

**Human Sexuality and
Mental Illness:
Consumer Viewpoints
And Recovery Principles**

**By
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Those of us who have been diagnosed with major mental illness do not cease to be human beings by virtue of that diagnosis. Like all people we experience the need for love, companionship, solitude, and intimacy. Like all people we want to feel loved, valued, and desired by others.

The greatest and most healing service that can be offered to people with psychiatric disabilities is to treat them with respect and honor them as human beings. This means honoring us in our full humanity, including our sexuality and our desire to love and be loved.

In the spirit of honoring the full humanity of people diagnosed with major mental illness, I invited a group of people to discuss how mental health services affect our sexuality and our capacity to love. All of the members of the group were diagnosed with major mental illness, have had multiple hospitalizations, and are receiving a wide range of mental health services including residential and case management. I found the stories and insights shared in our discussion to be inspirational and filled with humor, common sense and wisdom. They deserve thoughtful reflection, and so I have organized this paper around the themes which emerged in that discussion. These themes include:

- Psychiatric medications and sexuality
- The reduction of sexuality to psychopathology
- The need for clear and comprehensive policies regarding sex and romance in mental institutions
- The possibility that mental institutions (and not the sexuality of the people in them) are problematic
- The unnecessary practices that shame and humiliate us

In addition to reflecting on the group's comments, I will also outline principles of the recovery model that can inform and guide decision-making regarding human sexuality and mental illness.

Psychiatric Medications and Sexuality

My biggest problem with sex is medication. These pharmaceutical companies should warn you and they don't. They don't warn us about the sexual side effects. The pharmaceutical companies should put the warning right on the bottle.

All members of the focus group echoed the theme expressed by this first speaker. We all felt psychiatric medications had interfered with our sexual function and/or desire. For some, the problem with medications was ongoing. For others, it had been resolved either by going off the medication or changing it.

This first speaker suggests a warning be placed directly on the pill bottle. He clearly would have preferred to know about possible drug effects on his sexuality before he took it. I would add that it is also his legal right to be informed directly about drug effects by the prescribing physician or nurse practitioner. Thorough discussions of unwanted drug effects, however, were not the norm in our group's experience. Rather, many of us had never been informed about possible sexual dysfunction related to medication use or concomitant emotional blunting, anhedonia, apathy, indifference, anorgasmia, and reduction in sex drive. We tended to blame ourselves for our sexual dysfunction and subsequently felt ashamed and fearful of engaging in intimate relationships. Most of us learned about these medication effects from peers who used the drugs or from reading about the drugs in books that we found on our own which were not provided by mental health centers or professionals.

One member of the group said he did report his sexual dysfunction to his psychiatrist: *I have the problem that my medication gives me which is premature ejaculation. They keep telling me, "You have to be on this medication. There is no other medication you can be on. You have to accept this side effect." I don't think I should have to accept this side effect. They want me to commit sexual suicide.*

The option of "sexual suicide" is unacceptable and only sets this speaker up for eventual medication non-compliance. When most of us with psychiatric disabilities encounter drug effects that impair our quality of life, we want to be able to work collaboratively with our doctors/nurse practitioners to find alternatives. Remember that alternatives include other medications, different dosages, as well as the opportunity to learn non-drug coping strategies to eliminate or decrease distressing symptoms (Deegan, 1995).

Never tell people they will have to stay on medications for the rest of their lives. Such a message is utterly demoralizing and empirically unfounded (Harding & Zahniser, 1994). Rather, always suggest a trial period. Put a reasonable time frame around the length of the drug trial. Most people can endure uncomfortable or disabling drug effects if there is a firm rationale for expecting a good outcome from the drug trial and if they know there is an end point at which the outcome of the trial will be collaboratively discussed.

When evaluating a person's long-term medication use, take the time to inquire about unwanted effects. Some people have become so accustomed to sexual dysfunction and/or loss of sexual desire they may not even mention it. In taking the time to reach out to these people and explore medication

reductions, changing medications and self help strategies, care is demonstrated for the *whole* person and the overall quality of his/her life.

The Reduction of Sexuality to Psychopathology

On the one hand they don't let you have sexual relationships with other people when you're in the hospital. On the other hand they say you can't masturbate. They say the reason you can't masturbate is because of the thoughts you might have later. They say there's nothing wrong with masturbation but that the thoughts it might stir up would cause you problems later in the day.

The association between sexual acts and “problems” is not new. Throughout the history of American psychiatry the sexuality of people diagnosed with mental illness has been suspect. Under the lens of medical/institutional scrutiny, that which was private became open to clinical scrutiny and academic debate. Historically, sexuality has been reduced to either the cause or symptom of psychopathology.

Masturbation has been understood as a primary cause of mental disorders. In the 18th century the father of American psychiatry, Benjamin Rush, wrote a chapter, “Of the Morbid state of the Sexual Appetite.” He claimed that onanism (masturbation) “produces seminal weakness, impotence, dysury, tabes dorsalis, pulmonary consumption, dyspepsia,, dimness of sight, vertigo, epilepsy, hypochondriasis, loss of memory, manalgia, fatuity, and death.” (Rush,1812, p. 347) A century later Samuel Woodward, the founder of the American Psychiatric Association, echoed Rush’s concern about masturbation. Loss of semen was thought to be debilitating and could lead to madness and even death. In an introduction to Sylvester Graham’s A Lecture to Young Men on Chastity (1839), Woodward wrote “The evil of which [this book] treats . . .is more extensively sapping the foundation of physical vigor and moral purity, in the rising generation, than is generally apprehended even by those who are awake to the danger,” (Gamwell & Tomes, 1995, p.112).

In 1888, the physician John Harvey Kellogg noted the dire effects of masturbation upon the nerves of young men. He wrote, “In the insane asylums of the country may be seen hundreds of these poor victims in all stages of physical and mental demoralization” (Gamwell & Tomes, 1995, p. 112). Although women were also swelling the ranks of mental institutions, physicians and psychiatrists of the 19th and early 20th century did not generally attribute this insanity to indulgence in the ‘secret vice’. Rather insanity in women was, in many cases, thought to be caused by a defect or irritation of the reproductive organs,

especially the uterus (Geller & Harris, 1994). Treatment included the administration of various vegetable and mineral tonics as well as opiates to calm the excited uterus. Physicians judged that women who appeared excited during menstruation should have their ovaries removed in an effort to calm them. An ovarian restraining apparatus was devised. In an effort to calm the agitated uterine system, physicians injected hot water into a woman's vagina. They developed a procedure to cauterize a woman's clitoris. In women who were not virgins, an apparatus called the double uterine exciter was indicated. It "applied an electrical current to the uterus" and

"was employed for periods lasting up to ten minutes." (Geller & Harris, 1994, p.100-111)

The eugenics movement marked another wave in the assault on the sexuality of people diagnosed with mental illness. In America the eugenics movement was marked by an effort to purify and insure the dominance of the white Anglo Saxon race. One of the methods devised to achieve this end was sterilization or the "asexualization of the unfit" (Barr, 1912, 1915). People considered unfit included convicted rapists and criminals, people with mental retardation and people judged insane. By 1907 Indiana passed the first state laws permitting sterilization. By 1931, thirty states had passed sterilization laws and over 20,000 people had been sterilized (Bell, 1980).

Another reduction of sexuality to a form of psychopathology is illustrated in psychiatry's view of homosexuality. As Gamwell and Tomes (1995, p. 111) summarize, in 1932 the American Medical Association, in conjunction with the American Psychiatric Association, classified homosexuality as a psychopathic personality disorder in the *Standard Classified Nomenclature of Disease*. In 1952 the American Psychiatric Association included homosexuality as a sociopathic personality disorder in the first *Diagnostic and Statistical Manual of Psychiatric Disorders*. It wasn't until 1973 that homosexuality was removed from the DSM.

As a person with a psychiatric disability, I feel a combination of outrage, sadness and fear when I read about what has been done to us in the name of treatment. I am horrified that society would seek to protect itself against those of us with mental illness by sanctioning mass violence against us (albeit this violence was in the guise of treatment). Never has a single person or organization of people with mental illness perpetrated violence on such a scale. It has only been normal, non-diagnosed people who have been empowered by our society to treat tens of thousands of mental patients through the use of forced

sterilization, clitoral cauterization, applying electrical currents to reproductive organs and mass incarceration of gay men and lesbians.

I understand mental health professionals' intent is to help people, not to hurt people. However, they must not avert their eyes from the facts of history. The track record regarding the sexuality of people diagnosed with mental illness is not very good. The temptation of dismissing the past as past must be avoided. It will not do to rest comfortably in the illusion that today's clinicians live in a scientific age in which their work is guided solely by empirical progress (Kuhn, 1970). Rather, mental health professionals must learn from the past and dare to question the assumptions which guide their work and the very questions they ask about their work. For instance, they might ask:

- Where are the programs in the service system that provide in-home supports and skills training for parents with major mental illness and their children? Where are the residential programs for married couples or single parents with children? If these services do not exist, what does that say about assumptions regarding the sexuality of people with major mental illness?
- How are inpatient units and community based programs organized to be inclusive of people who are gay, lesbian or bi-sexual? How are gay, lesbian and bi-sexual men and women who also have major mental illness, assisted in coping with the double discrimination they encounter? How are issues of staff homophobia and heterosexism addressed in programs? If these issues are not being addressed, what does this say about assumptions regarding the sexuality of people diagnosed with major mental illness?
- When a woman is using neuroleptics do we consider the abatement of her psychotic symptoms more important than the fact that she also develops amenorrhea and loses her reproductive capacity while on the drug(s)?
- How is a woman with major mental illness who is approaching 40 years of age and states her intent to "have a child before it is too late" counseled? How are genetic studies of the incidence of schizophrenia and affective disorders interpreted? Do clinicians oversimplify and tell clients that mental illnesses are genetically transmitted in a linear, causal, and/or deterministic way? Is the eugenics agenda at work in such consultation?

- Are there services in place to support a pregnant woman in discontinuing her psychiatric medications to ensure the safety of her baby? If these services are not available, what does that say about assumptions regarding the sexuality of people with major mental illness.

The Need for Clear and Comprehensive Policies Regarding Sex and Romance in Mental Institutions

First they tell you there is no sex allowed in the hospital. Then they pass out condoms and tell you to be sure to use them for safe sex.

This member of the focus group captures the mixed messages that are sent to people in mental institutions regarding sexuality and romance. Instructing patients in the No Physical Contact Rule and then supplying condoms is contradictory and confusing both for the staff who are expected to enforce the rule and for the patients who are supposed to abide by it.

Most hospital units have an obligatory policy statement regarding patient sexuality. However, a policy prohibiting sex does not necessarily eliminate it. For instance, in one study looking at the sexual activity of women diagnosed with schizophrenia in a long-term institution, 65% of women reported having intercourse while in the hospital during the prior three months (McEvoy, Hatcher, Appelbaum & Abenethy, 1983). Despite the official policy prohibiting sex, the operational policy in many inpatient settings is something akin to “Don’t ask, don’t tell; don’t look, don’t see.” A comprehensive policy addressing the real issues is required.

When you’re in the hospital you feel the most vulnerable. You are going through a lot of pain and suffering. Reaching out to someone is healing and reassuring. But then your psychiatrist says that if you reach out for intimacy, love, affection, touch. . .that is about being predatory. That’s about taking advantage of vulnerable people. That’s inappropriate.

This member of the focus group clearly states the tension he experiences regarding life in an institution, including short term and intermediary stay units. He does not cease to be a human being with needs for intimacy and comfort upon being diagnosed or admitted to a mental institution. In fact, in an institution loneliness and pain can be amplified. In such circumstances it is quite natural for anyone to seek solace in the warmth of an embrace. This group member sees interpersonal physical affection and love as something that could be healing for him. Yet he also reports when he acts on these human needs in an

inpatient setting, he is told he is being inappropriate and predatory. He is told the other people in the setting are vulnerable and could be taken advantage of.

A comprehensive policy regarding sexual activity in mental institutions must address the tension so clearly captured in the statement above. A policy must address the needs and the rights of adults to seek intimacy, love, and physical comfort as well as addressing the responsibilities of the institution to protect people from the exploitative and predatory behaviors of both staff and other inpatients. Attorney Susan Stefen (1995, p. 2) suggests a comprehensive policy will:

- Address the prevention of rape and coercive sex
- Contain detailed plans of action in the case of allegation of rape or coercive sex
- Address issues of sex education
- Address issues relating to contraception
- Address issues relating to client pregnancy
- Address issues relating to voluntary sexuality including masturbation and expressions of physical affection short of intercourse
- Address issues of client privacy
- Address HIV/AIDs related issues.

Stefen also suggests mere consent is not a sufficient standard for policies regarding sexuality on inpatient units. She suggests that mutuality and voluntariness are superior standards. “It should not be sufficient to consent: the relationship should be mutually desired by both parties”(Stefen, 1995, p.5). The standard of mutuality and voluntariness is particularly important in light of the relatively high percentage of men and women with major mental illness who have histories of sexual abuse and who are vulnerable to reenacting that trauma by consenting to unwanted sex.

The Possibility That Mental Institutions (and not the sexuality of the people in them) Are Problematic

I was married for ten years before coming into the hospital. Outsiders never told me what I could and couldn't do sexually in my marriage. And then when I'm in the hospital under their control, the things they are telling me I can't do make me feel like a kid.

This member of the focus group helps us understand that in an institution, what is usually private becomes a matter of public concern. Is it possible to insure privacy for adults who are patients in psychiatric institutions? The very notion of developing a policy that allows privacy and or private space to engage in mutually desired sexual relations in institutions seems aberrant (Stefen, 1995). For instance, how would use of a private room be monitored? Who could use it and who would not be allowed to use such a room? Would the room be available 24 hours a day or just at certain times? Would use of the private room be considered a privilege or a right or a clinical issue? What if a couple ran overtime in the private room? How would they be informed that another couple might be waiting and who would inform them?

As one begins to grapple with the mechanics of a policy that would allow privacy in an institutional setting, it becomes clear it is the institutional setting itself, not the inmates of that institution, which is unnatural and problematic. The problem is not that people diagnosed with major mental illness want to engage in intimate relationships. The problem is that institutions strip away their control over what remains private and what they choose to make public. Perhaps, rather than focusing efforts on controlling the sexual expression of people in mental institutions, time should be spent considering the possibility of dismantling such institutions and working with people in their own homes, in the context of their ongoing lives.

Knowing that the dismantling of mental institutions will be a long time coming, Stefen (1995) suggests a middle ground. She suggests that:

all institutions should provide on each ward a private room where a client can go to get away from the chaos and overstimulation on the ward. People who have been institutionalized, particularly with histories of sexual abuse, describe repeatedly the crucial and desperate need for a place to be private, alone, and quiet. A client could get a key to this room from a staff member, and could lock herself in and perhaps listen to music on headphones, read, write, draw, or simply be still. If the time came that a decision was made that voluntary and mutual sex was permissible in the case of certain residents, the room would already exist. (p.7)

The Unnecessary Practices that Shame and Humiliate Us

I kicked over a clothes hamper. I did it on purpose. They tied me in four point restraint for 12 hours plus they shot me up with drugs. I'm not a horse! They left me tied up in just my underwear. There were both men and women staff when I was in restraint. They left the door open. A guard sat in the doorway watching me and people passing in the hall could see me. They treat you like an animal. It's not helpful. I felt ashamed. I lost my appetite. It makes you worse.

This focus group member graphically describes the shame, degradation, and humiliation he experienced while in mechanical and chemical restraint. It is significant that he made this comment in the context of a focus group on sexuality and mental illness. For decades ex-patients have been drawing an analogy between rape and the experience of being forcibly restrained and injected with psychotropic drugs (Chamberlin,1977; Burstow & Weitz,1988; Pritchard,1995). Just as rape and violence can damage human sexuality, so too can restraint. It can be traumatic. Such trauma and wounds to our self esteem linger long after hospitalization. Indeed, it can often be more difficult to recover from these iatrogenic wounds, than from mental illness (Deegan, 1990,1993).

I've been in restraint and seclusion. They keep the cuffs loose. I don't see the reason for it, though. It's supposed to be therapeutic but I can't figure that out.

New Zealand and a number of provinces in Canada have learned to completely eliminate the use of mechanical restraints in mental institutions. An increase in staff to patient ratio has been the key to changing long held attitudes about the need for it. In the United States there is a growing awareness of how mechanical restraints can re-traumatize people with major mental illness who have histories of sexual abuse. For instance the Massachusetts Department of Mental Health Task Force on Restraint and Seclusion of Persons who have been Physically or Sexually Abused (Carmen et al.,1996) has published its recommendations which include: banning forms of physical restraint that require a patient's legs be spread apart; exploring with the patient alternatives to restraint and including these alternatives in the treatment plan; insuring that the staff person assigned to the 1:1 during and after restraint is not the same gender as the patient's sexual abuse perpetrator; and that a Trauma Assessment Form and Restraint Reduction form be used as guides to gathering critical information necessary for humane treatment of patients with sexual abuse histories.

There are many other practices which shame and humiliate and in turn, affect the sexuality of mental health clients. Some of the others that were mentioned in the focus group included procedures for using toilets and showers when on 1:1 as well as wearing johnnies that expose breasts or genitals when on suicide watch. Room checks can interfere with privacy when dressing, especially when staff do not knock. The practice of putting more than one person in a bedroom on inpatient units and in community residential settings is problematic. It interferes with an adult's sexual activity (from masturbation to sexual intimacy with partners). A number of group members complained of lack of privacy during administration of depot injections. Women complain of having to ask male aides or male residential workers for sanitary products. Perhaps the best way to understand the myriad of overt and subtle practices that shame and humiliate people is to organize a focus group of patients/clients who meet to discuss their concerns with administrators on a regular basis. A guide to forming such groups has been developed by Anderson and Deegan (1998).

Recovery Principles

Anthony (1990) declared the 1990's to be the Decade of Recovery. The recovery model recognizes that people can and do recover from major mental illness (Deegan, 1988,1996; Fisher, 1994) and that the rates of recovery for severe illnesses such as schizophrenia are higher than previously thought (DeSisto, Harding,, McCormack, Ashikaga & Gautum, 1995a,b; Harding & Zahniser, 1995). The recovery model emphasizes the person-in-relation - to illness, self, others, social role, society etc. Recovery approaches emphasize the principles of choice, self determination, skill building, self-help, recovery of social role, peer support, and empowerment. The model offers valuable guidelines for working with issues related to human sexuality and mental illness.

One of the fundamental principles of a recovery model is the dignity of risk and the right to failure. This principle was first described by people with physical disabilities (DeJong, 1979) and has been adapted by people with psychiatric disabilities (Deegan, 1992). It is based on the observation that there is a dual standard for people who are diagnosed and those who are not. People who are *not* diagnosed with a major mental illness have the "right" to make self-defeating choices without intervention from authorities wishing to protect them from the consequences of their poor choices. This is best illustrated by thinking of non-diagnosed friends or acquaintances. These people may make poor, unwise, self-defeating and even

self-endangering choices about sexual partners, marrying again after several divorces, engaging in unprotected sex, being a poor parent yet deciding to have another child, etc. Authorities do not intervene and stop these people from making unwise choices. In other words society accepts that poor judgement and lack of insight are parts of everyday living and that non-diagnosed people can and do make self-defeating choices. Hopefully they learn and grow through such risks and failures. However, once diagnosed with a major mental illness it is often assumed that our behavior is solely determined by the illness. Thus if we make the very same un insightful or self defeating choices that a non-diagnosed person makes, authorities feel compelled to paternalistic interventions into our lives.

A recovery model recognizes this double standard and urges clinicians and policy makers to distinguish between poor choices and psychopathology. I have worked closely with mental health providers in developing policies regarding consumer choice. In my experience it is helpful to create policy guidelines across the following domains :

- The Comfort Zone: When consumers make choices that providers agree with
- The Conflicted Zone: When consumers make choices that appear to be self defeating or that diminish quality of life
- The Risk Management Zone: When consumer choice becomes a safety and/or liability issue for providers

These domains can be adapted for use in the area of consumer choice and sexuality. Using these domains will help policy makers steer clear of the dual standard described above. It will promote recovery by minimizing paternalism and allowing people the dignity of risk and the right to learn and grow through failure as well as success.

Another principle of the recovery model is to minimize the loss of valued social roles and provide support in the acquisition of new roles after being diagnosed with mental illness. Too often diagnosis with a major mental illness is accompanied by the loss of valued social roles (Fisher, 1998). The loss of roles such as mother, father, worker, community leader, pastor, artist, etc., and the prescription of the role of “persistently mentally ill” has dire consequences for the individual looking to recover from mental illness.

With regard to human sexuality it is imperative that clinicians help clients keep the valued social roles they already have – as lover, spouse, parent or grandparent. Although some clinicians view these roles as possible stressors, they can also be a powerful motivating force for recovery. Lewis (1998, p. 4) reports that one mother in her focus group stated, “Being a mom helped me start thinking as a person instead of as a patient.” Mothering has been shown to be a powerful role around which women can re-organize their lives (Mowbray, Oyserman & Ross, 1994; Schwab, Clark & Drake, 1991). In addition, psycho-education for family members and friends regarding the importance of maintaining social roles is helpful. Finally, if functioning in a valued social role is disrupted during the course of the illness, role recovery becomes an important focus of rehabilitation and self-directed recovery.

Another principle of the recovery model is that people can learn non-drug strategies for coping with distressing symptoms. For instance non-drug coping strategies for dealing with major depression (Copeland, 1992), manic depression (Copeland, 1994) and auditory hallucinations (Romme, 1989; Watkins, 1990; Romme & Escher, 1993; Deegan, 1995) have been described. Providing opportunities for people to learn these coping strategies means that many can reduce or completely eliminate the use of psychotropic medications. In turn, medication reduction/discontinuance can lead to the restoration of sexual function.

Conclusion

A final principle of the recovery model is to recognize that mental illness is not “all in our head”. Mental illness is also a social construct that carries with it all of the stigma and discrimination associated with devalued people. Thus there are many other external, societal factors which affect our sexuality and our capacity to love. For instance mental illness too frequently comes as a package plan that includes poverty, unemployment, poor medical care, marginalization and second-class citizenship. It is difficult to engage in courtship while living below the poverty level on \$560 per month. It is difficult to imagine pursuing intimate relationships with people in the community when our neighbors protest the proximity of our group homes. It is difficult to initiate new romantic relationships when the stigma of mental illness is

sure to scare most people away. It is difficult to love ourselves when we have internalized the stigma that surrounds us and have learned to hate and fear ourselves.

The problem is not always inside our head. Sometimes the problem of human sexuality and mental illness is found in an unjust society that does not tolerate difference. No amount of medication or psychosocial support is going to cure the dominant culture's discrimination against people with mental illness. Clinicians must be careful not to locate all problems with intimacy and sexuality "inside" of the person with mental illness. We must not fall into the trap of blaming the victim (Ryan, 1976). Sometimes the clinical becomes political and the challenge of striving for a more just society belongs to us all.

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