4TH Annual
CLINICAL FORUM ON MENTAL HEALTH
"Turning Knowledge Into Practice"

Wednesday, May 14, 2008
12:30 p.m. to 2:00 p.m.

"Overcoming the Language of Oppression: Promoting Cultural Change with Words"

by

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This presentation will be up at:
http://home.att.net/~parisser
within the next couple of weeks
CULTURE CHANGE

➢ Culture change means being open to willfully changing one’s thinking, one’s feelings and one’s behavior.

➢ Culture change seeks to end the prejudice, discrimination and fear of people labeled with mental illness.

➢ Culture change is dedicated to change from fear to people first.

➢ The heart of culture change is to use words in ways that understand the situation of a person who is labeled with a mental illness.

➢ This presentation will focus on the development of policies and partnerships that promote a positive culture for mental health professionals and those labeled with mental illness.

➢ Leadership by example will also promote the change necessary to make a difference in our culture.
FEAR OF OTHERS IN AN ANXIOUS AGE

"Could we up the dosage? I still have feelings."

@ The New Yorker collection (January 22, 2007), Alex Gregory, from cartoonbank.com. All rights reserved.

From:
Mentalism = Discrimination
(aka Sane-ism)

Similar "ism's" are:
Racism
Sexism
Ageism

Discrimination can be blatant but more often consists of:

Micro-aggressions*

1. Not powerful individually
2. hundreds, even thousands daily
3. cumulative effect over years

* Dr. Chester Pierce, an African-American psychiatrist and author writing about racism in the book, "The Black 70's", termed the multiple small insults and indignities directed at people "micro-aggressions."

Effects of Mentalism

- People internalize the negative attitudes
- People feel ashamed
- People blame themselves for their difficulties
- People feel worthless
- People feel hopeless about their future
- People lose confidence about their abilities
- People feel they must hide their histories
- People fear losing their job, their friends, their credibility
- People become demoralized
- People direct their anger and helplessness back upon themselves creating a worsening spiral downward
**Us vs. Them**

<table>
<thead>
<tr>
<th>Power-up group</th>
<th>Power-down group</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;Normal&quot;</td>
<td>Sick</td>
</tr>
<tr>
<td>Healthy</td>
<td>Disabled</td>
</tr>
<tr>
<td>Reliable</td>
<td>Crazy</td>
</tr>
<tr>
<td>Capable</td>
<td>Unpredictable/Violent</td>
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This black-and-white, all or nothing style of thinking is referred to in psychodynamic literature as "splitting."

- Behaviors of the **power-down group** are framed in pathological terms.
- The same behaviors are excused or even valued in members of the **power-up group**.

**A quiet client who causes no community disturbance is deemed "improved" no matter how miserable or incapacitated "they" may feel as a result of the "treatment."**

"They" may be miserable but that's not the point.

"Their" misery doesn't matter. The only thing that matters is any inconvenience "they" may cause "us."

Labeling, diagnosis and other practices tend to **decontextualize** people.

Typically, when treatments are ineffective or unacceptable, the recipient is blamed. He or she is:

- "treatment-resistant,"
- “uncooperative,"
- "non-compliant,"
- "characterologic"

and, has therefore failed the provider rather than the other way around.
• Mentalism and Language •

There is NO such thing as a "side-effect."

There are only "effects" from taking drugs. Some effects are desired and others are undesirable.

Calling an adverse effect a "side-effect" obscures and minimizes the resultant pain, suffering and misery that can be caused by psychoactive drugs. This discounts our experiences and perceptions and thus denies our reality.

"Decompensating" is an us-them term

Under stress "we" may not do well; "we" may cocoon, take to bed, get bummed out, get burned out, get a short fuse, throw plates, scream, call in sick, or need a leave of absence. "They" decompensate.

The demotion from "us" to "them" is a loss of one's designation as a person.

A person with a diagnosis can become:

"a schizophrenic" or
"a bipolar" or
"a borderline,"
or
CMI, SMI, SPMI, ADHD, etc.
THE LANGUAGE OF US AND THEM
Mayer Shevin, © 1987

We like things.
   They fixate on objects.

We try to make friends.
   They display attention-seeking behaviors.

We take a break.
   They display off-task behavior.

We stand up for ourselves.
   They are non-compliant.

We have hobbies.
   They self-stimulate.

We choose our friends wisely.
   They display poor peer socialization.

We persevere.
   They perseverate.

We love people.
   They have dependencies on people.

We go for walks.
   They run away.

We insist.
   They tantrum.

We change our minds.
   They are disoriented and have short attention spans.

We are talented.
   They have splinter skills.

We are human.
   They are.......?
<table>
<thead>
<tr>
<th>OFFENSIVE MESSAGES</th>
<th>TREATMENT REALITIES</th>
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</thead>
</table>
| “You mental patients are sick – we must protect you for your own sake.” | • Providers identify the client’s illness, dysfunction, problem list  
• Providers determine which treatments are in the client’s best interest  
• Providers determine “realistic” goals for the client  
• “You patients are sick – we must direct you for your own sake.” |
| “We professionals are right – you mental patients are here at our forbearance.” | • Providers are assumed to know more about the client’s needs than the client does  
• The client is consulted about his/her treatment but decisions are made by others; often the choices offered are trivial  
• “We providers know what’s right for you – you patients are consulted at our forbearance.” |
| “We love you mental patients to death – you don’t appreciate our concern.” | • Providers want to be recognized for their good intentions and skill; clients who resist their intervention are lacking in judgment and insight, or are excessively “entitled”  
• “We care about you patients – you are too sick to appreciate us.” |
| “We’re good to you mental patients – you should be grateful that we control you humanely.” | • Physical and chemical restraint, involuntary hospitalization and treatment continue to be used in what is considered to be a humane fashion when a client is deemed to be our of control  
• The unappreciative client is pejoratively labeled: oppositional, borderline, noncompliant, unmotivated for treatment, etc.  
• “We’re good to you patients – we employ our treatments humanely.” |
| “You mental patients come see us -- we’ll help you if you beg.” | • Clients are offered services and support contingent upon compliance, which includes that the client demonstrate insight by agreeing with providers that s/he is sick (i.e., buy into the stigma and power differential.)  
• “You patients come for treatment – we’ll help you if you comply.” |
<table>
<thead>
<tr>
<th>STATED TERMS</th>
<th>OUR PREFERRED REALITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>The mentally ill</td>
<td>People who cope with mood swings, fear, voices and visions</td>
</tr>
<tr>
<td>Brain disease</td>
<td>Problems in living</td>
</tr>
<tr>
<td>Treatment</td>
<td>Alternatives</td>
</tr>
<tr>
<td>Assisted</td>
<td>Forced if unwilling to be voluntary</td>
</tr>
<tr>
<td>Evidence-based, best practices, needs, prevalence</td>
<td>Childhood abuse, trauma, community</td>
</tr>
<tr>
<td>For</td>
<td>With</td>
</tr>
<tr>
<td>We can all agree ...</td>
<td>Excludes users and survivors</td>
</tr>
<tr>
<td>Mental health courts</td>
<td>Discrimination on the basis of disability</td>
</tr>
<tr>
<td>We can all agree</td>
<td>Nothing About Me Without Me</td>
</tr>
<tr>
<td>Parity</td>
<td>Funds for involuntary treatment</td>
</tr>
<tr>
<td>Safety</td>
<td>Anomaly</td>
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</table>
7 DIRTY WORDS
...we hear from our providers that hurt like sticks and stones
Please read with a hint of humor and a pinch of humility.

1. Compliance
"Compliance" suggests conforming, acquiescing, or yielding in a subservient way. We're more likely to "adhere" to a co-authored wellness plan than we are to comply with a mandated treatment regimen.

2. Patient Failed the Treatment
Patients don't fail treatments. Treatments fail patients.

3. The Bipolar
Every time we're known as "the bipolar in room 3," or "the schizophrenic in the waiting room," we feel a little less human.

4. Treatment Team
We love teams -- especially teams that are helping us become well. The problem is that we're very often not on the team. Sometimes we're not even on the playing field! Let us be the captain of our team, or consider yourself cut from the roster.

5. Treatment Resistant
Trust us; we are not resistant to treatment. We're all for it! Please don't blame the fact that the treatment doesn't work on us.

6. Minimal Side-Effect Profile
Weight gain, sleep interruption, and sexual dysfunction are not minimal side-effect profiles. These are issues at the very core of how we see ourselves. Please don't call these "minimal side-effects" minimal, because they're major life obstacles to us.

7. Front Line Staff in the Trenches
When did treating us become warfare? We'd like to partner with you to bring meaning to your life's work -- not be your enemy on a battlefield.

EMPOWERING LANGUAGE CHOICES

<table>
<thead>
<tr>
<th>DIRTY WORDS</th>
<th>EMPOWERING WORDS</th>
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</thead>
<tbody>
<tr>
<td>1. Compliance</td>
<td>1. Adhering to our plan</td>
</tr>
<tr>
<td>2. Patient Failed the Treatment</td>
<td>2. The Treatment Failed</td>
</tr>
<tr>
<td>3. The Bipolar / The Depressive</td>
<td>3. Person</td>
</tr>
<tr>
<td>4. Treatment Team</td>
<td>4. Patient Driven Supporters</td>
</tr>
<tr>
<td>5. Treatment Resistant</td>
<td>5. In Need of More Treatment Options</td>
</tr>
<tr>
<td>7. Front Line Staff In The Trenches</td>
<td>7. Partner</td>
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</tbody>
</table>
Rulebook for Consumer Compliance

1. You will supply answers rather than questions. And smile.

2. You are herewith relieved of the burden of considering options and expressing preferences. Highly-trained specialists will determine your needs, and smile.

3. Should a consumer specialist make remarks or inquiries that seem to you ill-mannered, or too personal, you are mistaken. Answer politely, and smile.

4. Should professional persons enter a space or touch a part of your body you consider to be "yours," private or personal, you are again mistaken. A smile will be sufficient.

5. Program guidelines have been painstakingly developed in the best interests of consumers with your particular deficits. All you need to do is comply, and smile.

6. Persons who are not consumers may seem uneasy in your presence. A quiet but not over-familiar smile will put them at ease.

7. Gatherings and locations which are off-limits to you are identifiable by barriers preventing your participation. Back away quietly, and smile.

8. Should persons who are not consumers seem to stare at you, you are no doubt mistaken. Smile.

9. Don't call attention to yourself. Don't get angry. Don't make a scene. Don't take it personally. Smile.

10. You must endeavor to get well, recover from your tragic loss, mind your manners, put thoughts of sex out of your mind, do your best to fit in, and smile.

[Reprinted from Mouth Magazine, May 2001]
<table>
<thead>
<tr>
<th>&quot;Borderline&quot; Trait</th>
<th>Observed Behavior</th>
<th>Trauma Paradigm</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;manipulation&quot;</td>
<td>Person asks indirectly to have needs met, usually by changing interpersonal environment.</td>
<td>Abuser will often deny overt requests; person has learned to adapt to get needs met.</td>
</tr>
<tr>
<td>Self-mutilation</td>
<td>Person engages in injurious behavior in order to feel pain, feel real, punish self.</td>
<td>Pain often stops dissociation, de-personalization, or de-realization associated with PTSD.</td>
</tr>
<tr>
<td>Suicidality</td>
<td>Attempts to kill self accompanied by expression of hopelessness, rage, intense pain, feeling out of control.</td>
<td>Person feels need to take charge of pain/fate/life in a definitive way.</td>
</tr>
<tr>
<td>&quot;Splitting&quot;</td>
<td>1. Person sees the world, especially relationships, in the extreme (&quot;black and white thinking&quot;). 2. Person asks one person after another for what s/he needs.</td>
<td>1. Person has learned from abuse relationship to expect unpredictable extremes (e.g., violence or neglect alternating with indulgence). 2. This is self-advocacy, a strength.</td>
</tr>
<tr>
<td>&quot;Drug-seeking&quot; and substance abuse</td>
<td>Person requests benzodiazepines or stimulants, or uses alcohol and street drugs.</td>
<td>Person seeks relief from autonomic hyper-arousal and psychological symptoms of PTSD.</td>
</tr>
<tr>
<td>Intense Emotion: Rage, Fear, Mood Swings</td>
<td>Responses seem to be extreme or unexplained by present events or situations.</td>
<td>Current situation triggers PTSD symptoms of flashbacks, reliving of emotional aspects of trauma, autonomic hyper-arousal, &quot;repetition compulsion.&quot;</td>
</tr>
<tr>
<td>Self-defeating behavior and &quot;Impulsivity&quot;</td>
<td>Person helplessly or defiantly continues behaviors or makes choices that undermine her goals or expose her to risk.</td>
<td>&quot;Repetition compulsion;&quot; may also reflect a symbolic demonstration of strength, courage, or control.</td>
</tr>
<tr>
<td>&quot;Dependency&quot;</td>
<td>Person attaches desperately to helpers as if life is very dangerous and precarious.</td>
<td>Abuse milieu is extremely dangerous, unpredictable, may be life-threatening; person may have been exposed to threats or reality of abandonment; person may have adaptively learned to hang on to positive relationships.</td>
</tr>
<tr>
<td>&quot;Blaming&quot;</td>
<td>Person is unclear about attributing responsibility; person holds others responsible for his internal state.</td>
<td>Abuse relationship may have exposed person to blame for the abuse (&quot;You asked for it.&quot;) or blame for other things out of his control or the abuse-apology cycle; no early role models of interpersonal accountability; may trigger feelings that abuser is the source of the distress.</td>
</tr>
</tbody>
</table>

Table from Tamra Dodson and Coni Kalinowski, "Re-evaluating borderline personality disorder from the trauma paradigm"
• Myth of Compliance •

Nowhere in medicine are physicians more preoccupied with enforcing "compliance" than psychiatry. Most non-psychiatric physicians have come to accept that compliance itself is a myth.

- Humans don't comply with anything (Studies of "compliance" with everything from diabetic diets to anti-hypertensive agents show that humans don't comply with anything. At least one third of people in these studies fail to follow their doctors' instructions and many studies have shown rates of "non-compliance" of over 50%.)

- Best results are obtained when people are well-informed and in control of their treatment

- Incarceration is used to contain the person who will not comply, though, because the incarceration occurs in a hospital, it is deemed to be "treatment"

- Imagine jailing a diabetic for having dessert or incarcerating a person having chronic bronchitis for lighting up a cigarette or forgetting his/her inhaler
Mentalism can cause further difficulties for those who have a past history of trauma.

Trauma Facts:

In the United States, a child is reported abused or neglected every 10 seconds.

Roughly 4 – 6% of our elderly are abused, primarily by family members.

70% of women who are homeless were abused as children. Nearly 90% of women who are both homeless and have been diagnosed as having a mental illness experienced abuse both as children and adults.

80% of incarcerated women have been victims of physical and sexual abuse. The majority of murderers and sexual offenders, who tend to be male, have a history of childhood abuse, neglect, maltreatment and trauma.

The majority of both men and women in substance abuse programs report childhood abuse or neglect.

Each year, 2,000 children die from maltreatment: 90% are under the age of five.

40-50% of males with mental health issues were sexually abused in childhood.

Actual numbers are uncertain due to differences in how data were collected (chart review vs. interview)

Instead of proclaiming, "What's wrong with you?" mental health professionals need to learn to ask,

“What happened to you?”
Mental Health Clients and Trauma

- 90% of public mental health clients have been exposed. (Muesar et al., in press; Muesar et al., 1998)

- Most have multiple experiences of trauma. (Ibid)

- 34-53% report childhood sexual or physical abuse. (Kessler et al., 1995; MHA NY & NYOMH 1995)

- 43-81% report some type of victimization. (Ibid)

- 97% of homeless women with SMI have experienced severe physical and sexual abuse - 87% experience this abuse both as child and adult. (Goodman et al., 1997)

- Current rates of PTSD in people with SMI range from 29-43%. (CMHS/HRANE, 1995; Jennings & Ralph, 1997)

- Epidemic among population in public mental health system, especially women. (Ibid)

- 74% of Maine’s AMHI C/S/X reported histories of sexual and physical abuse. (Craine, 1988)

- Majority of adults diagnosed BPD (81%) or DID (90%) were sexually or physically abused as children. (Herman et al., 1989; Ross et al., 1990)

The literature substantiates that:

- Sexual abuse of women was largely under-diagnosed

- Coercive interventions like S/R caused trauma and re-traumatization in treatment settings

- “Observer violence” in treatment settings was traumatizing

- Complex PTSD, DID and related syndromes frequently misdiagnosed in treatment settings

- 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)

People who are psychotic and delusional can respond reliably to trauma assessments if asked appropriately with one person sensitively asking the questions. (Rosenberg, 2002)
We need to learn to listen to people’s stories.

It is important to understand that, due to the power differential between staff and recipients, many psychiatric interventions trigger or retraumatize the survivor.

Triggers and retraumatization can occur in both the physical and interpersonal environments.

Examples include spread-eagle restraint of a rape victim or disbelieving the history given by a survivor of incest.

Because powerlessness is a core element of trauma, any treatment that does not support choice and self-determination will tend to trigger individuals having a history of abuse.

People may re-experience the helplessness, hopelessness, pain, despair, and rage that accompanied the trauma.

They also may experience intense self-loathing, shame, hopelessness, or guilt.

Mentalist thought tends to label these negative effects of treatment in pejorative terms that blame the survivor: "He's just acting out," "She's manipulating," "He's attention-seeking."

These labels are often communicated through the attitudes and language of staff, and become re-traumatizing in themselves.

Mentalism, like racism or sexism, is abuse.
The system’s biological approach reduces human distress to a brain disease, and recovery to taking a pill. The focus on drugs obscures issues such as housing and income support, vocational training, rehabilitation, and empowerment, all of which play a role in recovery.
STIGMA

Stigma has to be adopted by the person to be shamed.

Stigma is consumer inaction in the face of oppression.

It doesn't exist without the collusion of the target person.

The whole stigma, anti-stigma issue is primarily about marketing mental health services, shifting responsibility for a system in shambles, from the system to the would be service user, who doesn't ask for help because of 'stigma.' Mental illness clients, just like the general public, have been convinced by "Big Pharma" marketing.

We are the victims. Stigma is not 'our' behaviors; it is behavior of those who learn it in school, law enforcement, media, and the general public.

The proper words are prejudice and discrimination. One is social, the other legal. They are legally actionable!

Stigma is a stigmatizing word in itself, why have a different word for prejudice against mental health consumers than for prejudice against other groups?
Rules for successful interaction:

1. We are/were mad, not stupid, speak to us accordingly.

2. If you haven't done anything for us, don't expect us to act grateful just for being allowed at the table because it's our table and you just happen to be occupying it at this unenlightened moment in time.

3. Try to go a whole paragraph without using vulnerable or violent in a sentence. If it helps you to accomplish this, try leaving out the letter "v" entirely as you speak.

4. Don't praise us for things you would take for granted in anyone else—e.g. speaking well, having a large vocabulary, having opinions, being "stable" (whatever that might be), not breaking the law (no matter how often laws have been broken against us), holding down a job, owning a home, taking care of pets, voting, not visibly shaking (no matter how much we may be shaking inside).

5. Don't say, "Let me finish", you have had your turns of talk for a hundred years now and we are the worse off for it. This is our struggle not yours.

6. Don't tell us we do not represent our sisters and brothers in struggle. Who are you to say and how would you know? You never ask us who our friends are, who we talk to, what we talk about when you aren't present and we don't tell you because you are not part of our group anymore than we are part of yours.

7. Don't diss one of us in front of another one of us. We talk, we will hear about it and we will be even less likely to let you into our plans for freedom and equal rights.

8. Do not say you are one of us if you are not. Would you lie about having had cancer or a heart attack?

9. Don't pretend to give us power when you have no intention of really doing so. This just makes us angry and more likely to pursue a separate peace with society, free of self-declared advocates of any stripe.

10. Don't tell us our life is tragic because we may not be feeling particularly tragic that day but we will feel alienated from you after you say that.

11. Don't take our words and co-opt them into your own agenda. "Nothing about us without us" really means everything about us without you.

12. Don't act out on us as if we do not have feelings, we have lots of feelings and we do not accept bad behavior any better than anyone else, we are probably less tolerant of it in fact, having put in so much hard work to overcome it in ourselves and each other.

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