger. Sometimes it is hopelessness that erodes a person's capacity to take action on their own behalf, amplified by feeling unworthy and not wanting to be a burden; guilt and shame add to their psychic state; or they have had bad experiences with mental health care, or fear it. These are powerful forces to contend with, but families need help to manage them successfully.

Even when these families do reach out to professionals (medical, mental health, police, etc.), their calls are often rebuffed. They are told that professionals cannot speak with them because of HIPAA (federal privacy) regulations, or that no action can be taken to hospitalize a person with a mental illness unless they demonstrate "imminent" dangerousness, which is to say at that very moment (a moment in which many an ill person will manage to put on a good face for the doctor and promise to go to an outpatient appointment - -though they have steadfastly refused for months). This has been termed "[dying with your rights on.](#)"

Family alarm calls often occur months before what become difficult to reverse setbacks in school or work accumulate. Their calls come at a time when early intervention could prevent crisis and the need for involuntary treatment or the assistance of police. Their calls come when there is greater likelihood of success and greater opportunity to avert disability and potential catastrophe. I meet these families all the time. I see their demoralization and outrage about how handcuffed they feel in trying to get help for their loved one.

No mental health system will ever be able to identify serious behavioral problems as early as a family. [We have tried.](#) But "random" acts of violence [are not so random.](#) In addition to privacy and civil rights requirements that limit how families can assist their loved ones, families have too often been led to doubt what they see, to attribute problems to phases in a life (like adolescence or being older) or to external events (like loss or disgrace). At other times, these families know very little about mental illness, or addictions, television notwithstanding -- or consider these to be problems others have, not them. Or they feel guilty, or ashamed, or just do not know where to turn.

These are real and remediable problems.

While I think mental health professionals and legal authorities could say many smart things about what can be done to correct the ways we miss opportunities to do more (and earlier), I sincerely, and with all due respect, suggest they (we) are not the ones to tell us all what needs to be done. It is families who are the true experts, the people who have learned all too well from experience what they need to help their loved one get help. It would also be a good idea to invite the opinions of those people with mental illness, who are well into their recovery, about how we can do better in engaging people with serious mental illness in the treatments that will keep others from losing ground, or from acts of aggression that blight their lives and ours.

There is a great and inescapable tension that exists between those advocates and experts who represent patient civil rights and those who call for more involuntary control of people with mental illnesses. But the pendulum has swung hugely since the 1960s, when commitment to a mental hospital was far too readily exercised (and little treatment offered once admitted). The former group is passionate about privacy and self-determination and deploys lawyers to defend patient rights for freedom and choice in psychiatric units throughout this country. The latter group, no less passionate, call for increasing involuntary hospitalization for people with serious mental illness, including outpatient commitment and requiring that patients take medications they refuse. Neither group has it all right nor is all wrong about what may be the best course for our country (and for mental health services and the law) to take. After Newtown, however, we are pressed to ask, and answer, is it our children or our rules?

So, as the tide of ideas carries on in the wake of Newtown, my suggestion is that we be sure to ask those who are first to notice, most determined to help, and whose ongoing love and support will be essential to whatever the professionals (like me) have to offer: the families who have member with a serious mental illness. Some have called this approach user driven design.

More money for treatment, while always welcome, is imprecise, if unlikely. We already spend a great deal of money poorly for mental health care. Let's start by formally inviting families with members who have a serious mental illness to the "invitation-only" policy and planning meetings that dedicated public officials will call to see how future mental health disasters can be averted -- including those that take the lives of one person at a time, not just the ones that wind up the focus of national attention.

I am sure that families, represented by exceptional organizations like the National Alliance on Mental Illness and other established family advocacy groups, can help medical, mental health, social service, and legal and law enforcement professionals more responsively change many of the encrusted and ineffective practices that exist today. Let's involve these families in engineering the most effective systems for involving their early warnings, using their leverage with their loved ones, and capitalizing on their ongoing support of the treatments that, if delivered early and consistently, will reduce the risks for tragic events.