

# **Collaborative Support Programs of New Jersey Position Paper-February 10, 2012 Medication Optimization**

CSPNJ believes that mental health services should be designed from the perspective of the lived experiences of people in recovery. CSPNJ will be issuing position papers that represent the consensus views of the Governing Board and administration of the agency, concerning issues impacting recovery. This paper discusses the pros and cons of psychotropic medications and offers suggestions related to their use.

The following is the story of Nancy D. Brown, a survivor, advocate and current Governing Board president of CSP, in her own words.

*“Why did I escape relatively unscathed from my serious bout of manic depression? I have always wondered just why my recovery enabled me to work and lead a fairly normal life after several years of pure hell. After hearing and talking with Bob Whitaker and Dr. Courtenay Harding at the annual Wellness Conference in spring 2010, I finally connected the dots.*

*My first psychic break quickly brought me home from college when I was 17 years old. My parents took me to a psychiatrist who told me to go back to college (I told him no way did I want that so I isolated myself for two months at home). At that time I was never medicated and never put on any drugs of any kind. My second wipeout occurred several years and another college later when I was fired from a well-known company in New York City for falling asleep at my desk, and back home I went again. This time I was diagnosed with a thyroid condition, and once again no psychotropic medications.*

*In the ensuing years, I worked, attended a few colleges, got married, raised two sons, and led a relatively normal, if slightly zany, life. My Big Bang, as I call it, came at 37 years of age. With the Big Bang also came my first encounter with psychotropic medications. During the next several years, I lost count of the many drugs given to me to try to stabilize my wicked mood swings, delusions and hallucinations, all to no avail.*

*Six psychiatrists, twelve hospitalizations (including two at Trenton Psychiatric), two or three rounds of ECT and one notorious failed suicide attempt- that was my life for a while.*

*I finally found an amazing psychiatrist, one who actually listened and inspired trust. He tweaked my medications in a thoughtful and judicious manner. He insisted on annual physical and dental exams for me. My medications were changed forever. What a difference-on his watch, I attained good recovery. I am now on a low maintenance regimen of Depakote and Topamax easing the mood swings I still encounter.*

*As one gets older, one ponders. After meeting Bob Whitaker and Dr. Harding, and connecting the dots, I realized how much there was to be thankful for and relieved about. I often wonder what would have happened if I wasn't challenged to push myself. What if I had accepted a passive role? What if I had been medicated when I was 17 years old? What if I had spent those early years in a state facility?*

*I may never have married, raised a family nor had the joy of grandkids. I may never have had my career as a P&A advocate or the opportunity of serving as the president of the CSP Governing Board in my mid-70s."*

The widespread use of psychotropic medication has become increasingly controversial in society as well as in the mental health field. Some people believe that medication has been a catalyst helping them to be able to pursue recovery goals; for many others it has resulted in more problems than benefits. **That being said, we understand that once persons begin taking psychotropic medication for psychosis, mood disorders, attention deficit disorders or anxiety, they should not abruptly stop.** Anyone who decides to stop or reduce his or her psychiatric medications should work closely with a psychiatrist, primary medical doctor or other qualified supporter. For some, maintaining the current prescribed dose may be best, for others some reduction to a lesser dose will be best, and for still others a long term strategy of gradually discontinuing psychotropic medications completely may be best.

*"Currently millions of people world-wide take psychiatric drugs when they are diagnosed with such labels as bipolar disorder, schizophrenia, depression, anxiety, attention deficit, or post-traumatic stress. The medical community, advertisements on television and the internet have influenced society into believing that these medications correct chemical imbalances and create a happier life. Once people are given a diagnosis and prescribed medication, it is easy to think of the medications as physically necessary for survival. There is no solid science behind viewing mental disorders as caused by biology, and many people living with severe symptoms and associated secondary impacts of schizophrenia or bipolar go on to recover completely without medication. For some people psychiatric drugs are helpful tools, but they are not medically necessary treatments for illness".<sup>1</sup>*

<sup>1</sup>Will Hall, *Harm Reduction Guide to Coming Off Psychiatric Drugs* (New York: Icarus Project; Northampton, MA: Freedom Center, 2007) 9.

We believe the following:

- People should have the opportunity to engage in shared decision-making regarding medication selection and use. Opportunities for exploring alternatives or tapering to lower dosages should be a standard practice within mental health and integrated care settings.
- Psychotropic medications, as are many medications, are innately toxic, thus people should be fully informed of the short and long term benefits and side effects as well as all treatment options and alternatives.
- Psychotropic medications can be helpful tools to assist people in pursuing valued social roles, but they are not the only such tools. Other wellness strategies should be provided to support and assist users in tapering their medication use if they choose to do so.

### The Problem

Psychotropic medications are one of the key treatment modalities for persons diagnosed with a mental disorder. It has been assumed that the medications are a significant reason why people have been able to live in the community after leaving psychiatric institutions. Some people feel that their medications are crucial for their stability and recovery, although it is increasingly clear that these medications have troubling and serious side effects related to their toxicity. Many medication users report feeling like “guinea pigs,” as various medications are tried but found ineffective. Many cause excessive weight gain, metabolic syndrome, permanent damage to the nervous system such as tardive dyskinesia, and even the often fatal neuroleptic malignant syndrome. Psychotropic medication users also report that these medications make them lethargic, apathetic, dull and fidgety, and can cause dry mouth, in some cases drooling, excessive sweating, and significant interference with sexual functioning and libido. Besides the physical issues these side effects also lead to social discomfort.

It is well documented that people with mental and substance use disorders under the care of the public mental health system have a shortened life span, dying on average twenty-five years earlier than the general population. We believe that a significant factor in this shortened life span is the toxic effect of psychotropic medications, especially at higher doses, with prolonged use and polypharmacy.

Medications are often over-prescribed and polypharmacy has become wide-spread with psychiatrists and other physicians prescribing several neuroleptics simultaneously in an attempt to alleviate symptoms and side effects. Unfortunately, this type of prescribing appears to exacerbate medications’ toxicity causing numerous iatrogenic (adverse effect) medical issues. Still, some prescribers apparently hold to a standard that more

(medication) is better and that most psychiatric issues can be mitigated by proper prescribing and patient compliance.

Often when people are hospitalized, their medication dosage levels are increased. When they return to the community, their prescribers do not suggest tapering off from the higher dosage levels. Psychiatrists and patients can become overly dependent on medications. Psychiatrists tend to view medication as the primary tool to assist in stabilizing people. Medication users often become overly dependent upon medication as the key strategy to handle life's stress. Mental health workers frequently reinforce current beliefs that medications are magic bullets, claiming "if you would only take your medications you would not have all those problems". They quickly fall back on medication compliance or increasing dosage as the single solution for increased symptoms. Mental health workers may be more single-minded about the medications than the prescriber. The good patient is seen as someone who is compliant and reserved, who sees the doctor as the expert and only needs to follow his or her clinical direction to remain stable. Those of us who have the lived experience of mental illness and/or who have worked in the profession for any length of time realize that many people do not have better outcomes by being compliant and may fare worse.

Given the economics of community mental health, the opportunity to create and sustain a therapeutic partnership between the psychiatrist and patient is often lacking. The relationship is reduced to one of monitoring medication tolerance and the effects the medications have on symptoms such as auditory hallucinations or delusions. During the interview, there is little time for getting to know the person, his or her aspirations, strengths, skills, stresses and dreams. The visit is usually around fifteen minutes. This brief time period does not allow for any in-depth discussion or relationship building. Consequently people are seen only in terms of their deficits or illness. The relationship is not an open one, as the psychiatrist is not only seen as the "expert" but also as the "enforcer" with the power to commit individuals against their will. This is a definite barrier to frank discussions and therapeutic trust throughout the relationship.

### Psychotropic medication development

Psychotropic medications were first discovered by happenstance in the 1950's. Thorazine was first used to treat psychosis in 1952 in Paris. All these early medications were developed for other medical needs but, by chance, were found to calm people who had acute psychiatric episodes. It is still the case, even after extensive research, that the underlying mechanisms which cause the actual effects, whether positive or negative, are unknown. Despite initiatives like the "Decade of the Brain" in the 1990's that endorsed prescribing newer and better medications as the answer to managing major mental disorders, there has been no conclusive proof that these medications lead to long-term positive outcomes.

Robert Whitaker examines the development and widespread use/abuse of psychotropic medications in his publication *Anatomy of an Epidemic: Magic Bullets, Psychiatric Drugs and the Astonishing Rise of Mental Illness in America*.

Relying on psychiatric research, Whitaker unveils startling revelations about the apparent long-term ineffectiveness of psychiatric medication for many people being treated for a mental illness. He shows the limits of the research that supports the long-term effectiveness of these medications and cites several studies documenting the poor results of these medications over longer periods.

He looks at a number of factors, including the worsening employment records, for those who are taking these medications for extended periods of time. He provides some compelling psychiatric research evidence suggesting that a significant majority of people diagnosed with serious mental illness may fare far better in the long term by not taking these potent and possibly further disabling medications. Most importantly, Whitaker points out psychiatric research that suggests that the long-term use of these medications alters brain chemistry, possibly leading to dependence on these substances to avoid relapse.

### Current Practice

While many agree that the short-term use of these medications is generally effective, and studies support this, Whitaker cites studies of long-term use that show the opposite effect (e.g., Harrow, 2007). He also provides substantial evidence of how and why these studies are discredited by the pharmaceutical industry, the government, and psychiatry. He speaks to the vested interest of these groups in keeping the use of psychotropic medication a growth industry. Even with growing evidence against the long-term use of these medications, these powerful groups market a message that they are necessary for psychiatric stability over the course of a user's life. This message has been embraced by mental health professionals and service recipients alike.

It seems that our field has been blinded by the promise of "magic bullet" breakthroughs that were quick fixes in their initial short-term use but capable over a long period of time of causing irreparable damage.

### Recommendations

- The therapeutic relationship between provider and recipient should be redefined, and the goals of patient education, empowerment and choice prioritized. The length of the average interview should be increased to at least one-half hour.
- People should be given the message that for many, mental illness does not have to be a lifelong phenomenon, and that much can be accomplished by self-direction, hope and self-actualization.

- Alternative treatments should be offered to people experiencing emotional distress, both during crisis and their continued care, in place of or as an adjunct to psychotropic medications. These include psychotherapy, wellness and life coaching, peer support, relaxation, daily exercise, eating healthy food, daily journaling, getting adequate sleep and a growing array of environmental and personal activity choices referred to as personal medicines.
- As part of their medical school pharmacological training, and initial and ongoing continuing education coursework, psychiatrists should learn to apply psychotropic medication tapering skills. In light of the inherent dangers of psychotropic medication, psychiatrists should be taught the importance of explaining those dangers clearly to patients, and the importance of prescribing the lowest dosage possible for as short a time as possible.
- Advanced Practice Nurses should be given an increased role as prescribers. The cost differential will lend itself to longer sessions with consumers and APNs are trained holistically.
- Mental health organizations that have medication prescribing services should be required to implement quality improvement measures that promote best practices in medication management. This should include monitoring dosage levels by individuals, prescribers, and program, and using this data to teach emerging and best practices.
- Pharmaceutical companies should be barred from issuing research findings for their products without having them scrutinized by unbiased third parties, from hiring psychiatrists to market their products, and from endowing psychiatric chairs at universities.

## References

- Hall, W. (2007). *Harm Reduction Guide to Coming Off Psychiatric Drugs* (New York: Icarus Project; Northampton, MA: Freedom Center).
- Harrow, M., & Jobe, T.H. (2007). Factors involved in outcome and recovery in schizophrenia patients not on antipsychotic medications: a 15-year follow-up study. *Journal of Nervous and Mental Disorders*, 195(5):406-14.
- Kirsch, I (2010). *The Emperor's New Drugs* New York: Basic Books.
- Whitaker, R (2010). *Anatomy of an Epidemic: Magic Bullets, Psychiatric Drugs, and the Astonishing Rise of Mental Illness in America*. New York: Crown.