

Our Liberation is a Catalyst for Changing Our Culture

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Escaping the Trap: Women Caught in the Mental Health System

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I don't know what the complete liberation of women would look like. Does anybody?

This is a journey we're taking together. The concept of liberation is a catalyst for making us think differently about everything. How can we take charge of making our mental health and health care system work for us? The more accurate question is, how can we create a better world? It's up to us. Although our sisters, daughters and mothers too often get caught in the mental health system, the real trap is the oppression of women, which is so tightly woven into the fabric of our culture that it is often hard to see.

Harvey Jackins, the founder of Re-evaluation Counseling – which teaches people to help each other in order to free themselves from the effects of past distress experiences – said, “An effectively caring person is the most ‘dangerous’ revolutionary you can let loose.”

I am going to talk about some of the underlying dynamics of the mental health trap. Then I will share some data and, then we'll get to action steps you can take.

The mental health system plays a very significant role in our culture; but other systems – education, criminal justice, foster care, public housing, and others – intersect with the mental health system to form a larger oppressive trap. This trap is a tapestry of silos and of bulging, inefficient bureaucracies that don't collaborate with one another. As a result, we waste a lot of resource and we have trans-institutionalization. Perhaps the worst example of that is the largest mental institution in the U.S., which is the L.A. County jail.

Navigating and transforming this maze of systems is a complex task. It involves very different philosophies and service delivery systems, and various segregated funding streams.

That's a quick broad brush picture, let's come back to the mental health system.

At the age of 16, I was diagnosed with chronic schizophrenia, locked up in a mental institution, and isolated in a seclusion room within the mental institution. The prognosis was that I would never recover and would always be on psychiatric drugs. Fortunately, the experts were wrong. I escaped the mental health system trap.

I now see clearly what I needed back then. I needed someone to listen to me well enough to engage me in dialogue, because I was stuck in monologue. I needed to know that I mattered. At the time I was tormented by not knowing why I was alive. I needed support to figure out my purpose in life and find a meaningful role in the community. Instead, what happened to me taught me about coercion, force, and control by others, which added layers of trauma, hurt, humiliation, and shame.

I want to differentiate the external trap from the internal trap. The external trap, for the purpose of this workshop, is the oppression of females. It comes from the outside. We are mistreated, traumatized, abused, humiliated and degraded by the mental health and health care systems and by society.

In contrast, the internal trap happens when we come to believe the oppressive messages and internalize the way we were treated. When we think these hurtful experiences are our fault, we have internalized the oppression. Once we have internalized the oppression we don't need it to come from the outside anymore, because we tell ourselves the oppressive messages. It is not our fault that we get stuck in the internal trap: oppression is insidious. But it is our responsibility to get out of it.

I am simplifying a half-day workshop in three paragraphs. When we call someone insane, sick or "crazy," and when we've judged them, labeled them and treat them like they don't know what they are talking about, that is an example of mental health oppression. It comes from the outside. And when we see ourselves as damaged and don't trust our own thinking, that is an example of internalized mental health oppression.

Sexism is another form of oppression. One example of sexism is that a woman gets paid less than a man for doing the exact same job. Internalized sexism is when you accept that you deserve to be paid less. Mental health oppression reinforces sexism. It makes us feel like we can't lead, or can't lead in important ways. Our sisters need us to lead in important ways. We won't be liberated until we lead. Are you energized, women warriors? Good!

What happens to females? How do we get trapped?

Trauma is increasingly being recognized for the very significant role it plays in the development of mental health problems.

Trauma shapes and transforms our interactions with ourselves and others. It has a profound impact on our body, mind and spirit, often resulting in isolation, disconnection, learned helplessness, shame, rage, self-loathing, humiliation, and adverse physical conditions. Traumatic events can be shocking and terrifying; they render us powerless. Trauma is the accumulated effect on body, mind and spirit of events that can include violence between people; abuse of any kind; neglect; and institutionalization, disasters or war. Trauma often involves betrayal by a trusted person or institution. Trauma is part of the warp and weft of our society. Recovery from trauma is possible for all. The healing experience is transformative. (Rene Andersen, Personal Communication, 2008).

Many of us are traumatized as young people or as adults. We were not provided with the knowledge, resources or supports we need in order to heal. Over time, we continue to re-traumatized and humiliated; and, day by day, our humanity slips away. We get hard and tough, in order to survive. Many of us lose our sense of self, our trust that other people

will really be there for us. We become isolated and lose our sense of connectedness with others and with the community.

Trauma typically makes us feel trapped. It disrupts our sense of control, connection, meaning and purpose. It evokes feelings of shame, helplessness and terror (Herman, 1992).

In my childhood, I often felt as if I had no control. Life at home was like a war zone. I never knew when I would be physically or emotionally abused. Then later, my experience in the mental health system taught me to shut up, look good, play the game right so I could get out of the trap, the locked psychiatric ward. For many years I was afraid to speak up against the system. Eventually, as Anais Nin so eloquently wrote “And the day came when the risk to remain tight in a bud was more painful than the risk it took to bloom”.

When females come into the health care system, there are three common institutional responses that are often re-traumatizing. The first is institutional crisis intervention, which often includes forced disrobing, constant observation, physical and/or chemical restraint, and isolation. The second involves institutional routines, which include intrusive medical examinations (such as pelvic and breast exams), disrobing, body searches and handcuffs, all coupled with a lack of information.

And, third, all of this is in an institutional environment that is restricted, noisy, crowded and controlling, with a lack of privacy and the continuous presence, and threat, of force.

We need to transform these institutional service delivery responses by infusing the treatment culture with a humane, trauma-informed approach that bears witness to the individual’s history (Prescott, L., Personal Communication, 2008). We must create warm, welcoming, empowering, healing environments.

What is mental health recovery? SAMHSA defines it as “a journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her full potential.”

Due, in large part, to continuing oppressive policies, practices, and services in the mental health system, the National Coalition of Mental Health Consumer/Survivor Organizations was formed. We realized that we had to change the system. No one else can speak for us. We are the ones dying, we have the most at stake, and we know what we need in order to recover and be integrated into the community. The National Coalition’s mission is to ensure that consumer/survivors have a major voice in the development and implementation of health care, mental health, and social policies at the state and national levels, empowering people to recover and lead full lives in the community.

We are two years old and our membership includes 32 statewide consumer-run organizations and four national technical assistance centers.

Our values are that, first, recovery is possible for everyone. Second, we need to be in control of our own lives. Third, we need opportunities and choices that provide assistance with housing, education, and career development. Fourth, we must be centrally involved in any dialogues and decisions affecting us. We embrace the motto of the disability rights

movement: “Nothing about us without us.” And, fifth, we will campaign to eliminate the prejudice and discrimination associated with mental illnesses.

There is a movie, “Iron Jawed Angels,” about women who picketed the White House and fought for the right to vote during World War I. They were sent to jail because it was illegal to protest during a war. In the movie, a sympathetic doctor says, “Courage in women is often mistaken for insanity.”

There is a silent epidemic in this country. Our sisters are not escaping the trap: the external one or the internal one. Our society is increasingly creating a mental illness industry fueled by drug company profits.

Can you believe that infants as young as six months are being diagnosed psychotic and put on psychiatric drugs?

Young women today tell me that they are afraid to feel. They say that they are told that everything is fine; they aren’t oppressed. They fear that if they show their outrage and talk about how they really feel, they will be put on drugs. There is a pervasive fear of feeling in our culture – that too, is mental health oppression.

Females are often misunderstood and misdiagnosed, which results in our lives being further damaged by institutionalization, drugs and “chronic-style” programs, instead of getting appropriate help that would divert us from the trap. As a result, females often end up getting help wherever we can: homeless shelters, the streets, jail.

There is a very strong relationship between mental health oppression and women’s oppression that is evident in the data that I will share with you. Let me first say that there is a lot of very good work being done across the country. There are many ways we can help our sisters get out of the traps.

Collecting data for this talk was sobering. I think we need to see reality so that we have an accurate perspective on what is happening to females in this country. How can we increase the volume, numbers and audibility of our voices?

- 75% of all psychotropic meds are prescribed to women (Mental Health, Racism & Sexism, U Pittsburg Press, 1995). We must stop over-medicating women.
- Approximately 818,000 elderly Americans were victims of domestic abuse in 1994. Two-thirds of the victims were women (Jennings, A., 2004).
- The role of trauma in the lives of persons receiving psychiatric services is seriously under-addressed. “Many providers may assume that abuse experiences are additional problems for the person rather than the central problem...” (Hodas, 2004).
- 97% of homeless women with serious mental illnesses have experienced severe physical and sexual abuse; 87% experience this abuse both in childhood and adulthood (Goodman et. al., 1997).
- Victims of domestic violence sometimes have to choose between leaving their homes or losing their lives. Thirteen percent of homeless families report domestic violence as the cause of their homelessness. Six hundred thousand families and 1.35 million people

experience homelessness in the U.S. Homeless people experience high rates of physical and mental health problems often exacerbated by living on the streets and in shelters. (www.endhomelessness.org).

- Violence against women and girls is epidemic.

- Nine out of 10 women and children who die from abuse by partners and parents have come to the attention of the public prior to their deaths (Straus & Gelles, 1988). NEED REF

Over half of murdered women are killed by a current or former male partner (Browne, A., 1992). (The liberation of women is intricately tied to the liberation of men.)

- 50%-80% of women who are incarcerated have histories of physical or sexual abuse (Veysey, De Cou, & Prescott, 1998).

- 75% of girls adjudicated as delinquent have a significant history of trauma (Calhoun, Jurgens, & Chen, 1993).

- National survey estimates of intimate violence typically do not include: 1) the very poor, 2) those who do not speak English fluently, 3) individuals who are institutionalized, hospitalized, homeless, or incarcerated at the time of the survey (Commonwealth Fund Commission on Women's Health, 1993, 1995, 1998).

- More than 40% of women on welfare were sexually abused as children. These women are often unable to keep a job, and become homeless along with their children (Jennings, A., 2004).

- 50%-70% of women hospitalized for psychiatric reasons (Carmen, E.H. 1995), 70% of female psychiatric emergency room patients (Briere, J. & Zaidi, L.Y., 1989), and 40%-60% of psychiatric outpatients (Muenzenmaier et. al., 1993) report having experienced physical or sexual abuse.

- The literature substantiates that sexual abuse of women was largely under-diagnosed; that coercive interventions like seclusion and restraint caused trauma and re-traumatization in treatment settings; that complex post-traumatic stress disorder (PTSD), dissociative identity disorder (DID) and related syndromes were frequently misdiagnosed in treatment settings; and that inadequate or no treatment was common (Cook et al., 2002; Fallot & Harris, 2002; Frueh et al., 2000; Rosenberg et al., 2001; Carmen et al., 1996).

- Only one in 10 children in the U.S. tell about their experiences with abuse (Russell, et al., 1986); 42% of women and 33% of men never disclose their childhood sexual abuse experience to anyone (Janssen, 1984).

- Child abuse and neglect cost the United States almost \$94 billion per year, or \$258 million per day, according to a 2001 report. Direct and indirect costs include medical and mental health system, child welfare, special education, lost productivity to society, and legal/judicial and incarceration costs.

More specifically, direct costs (about \$24 billion) include hospitalization, chronic health problems, mental health system, child welfare system, law enforcement, and the judicial system. Indirect costs associated with the long-term and/or secondary effects of child abuse and neglect total about \$70 billion and include special education, mental health and health care, juvenile delinquency, lost productivity to society, and adult criminality (Jennings, A., 2004).

- Child sexual abuse has extremely severe consequences, including decreased school performance, delinquency, depression (Silverman et al, 1996), anxiety (Fergusson & Lynskey, 1997; Lynskey & Fergusson, 1997), suicide, substance abuse, anti-social behaviors (Martinez-Taboas & Bernal, 2000; Fergusson et al, 1997; Holmes & Slap, 1998), incarceration, promiscuity (McClellan, et al., 1995), teen pregnancy (60 percent of teens who become pregnant were sexually abused as children; Briere, 1989), prostitution (95 percent of teen prostitutes were sexually abused; Jennings, 2001), and HIV (Lindegren et al., 1998). Decades of research document that adults who were sexually victimized as children have a higher likelihood of being negatively impacted in their adulthood by numerous types of psychological and physiological ailments (Holmes & Slap, 1998; Silverman et al, 1996; Fergusson & Lynskey, 1997; Lynskey & Fergusson, 1997; McClellan, et al., 1995), including post-traumatic stress disorder, self-destructive behaviors (Blake, 1995), and chronic disease (Felitti et al., 1998).

- There is a relationship between mental health problems and involvement in the juvenile justice system. On any given night in the U.S., 100,000 youth are confined in juvenile detention or correctional facilities (Sickmund, M., 2006). Childhood abuse or neglect increases the likelihood of arrest as a juvenile by 53%, as a young adult by 38%, and for violent crime by 38% (Jennings, A., 2004).

- Reenactment of victimization is a major cause of violence in society. Many violent adult criminals were physically or sexually abused as children (Jennings, A., 2004).

- Drugs are often prescribed for children misdiagnosed with Attention Deficit Hyperactivity Disorder, Oppositional Defiant Disorder, etc., whereas these children's symptoms are indicative of trauma (chronic community/gun violence as well as sexual/physical abuse).

- The lack of a shared language or a shared conceptual framework (e.g., mental health and criminal justice, or mental health and public health) significantly impairs the capacity of systems to collaborate effectively.

Action Steps:

There are opportunities to get involved in all of these initiatives.

- There is a vast and compelling need for the general public to learn how to assist any person who is experiencing an emotional crisis. The NCMHR's public health education program, Emotional CPR, addresses this critical need. For more information see www.ncmhr.org

- We need more alternatives to psychiatric hospitalization
9<http://www.youtube.com/watch?v=aBjIvnRFja4>,
<http://www.youtube.com/watch?v=qnryFXxI7yU&feature=related>), peer-run crisis

respite (www.power2u.org/peer-run-crisis-services.html), other crisis respite services, such as warm-lines, and in-home supports.

- We need to control the influence of pharmaceutical companies by: 1) eliminating direct pharmaceutical advertising and doctor incentives, and 2) reforming the Food and Drug Administration to ensure that there is independent (non-conflict-of-interest) research on pharmaceuticals.

- The Substance Abuse and Mental Health Services Administration/Center for Mental Health Services (SAMHSA/CMHS) is the federal agency charged with oversight of mental health and substance abuse services; but many other federal departments and agencies affect the policies, priorities and delivery of services and supports. A Federal Interdepartmental Task Force is needed to coordinate an interagency federal action plan to effectively work towards eliminating the fragmentation and barriers so that service delivery is integrated and flexible to better meet the real needs of people. Services need to be available in school mental health programs, programs for older adults with mental health problems, and institutions (such as correctional facilities, nursing homes, and psychiatric hospitals).

- Women with knowledge and experience in how to escape the public mental health system trap need to be more represented on advisory committees, such as those at SAMHSA/CMHS.

- We need to end homelessness and increase the availability of affordable housing that is not contingent on receiving services. A very successful, cost-effective example of this is Housing First (www.endhomelessness.org/section/tools/housingfirst), which helps homeless individuals and families quickly access and sustain permanent rental housing contingent only on participants' complying with a standard lease agreement.

- Public awareness and education campaigns need to bring to light the prevalence of abuse and violence against females just as campaigns have raised awareness about breast cancer and HIV/AIDS. Short- and longer-term strategic planning and technical assistance are needed in the areas of: (1) individual and group counseling (to heal what has already transpired); (2) community education and outreach; (3) training of service providers; (4) advocacy; (5) policy development and application; (6) research and evaluation; and (7) other prevention measures (e.g., a focus on appropriately dealing with offenders) (Pine, P., Personal Communication, 2008).

- The National Institutes of Health (NIH) and the National Institute of Mental Health (NIMH) should ensure that a significant portion of their budgets are devoted to research into women's recovery, resiliency and alternative approaches to wellness.

- Medicaid, on both the state and federal level, should have an advisory board with responsibilities for oversight and accountability that addresses women's issues and promotes flexible funding streams that facilitate integration into the community.

Medicaid should ensure that states are knowledgeable about the flexibility within waivers and state plan options such as those that allow self-directed care and individual budgets. Self-directed care allows public funding to follow the person rather than the provider. This way, the individual can design a personal road to recovery by making decisions to the greatest extent possible with respect to service provision and spending their allotted

dollars. States must request permission from Medicaid to offer these flexible programs (e.g., www.flstdc.org, Florida Self-Directed Care).

- We need diversion programs and prevention programs so that mental health problems do not become criminal justice problems. When law enforcement does get involved, we need procedures that reduce and/or eliminate re-traumatization (for example, alternative transportation methods, minimizing use of handcuffs and shackles, etc.).

- We need school-based, preventive services and supports that focus on building resiliency and wellness before mental health problems develop.

- Organizations should consider expanding the use of technology to reach people (particularly in frontier and rural areas) and connect people to resources (including other people: human resources).

- Mentorship programs should be developed or expanded to assist women in their personal and professional development, and in systems transformation.

- Accrediting bodies, such as the Commission on Accreditation of Rehabilitation Facilities (CARF) and the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO), should incorporate standards that encourage providers to be more knowledgeable about recovery-focused, trauma-informed approaches to service provision. Knowledge of these approaches should be part of new staff orientation, ongoing training and professional development competencies. A list of resource-rich organizations, including those that are consumer-run and trauma-informed, should be made available to staff, administrators, and persons receiving services.

Recommendations for change:

- Mental health service delivery needs to be trauma-informed, culturally sensitive, developmentally appropriate, accessible, affordable, person-driven (not provider-driven) and community-based.

- We need a system that does not focus on “fixing” people but rather on providing opportunities to explore what works for each individual, and ensures that services, supports, and treatment help people attain or maintain independence and promote wellness and community integration.

- We need service providers to understand the difference between coercion and alliance and how to share power. Coercion destroys one’s sense of personhood and identity, whereas building a collaborative alliance is empowering. This means that provider and user must forge a partnership of equals, establishing a consensus on the problem, the goals, and the criteria for success that supports the individual’s unique journey to wellness.

- We need integrated, flexible care that is coordinated between mental health and primary health care providers, including hospital emergency room staff, who must adopt a values-based, trauma-informed service delivery approach.

- We need public and private partnerships to infuse trauma-informed care into all human service delivery systems. We need an enlightened society that understands that people

recover and that every person who comes in contact with a person on their recovery journey can assist in that journey by being respectful and hopeful.

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Resources

Alternatives to psychiatric hospitalization

<http://www.youtube.com/watch?v=aBjIvnRFja4>,

<http://www.youtube.com/watch?v=qnryFXxI7yU&feature=related>

Peer-run crisis respite -www.power2u.org/peer-run-crisis-services.html

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