Terry Grimes' Response
to a Presentation Given by
Dr. John Monahan on April 15, 2005

The presentation was entitled “The Use of Leverage to Improve Adherence to Psychiatric Treatment in the Community.” It was delivered in Roanoke, Virginia at the “Mental Health and the Law Symposium” sponsored by the Institute of Law, Psychiatry and Public Policy at the University of Virginia.

Terry: “When Jim Martinez contacted me a month ago to be on this panel, my first reaction was that I really felt more comfortable and knowledgeable about the presentation on advanced directives rather than the presentation on the use of leverage. Personal independence and choice, as it relates to coercion, is difficult, uncomfortable, and messy to discuss. This invitation has given me an opportunity to really look at what my position is right now about mandated community treatment and also do some very worthwhile reading. I hope that my brief comments will let you know how serious this topic is to us (people with a psychiatric label). This topic is relevant to our ability to overcome the often devastating discrimination and myths about our how dangerous we are and how limited we are seen in terms of how much we can contribute to society. This topic is also critical to the state's movement toward a recovery and hopefully empowerment array of more responsive service delivery.

I agree that there are rare situations where the actions of individuals with psychiatric disabilities are so harmful as to warrant forced treatment, treatment administered over a person's expressed objection. I have always wanted to know what those individuals who hold a “no forced treatment ever” position would suggest doing to protect themselves and others when they find themselves unable to make reasonable choices. But when outpatient ordered treatment is discussed I favor actions that don't infringe on the liberty interests of the individual.

I am very concerned that the leverage or the strategic advantage of those with power and authority is already being applied frequently in situations which do not warrant either expressed or implied force. I fear that the human rights that mental health consumers have fought so hard for will begin to erode when the right to object to or to refuse recommended treatment is challenged. A continuum of leverage or force actions needs to be evaluated in light of a continuum of intrusiveness or risk of the treatment in question as well as the predicted behavior of the individual. I also believe that we need to be extra vigilant to protect those individuals who are so

severely challenged that they cannot speak up for themselves , nor exercise their rights.

I have many consumer friends who have experienced both inpatient and outpatient court ordered treatment and yes there are more and more people who are finding themselves in situations where their freedom to return to their community is contingent on mandatory medication regimens and appointments with a provider. In most cases, however, due to dire shortages of psychiatric care these very individuals may have access to a nurse practitioner but still see a psychiatrist for 15 minutes once every three months. They often have no recourse when experiencing very uncomfortable drug side effects because of system lags and are afraid to rock the boat lest they find themselves in contempt of court or back in the hospital. This form of leverage, applied too arbitrarily, hinders openness and yes honesty by consumers who may still be experiencing distressing but manageable symptoms with non-mandated supports. We lie and say “no” we are not having suicidal or homicidal ideation just to escape the oppression of being hospitalized or forced to adhere to treatments we object to and whose therapeutic value may be in question for us.

I believe that balancing or reaching harmony with this issue may not only be found in such a process as developing an advanced directive which will be discussed this afternoon, but also found in other ideas and activities which may have potential in arriving at this sought after balance. The University of Illinois at Chicago National Research and Training Center on Psychiatric Disability offers a three part discussion framework of self-determination for people with psychiatric challenges:

First - individual or internal self-determination defined how we mostly think of this concept - the right of individuals to have full power over their lives, regardless of presence of illness or disability.

Second. - mental health services, supports and policies that foster self-determination, particularly recovery oriented services that respect client choice of treatment options

Third - which I find relevant to mandated community treatment - collective, social or shared self -determination.

Social connectedness is so important in achieving self-determination. We all exist in relation to others – our decisions or in some case inability to make decisions have consequences for ourselves and others. Social self determination also fosters mutual respect for difference in beliefs, viewpoints, lifestyles, needs, values, and may I add mental processes, in

order for self-determination to be truly realized. When a mental health consumer is in a very unstable state, one in which the occurrence of harm is likely, consequences not only happen to the consumer. Bad things can happen to others. I would hope that reasonable people care about themselves *and* how their actions affect others.

Another area to direct our efforts involves approaches to research and gathering data to support or refute the effectiveness of certain mandated community treatment orders. We must ask questions whose answers may lead to more significant changes in community services. Questions related to self-esteem, self-agency, intimacy/human connectedness, feelings of control, and self-management of symptoms are difficult to formulate but may yield better measures of well-being and engagement in treatment. Other approaches involving data that is easier to gather, such as measures of reduced hospitalizations and measures of reduced police contact, are much less helpful to us. The American Association of Community Psychiatrists notes that there is some evidence that outpatient commitment does impact positively on reducing inpatient days, ER visits, and reported incidences of violence, especially those involved with substance abuse. But improvement in individual functioning and actual treatment compliance has not yet been shown to sufficiently warrant expanding outpatient commitment by softening patient criteria.

An area of particular challenge, one that should be of great interest to those wanting to reduce situations of danger, severe deterioration and resistance to treatment has to do with the willingness of those offering and providing treatment to allow us to express our thought, feelings, urges, no matter how scary and alarming. Service providers need to let us be who we are without causing us to feel threatened or afraid of reprisal during our sessions with a therapist. In therapy the environment must allow us to be open and trusting. Discussions about objections to certain treatments can be therapeutic opportunities rather than situations to squelch. Mutually arrived at goals foster treatment success. Self-directed wellness programs with support are known to be even more successful in treatment adherence and personal growth.

Services need to be people driven, not rule or law driven or judicially ordered. Most of all the tremendous diversity, uniqueness, and potential of individuals with psychiatric challenges need to be recognized and fostered. I will continue to advocate for increased access to services in my community so that people are not turned away when feeling a crises looming or needing help managing uncomfortable symptoms. Many individuals and their family members who find themselves in community mandated situations are turned away. This certainly does not reinforce self-determination and the

knowledge consumers have about when they need support or crisis stabilization. I maintain that the use of mandated court ordered treatment may necessary in a few situations and but definitely should not become the norm during discharge planning and treatment protocols. I have been dangerous to myself and others when adhering to prescribed medication and treatment and functioned well during some periods when I did not have to take drugs or chose not to do so.

I will end by letting you know that in September 2002, the psychiatrist that treated me while I was an inpatient gave me a new label - "apparently competent". I leave you with that conundrum. "

Terry Grimes, Ed.D
Consumer Advocate
President, Empowerment for Healthy Minds
tgrimes@rbnet.com
http://www.efhm.com