

## The Honorable Tim Murphy

1. **You have said that the mental health system, as it is currently constituted, seems designed to handicap families in their efforts to obtain the best treatment and long-term outcomes for their loved ones. In his book, *Out of the Shadows*, E. Fuller Torrey discusses the different ways of ensuring accountability for and measuring performance of mental health services. He gives the example of the Riverside County Department of Mental Health in California that employs a full-time Family Advocate whose job is to solicit information from families about problems in the county mental health treatment system.**
  - a. **Could a Family Advocate, or someone like it, have been helpful to you while your son was committed to Riverview? Why or why not?**

I have read Dr. E. Fuller Torrey's comments that any organization funded by the government or by the pharmaceutical industry will find it difficult to criticize either. It is an excellent point that I have to agree with.

Rather than set up separate family advocacy systems, a more immediate and effective remedy is to rewrite HIPAA and PAIMI to remove barriers to family participation in the care of adult patients. In my opinion, three changes should be made to these statutes and regulations.

FIRST, as Peter Mills of Maine has suggested, "Mental health workers should have greater latitude in communicating with caregivers who are providing daily care for someone outside an institution. A limited sacrifice in privacy is the price that a patient should reasonably pay to receive effective care in the least restrictive setting."

I agree and respectfully suggest the following provisions (courtesy of Peter Mills) be added to HIPAA:

"Caregiver" is a person including a family member who shares responsibility for the day-to-day care or protection of an individual with mental illness.

If an individual with mental illness withholds consent for disclosure because of compromised insight into the nature and extent of the illness, a provider may, without the consent of the individual, disclose to caregivers such protected health information as the provider reasonably believes is necessary either for the health, safety, or welfare of the individual or for the safety of others.

A provider is not liable for failing to make a disclosure in those instances where a threat is not serious and imminent and the disclosure would, in the provider's good faith judgment, interfere with rendering effective care.

SECOND, I urge that Congress enact an amendment to PAIMI to prevent the Patient Advocates from supporting the rejection of treatment by severely mentally ill patients who lack insight into their illness. Peter Mills wrote the following on this subject:

“Approximately half the people with schizophrenia and 40% of those with bipolar disorder go through periods of ‘anosognosia’, a deficit of awareness or lack of insight into the nature and extent of the illness.

“In 1986, Congress passed the ‘PAIMI’ law (for Protection and Advocacy for Individuals with Mental Illness) to create P&A (‘Protection and Advocacy’) systems in all 50 states to prevent abuse and neglect of people with mental illness. It was modeled on an earlier statute to protect those with developmental disabilities.

“While the statute might have been written to focus on effective care, protection and treatment, it is worded instead to speak of ‘rights.’ In fact, there is a bill of rights appended to the law.

“The right to treatment has often been interpreted to include the right to reject treatment even if rejection makes the illness worse, causes permanent harm and leads to loss of liberty, incarceration or death.

“Does a patient with anosognosia have the right to a publicly paid advocate whose mission is to block the delivery of effective care? Does the right to reject treatment translate into the right to remain psychotic? What is an advocate to do when a delusional rejection of treatment conflicts with the right to receive treatment?

“PAIMI should define the advocate’s role to resolve this common and difficult conflict. It might be done either by prohibiting the advocate from interfering with necessary treatment or, at the very least, by granting the advocate discretion not to interfere even when the patient insists.

“In 42 USC 10802 add the following definition as a new paragraph 6:

“(6) The term ‘rights of individuals with mental illness’ includes a right to suitable care, protection and treatment. An advocate **may not support** an individual’s rejection of necessary treatment if the rejection arises from lack of awareness of a mental illness or lack of insight concerning the nature or extent of a mental illness.

“or

“(6) The term ‘rights of individuals with mental illness’ includes a right to suitable care, protection and treatment. An advocate **may refuse to support** an individual’s rejection of necessary treatment if the rejection arises from lack of awareness of a mental illness or lack of insight concerning the nature and extent of a mental illness.”

Personally, having seen the philosophical inclinations of the patient advocates first hand, I prefer the first suggested alternative because it removes discretion from the advocates to support a refusal of treatment.

THIRD, the Patient Advocates should be prohibited from lobbying. As Peter Mills wrote:

“Protection and Advocacy (P&A) groups have often ignored prohibitions against lobbying. In Maine, they intervened to make it more difficult for a parent to become the guardian of an adult disabled child. Throughout the U.S. they have vigorously opposed passage of outpatient treatment laws even though these laws have been successful in providing “least restrictive alternatives” for treatment.

“Although these laws enhance freedom and opportunity for the mentally ill, advocates on SAMHSA’s payroll have often shown up to oppose such measures in state legislatures.

“To the extent that lobbying has been justified by the fact that P&A groups receive some of their funding from non-federal sources, the law should perhaps be changed to prohibit lobbying by a P&A group that receives any funding under PAIMI.

“Law Professor Amanda Peters concluded:

‘The only effective way of preventing lobbying is to do as Congress has done with the Legal Services Corporation: consider passing additional laws that prevent patient advocates from using *any* funds to lobby, set up an agency to closely monitor their spending and lobbying efforts, and come up with a plan to unfund or otherwise punish advocates who nevertheless engage in such activity.’ 89 Oregon Law Rev. 133, 156.”

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In conclusion, I believe that these three changes would not only have helped the Bruce family, but would help families with severely mentally ill loved ones across the country and be in the best interests of the severely mentally ill themselves. Like the mothers of severely mentally ill individuals I have met from across the country, Amy Bruce was the greatest advocate our son could ever have had. Opening the iron curtain of HIPAA to allow family members to be involved in their adult loved ones’ treatment would simultaneously increase the efficacy of that treatment and provide costless oversight – which is currently lacking – of the activities of the individual patient advocates and of the entire system. In the case of the Bruce family it would likely have saved Amy’s life.

Thank you for giving me this opportunity to give you my thoughts on this important subject.

Sincerely,  
Robert (Joe) Bruce  
Caratunk, Maine